

An Ontology Guided Practice Support Tool for Palliative Severe Pain Management

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**Abstract**

One of the primary goals of palliative care is management of symptoms such as pain. Palliative clinicians experience difficulty in severe pain management (SPM) and therefore there is a need for enhanced approaches to SPM. This dissertation attempts to fulfill that need by applying informatics based approaches to SPM. The dissertation was done in three phases: conceptualization, construction and testing. Conceptualization developed a practice support framework and set of informatics based tools for palliative SPM, construction implemented the informatics based tools as a computer based practice support tool and testing performed usability testing on the computer based tool.

The results show that qualitative methods can be used to capture and understand the practice support needs for palliative SPM, which include a number of processes and information to support SPM. The practice support needs were then used to develop a set of informatics based solutions consisting of an ontology, a set of problem solving methods and an empirically derived vocabulary for palliative SPM. The informatics based solutions then became the design requirements for a computer based tool that provided comprehensive practice support for palliative SPM. The testing phase of the research used usability testing to test the functionality of the computer based tool. Usability testing was favorable to the question of how well does the computer based tool provide practice support for palliative SPM.

This dissertation makes contributions to the fields of health informatics and palliative care. For health informatics it illustrates how to apply qualitative research methods to capture and organize knowledge around a complex healthcare domain area. The dissertation also illustrates how to use that knowledge to extend existing work on

ontology based information system (IS) design by using that knowledge to develop a set of empirically derived informatics based solutions and then implementing the solutions as a computer based tool. The dissertation makes a contribution to palliative SPM by identifying practice support needs for SPM including linkages between research and practice, promotion of a common SPM vocabulary, and an approach to information handling to help manage the complexity of SPM.

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### **Dedication**

I dedicate this dissertation to my parents Adam and Gloria Kuziemy. From day one they inspired me to always do my best and instilled in me the value of education. Without their support, encouragement and belief in my abilities this dissertation would not have been possible.

Thanks mom and dad, I probably haven't said that often enough.

*Craig*

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## **Chapter 1 Introduction**

This chapter provides an introduction to the dissertation including an overview of the fields of palliative care and severe pain management, the research questions and objectives, overview of the study, significance of the research and an outline of the chapters.

### **1.1 Synopsis of Dissertation**

Palliative care is defined by the World Health Organization “as an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual”.<sup>1</sup> In Canada, recent initiatives such as the Canadian Senate Subcommittee for End-of-Life Care (2001) and the Romanow Report (2002) have both pointed to the need for increased palliative care services, but more importantly, increased palliative care research to support delivery of such services

The relief of symptoms such as pain is one of the predominate goals of palliative care. Yet the literature cites that 40-70% of palliative patients experience pain episodes of a moderate to severe magnitude and 20-40% of those episodes are not properly managed (Franks et al., 2000). This dissertation is directed at providing practice support for palliative care severe pain management (SPM). Although all pain is distressful to patients, families and clinicians, this dissertation focuses on SPM because it is particularly distressful. The need for new approaches to severe pain management has been detailed in the literature. Clinical accuracy of pain management is especially poor when assessing severe pain (Ingham and Portenoy, 1998) and although physicians feel confident in their abilities to manage pain they remain overly reserved and less confident in their immediate response to patients with severe pain (MacDonald et al., 2002).

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<sup>1</sup> <http://www.who.int/cancer/palliative/definition/en/>

However severe pain is complex and can have multiple causative factors including physical, spiritual and psychosocial factors, each of which has its own complexity with respect to management. Furthermore palliative patients often have more than one type of pain so that complexity must also be recognized. But making sense of an occurrence of severe pain goes beyond the presentation of pain as patients incorporate other factors into their perception of pain including past experiences of pain and illness, culture, expectations and the meaning of the situation in which the pain is occurring (Bouvette, Fothergill-Bourbonnais and Perrault, 2001).

There are a number of identified areas in palliative SPM where clinicians could benefit from practice support including the assessment of psychosocial issues, attention to non-drug techniques for pain relief (MacDonald et al., 2002) and overcoming ambivalence and discomfort about dealing with the practical implications and meaning of pain's subjectivity (Lasch, 2002). Furthermore the literature states that pain management requires a detailed understanding of all the issues around a pain episode that goes beyond just doing an assessment (Fainsinger, 2001).

### **1.2 Research Questions and Objectives of the Study**

To provide practice support for palliative SPM we require an understanding of what information is used in SPM and the processes that use such information. The overall objectives of this dissertation are to gain an understanding of the information and processes in palliative SPM, to formalize that understanding into a set of informatics based solutions, and finally to implement the informatics based solutions as a computer based practice support tool. However a research issue is how to obtain the SPM information so it can be classified and codified to become the content of informatics based solutions. Expert clinicians have a systematic approach to SPM that incorporates clinical experience, education and intuition. We need a means of unpacking that knowledge so it can be incorporated into computer based tools to allow the knowledge to be passed onto others as practice support.

The research questions of this dissertation are:

1. How can we capture and organize knowledge to extend existing work on development of ontologies within the context of SPM?
2. How to represent problem solving methods as a series of tasks that provide a continuum of practice support for SPM?
3. How and to what extent can a set of informatics based solutions (ontology, problem solving method and vocabulary) be implemented as a computer based practice support tool for SPM?
4. To what extent does the computer based tool provide practice support for SPM?

The specific research objectives to answer the above questions are:

1. To use a grounded theory-participatory design method to obtain and code three palliative data sources into concepts and relationships to make sense of the information and processes used in palliative SPM
2. To formalize those concepts and relationships into a set of informatics based solutions consisting of an ontology, a set of problem solving methods and an empirically derived vocabulary for SPM.
3. To implement the ontology, problem solving methods and vocabulary as a computer based practice support tool for palliative SPM
4. Perform usability testing in order to test the ability of the computer tool to provide practice support for SPM

### **1.3 Overview of Study**

Given the need for new approaches to palliative SPM this study will use a hybrid of research methods in order to capture and understand the practice support needs of palliative SPM and then apply those needs to healthcare information system (IS) design. The research will be done in three phases: conceptualization, construction and testing. Conceptualization will apply a grounded theory-participatory design (GT-PD) guided method to collect and code three palliative data sources (PDS) into concepts and categories. The concepts and categories will be developed into a SPM practice support framework. The SPM practice support framework will then be formalized into a set of

informatics based solutions consisting of an ontology, a set of problem solving methods and an empirically derived vocabulary of palliative SPM. The construction phase will use the rapid prototyping method to implement the informatics based solutions into a prototype computer-based practice support tool for palliative SPM. The testing phase will use the usability testing method to test the computer tool, which includes testing of the both the ease of use of the computer tool (i.e. interfaces and navigation) as well as testing of the usefulness of the practice support information contained within the tool.

#### **1.4 Significance of Research**

The work proposed in this dissertation has significance to the fields of health information systems (IS) and palliative care.

First, the research has significance to the field of healthcare IS design in that it will illustrate a methodological approach for capturing and understanding the work process and information requirements in a clinical domain area. Specifically the dissertation will describe how a grounded theory-participatory design (GT-PD) guided methodology can be used to draw out richness of detail of the domain area in terms of the processes that take place, what information is needed to support those processes and how a computer based tool can be developed to deliver those processes and information. Qualitative research methods have been described as optimal for understanding a phenomenon from the point of view of the participants and the social and organizational context of IS use (Stoop and Berg, 2003). However there is a need for empirical studies that illustrate how to apply such methods in practice settings. This research will illustrate how the GT-PD method is used for development of the computer based severe pain tool and how the method contributes to the field of healthcare IS design by providing a means of IS design that spans the paradigm of clinical requirements to conceptual models to computer based tool design.

Second the research has significance to ontology based information system (IS) research by illustrating a new perspective for developing an ontology and set of problem solving methods in a domain area. The dissertation will introduce the term 'practice support' to

refer to problem solving methods that support the overall scope of practice and encompasses multiple tasks and subtasks including decision support and information handling. The dissertation will also illustrate how the practice support requirements can be formalized as a set of empirically derived informatics based solutions consisting of an ontology, a set of problem solving methods and a vocabulary, and how those informatics based solutions are implemented as a computer based practice support tool. Such work is significant as conceptual models such as ontologies have been described as an effective means of modeling IS related phenomena, yet much of the research on developing models such as ontologies is atheoretical (Weber, 2003). This dissertation will illustrate a method of empirically developing an ontology, problem solving methods and vocabulary, which extends existing research around those concepts as much of the research to date has focused more on their use and not their development.

Third the research has significance to palliative SPM in that it will provide an enhanced approach to help clinicians understand and manage the complexity of SPM. The research will identify specific information and processes that are needed to provide practice support for SPM and how those practice support needs can be modeled and implemented through a computer based tool. The types of practice support identified for SPM will include linkages between research and practice, promotion of a common SPM vocabulary, and an approach to information handling to help manage the complexity of SPM.

### **1.5 Outline of dissertation**

This dissertation contains ten chapters; each of the chapters is detailed briefly:

- 1. Synopsis of dissertation** – Overview of need for the study and how the study will be undertaken
- 2. Literature Review** - The literature review is divided into 2 sections. The palliative care section describes the importance of palliative pain management (general and severe pain), specific challenges and opportunities for practice support of SPM, theoretical models of pain management and palliative care

including the challenges to using those models in practice. The health informatics section describes existing computer based tools in palliative care and information management, informatics based solutions for practice support, ontologies, problem solving methods and existing ontology based IS.

3. **Research Approach** – Describes the basis for research and how the study proposes to solve the issues and challenges in palliative SPM that were identified in the literature review. Also describes the four methodologies used in this study: grounded theory (GT), participatory design, rapid prototyping and usability testing.
4. **Research Design** – Describes the three phases to the research: conceptualization, construction and testing. Also describes the data sources used for the study and how the data is applied to each research phase.
5. **Results – Conceptualization Phase Part I - Problem Domain**— Introduces the complexity of palliative severe pain management using clinical scenarios, describes existing approaches to SPM in the form of a paper based Clinically Applied Pain Information Tool (CAPIT). Also describes the additional requirements that extend the paper based CAPIT and become the design requirements for the computer based CAPIT
6. **Results - Conceptualization Phase Part II – Conceptual Models** - Details development of the SPM practice support framework to summarize the additional requirements from chapter 5 and the formalization of that framework into three informatics based solutions, an ontology, set of problem solving methods and empirical vocabulary
7. **Results – Construction Phase** – Describes implementation of the informatics solutions as a computer based version of CAPIT. The construction phase is described from two perspectives, the technical perspective and the user perspective
8. **Results - Testing Phase** – Usability testing of the computer based practice support tool for severe pain management. Usability testing assessed both ease of use of the computer tool as well as the extent to which it provides practice support for palliative SPM

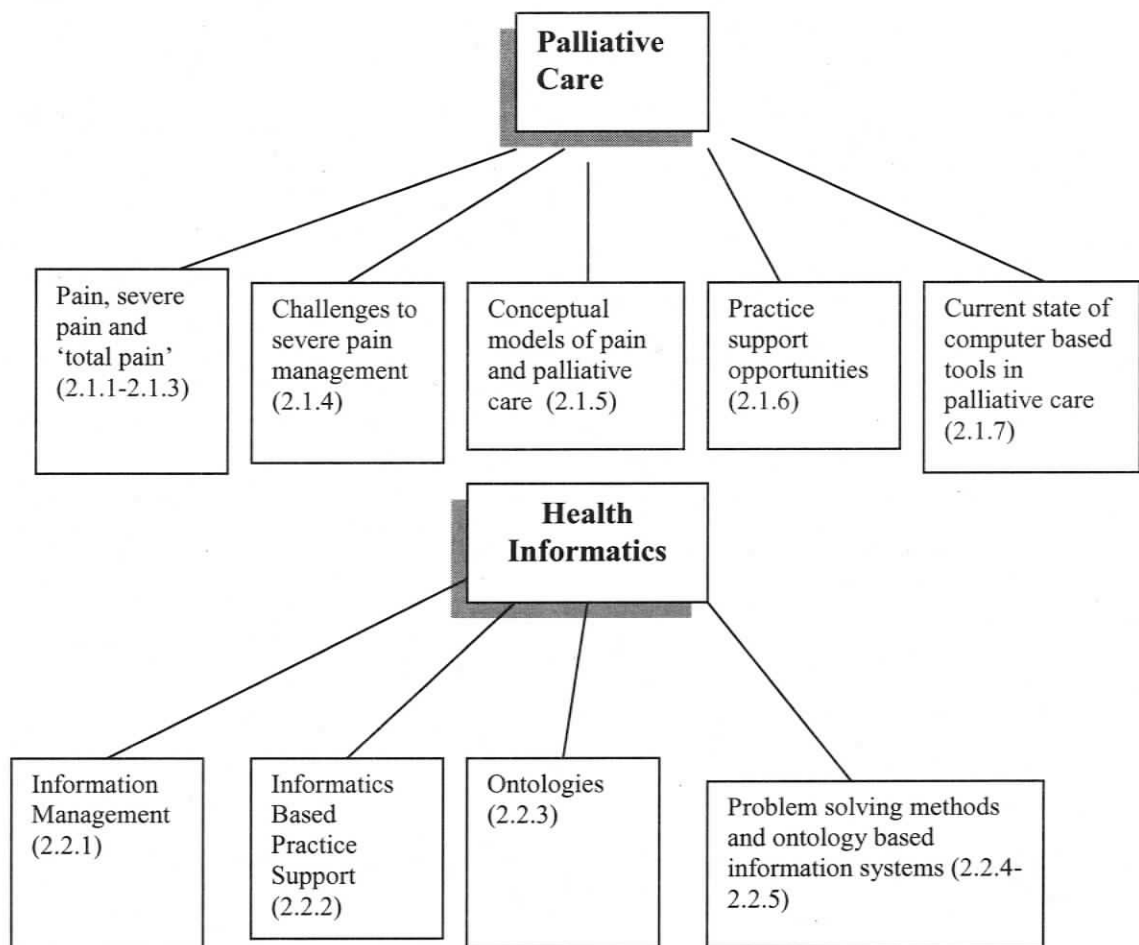
**9. Discussion - Summary of Results, Limitations of the Study and Future**

**Works** – Summarizes and discusses the results by research question and discusses limits of the study and future research

**10. Conclusion** – Contribution to knowledge and concluding summary

## Chapter 2 – Literature Review

The literature review will serve to provide a background to the two areas that are fundamental to this dissertation. The literature review has two sections: a review of palliative care and severe pain management as the setup for the problem this dissertation attempts to solve; and a review of the approaches that set up the informatics based solutions to the problem. Because those areas are very vast a framework showing how the pieces of the literature review fit together is provided in figure 1. The multiple boxes of the framework represent the parts of the literature review. Each of the two major sections is described briefly.



**Figure 1.** Framework of literature review. The top shows the issues and research opportunities in palliative severe pain management and the bottom is the informatics based solutions proposed in this dissertation to solve the problems. Numbers refer to sections in the literature review

The first section of the review looks at palliative care and identifies both the need for and the problems with current pain management approaches in palliative care. The review begins with a look at occurrences of pain in palliative populations, discusses the implications of poor pain management and then identifies some of the barriers to of pain management such as patient, healthcare provider and health system barriers. The literature in the palliative care section will be discussed in the context of the theoretical and methodological deficiencies that have been identified in research to date. Wherever possible it will be identified how the contributions from this dissertation overcome those deficiencies.

The second section of the review describes the basis for the informatics based approaches taken by this dissertation to address some of the identified deficiencies in palliative severe pain management. The review focuses on the specific informatics based solutions used in this dissertation by describing different approaches to information management, the use of ontologies for modeling information and processes within a domain area; and the application of problem solving methods to solve specific problems within the domain.

## **2.1 Palliative Care**

### **2.1.1 Pain and Severe Pain**

Although palliative care encompasses all terminal diseases, much of the research on pain occurrences and etiology in terminally ill populations has been done using cancer patients, as cancer is the most common disease seen in palliative populations. A systematic review on palliative care by Franks et al. (2000) states that pain is the most investigated symptom in terminal cancer patients. Among advanced cancer patients, pain is moderate to severe in 40% to 50% and very severe or excruciating in 25% to 30% (Dault and Cleeland, 1982).

### **2.1.2 Impacts of Inadequate Pain Management**

Adequate pain management is important because unrelieved pain causes unnecessary suffering and diminishes all aspects of quality of life including activity, appetite and sleep, which can further weaken an already debilitated patient (Gordon, Berry and Dahl,

2000). Aside from impacts to the patient, unrelieved pain can also bring consequences to the patient's family or informal caregivers including destroying relationships and creating anxiety, anger and depression. Hospice and palliative care nurses often witness the impact unrelieved pain has on family coping and functioning (Gordon, Berry and Dahl, 2000). Pain can lead to social isolation for the patient and cause feelings of anger, anxiety, resentment and despondency among family members (Ferrell et al., 1991). Differing perceptions among patients and family members about pain and how it should be managed can impede pain management and also create a climate of tension and mistrust in the family (Taylor, Ferrell and Grant, 1993).

### **2.1.3 'Total Pain'**

Aside from the physical dimensions of pain are emotional, spiritual and social dimensions such as increased anxiety and depression, which can alter both how pain is perceived by an individual but also the impact that pain has on the individual (Linklater and Leng, 2001). The summation of the above dimensions are said to contribute to the 'total pain' experience of a patient. The concept of 'total pain' is a hallmark of palliative care as Cicely Saunders first coined the term in the 1960's to describe pain as a key to unlocking other problems and as something requiring multiple interventions for its resolution. From that viewpoint Saunders formulated the idea of total pain as incorporating physical, psychological, social, emotional and spiritual elements (Saunders, 1964). Figure 2 shows a model with total pain being the hub of the model from which it is influenced by a number of factors such as physical, anxiety, anger and depression (O'Neill and Fallon, 1997). But each of the factors influencing total pain is multidimensional in its own way and therefore there are many iterations for how a model of total pain can be represented. Effective management of 'total pain' depends on careful and accurate assessment of the many dimensions that can impact pain (Linklater and Leng, 2001).



**Figure 2** 'Total Pain' and some of its influencing factors. (O'Neill and Fallon, 1997, page 802)

#### 2.1.4 Challenges to Severe Pain Management

The overall challenge of palliative severe pain management is to achieve effective relief with minimal side effects to all patients in need of pain interventions (Caraceni et al., 2002). Success in meeting that challenge requires characterization of pain syndromes, determination of optimal management strategies, identification and resolution of barriers to implementation of such strategies and monitoring of outcomes for purposes of continual quality improvement (Caraceni et al., 2002).

Although all pain is distressful to patient, families and healthcare clinicians, this dissertation focuses on severe pain management because it is particularly distressful. Furthermore clinicians may be less comfortable managing severe pain as opposed to milder pain occurrences. A survey of cancer pain management in Quebec found that although physicians feel confident in their abilities to manage pain they remain overly reserved in their immediate response to patients with severe pain (MacDonald et al., 2002). Furthermore clinical accuracy of pain management is especially poor when assessing patients with severe pain, suggesting that inferences about subjective states of a patient's pain episode may be most uncertain at a level of patient distress that is most clinically relevant (Ingham and Portenoy, 1998).

Further challenges to managing severe pain include the overall complexity of pain itself. Cancer related pain is a heterogeneous group of over 100 pain syndromes with varying underlying pathophysiologies (Cherny, 1998; Grond, Zech, Diefenbach et al., 1996) and most patients with advanced cancer have two or more types and/or etiologies of cancer-related pain (Foley, 1985). Franks et al. (2000) add that severe pain is not properly managed in 20-40% of cases. Finally the Oxford Textbook of Palliative Medicine identifies a number of difficult pain problems including neuropathic pain, breakthrough pain, pain in delirious patients and opioid poorly responsive pain (Ingham and Portenoy, 2003), all of which may require specialized management approaches. Difficult pain problems are a particular challenge to severe pain management in that such pain may not respond to standard protocols, and in some cases the pain could be made worse by rapid opioid escalation.

The above challenges speak to the complexity of SPM and that complexity provides a challenge to developing SPM resources that contain both the necessary breadth and depth of material. But the fact that clinicians have difficulty managing severe pain and the distress that severe pain provides to patients makes it imperative that we develop methodologies to help with the management of severe pain.

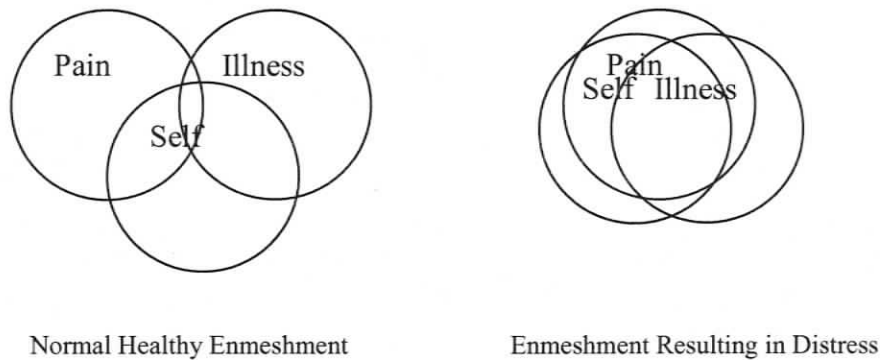
### **2.1.5 Conceptual Models of Pain and Palliative Care**

Palliative care is quite rich with its own conceptual models with respect to both pain and the delivery of palliative care. Incorporating such models into practice can draw attention to meanings of pain to help clinicians with making sense of a patient's pain episode. Such models also provide the means of making pain more 'visible' and help to provide a common bridge or language between clinician and patient views of pain, both of which will enhance severe pain management.

One such model is the Schema Enmeshment Model of Pain (SEMP) by Pincus and Morley (Pincus and Morley, 2001). The Pincus and Morley SEMP is key to the development of some of the results from this dissertation and will be described in detail. The concept of a schema represents the way that experiential knowledge has been

articulated and differentiated in memory and the schema functions to organize the processing, retention and retrieval of information (Pincus and Morley, 2001).

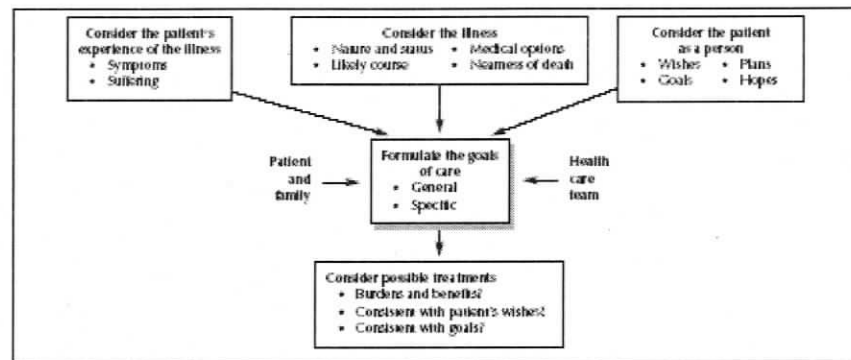
Pincus and Morley define three schemas: pain, illness and self (shown in figure 3) and the way in which a person is impacted by pain will depend on how pain related information is processed and retrieved from the schemas. The pain schema represents the temporal, spatial and sensory intensity aspects of a pain episode and represents the temporally immediate properties of pain. The self schema is dynamic, incorporates information over the life span, and gives priority to information pertinent to the self over more general world relevant information. The illness schema contains information related to affective and behavioral consequences of illness such as goal attainment and autonomous functioning. The extent to which the three schemas become enmeshed (the degree of overlap between schemas) is used to represent different visualizations of pain. For example in figure 3 the left image is normally healthy enmeshment whereas the right image shows enmeshment of the three schemas that is indicative of distress. Enmeshment represents an undesirable outcome as it means that pain and illness have become integrated with the essential aspects of the self, which brings cognitive and emotional consequences such as distress (Pincus and Morley, 2001).



**Figure 3.** Schema enmeshment model of pain as defined by Pincus and Morley (2001).

A second conceptual model of palliative practice that is relevant to this research is the Latimer Framework for End-of Life Care. The framework first published in 1991 is an approach for formulating goals and treatment plans for seriously ill and dying patients

(Latimer, 1991). Unlike the Schema Enmeshment Model which focuses on pain and how to make sense of a patient's pain experience the Latimer model is designed to inform about general decision making and treatment in palliative care. In the Latimer model the goals of care are formulated by both the patient/family and health care team after considering three aspects of the patient: experience of illness, the illness itself and the patient as a person (Latimer, 1991). The Latimer model is shown in figure 4.



**Figure 4.** Latimer model for formulating the goals of care and treatment plans for seriously ill and dying patients. (Latimer, 1991).

The inherent challenge from conceptual models is to be able to incorporate them into practice. The models provide a means of making pain more visible, which is identified as a practice support opportunity in section 2.1.6.1.2 by Lasch (2001) but we need to contextualize the models to help clinicians relate such models to real patient cases. Furthermore we need to provide clinicians access to such models so they can be used to support practice. In order to use Pincus and Morley's SEMP as a means of helping a caregiver understand a patient's pain the schemas must be contextualized to represent actual data elements that are reflective of patient cases. Pincus and Morley do not define what specific data elements constitute each of the three schemas, for example they refer to the pain schema as having temporal, spatial and intensity elements. A further challenge with the SEMP is that it is a general psychology model of pain and therefore it was not intended to be specific for any domain of medicine. Section 2.1.3 of the review described the total pain concept of palliative care and how pain is viewed as a multidimensional concept. Therefore the SEMP will need refinement to be used in palliative care. The

Latimer Model presents in a similar challenge in that we need to contextualize concepts such as 'Patient as a Person' And 'Patient Experience of Illness' into actual data elements to help understand empirical patient cases.

The challenge with the above conceptual models is to date there has been little work extending either the Pincus and Morley SEMP or the Latimer Model to clinical practice. The only published research has seen the SEMP instantiated as the Pictorial Representation of Illness and Self Schema (PRISM) tool (Denton, Sharpe and Shreiber, 2004) to measure the degree of suffering in patients with Systemic Lupus Erythematosus. However despite the challenges in using the Latimer and SEMP in palliative practice it is recognized that such models can enhance palliative practice. Downing (2006) introduces the SEMP into palliative care and describes the SEMP and the concept of enmeshment as useful in understanding some aspects of the relationship between pain and suffering. Downing also describes the Latimer model as being useful to help clinicians to work with patients, families and team together (Downing, 2006).

### **2.1.6 Practice Support Opportunities in SPM**

Three specific opportunities for practice support in SPM are discussed: support opportunities for assessment and management of pain, common language between clinicians and patients and reflective practice for helping clinicians to attend to their own well being.

#### **2.1.6.1 Practice Support Opportunities for Pain Assessment**

Assessment of severe pain is difficult given the challenges described in section 2.1.4 such as recognition of difficult pain problems as well as the need to consider the uniqueness of each individual patient as portrayed in the total pain concept from section 2.1.3.

Fainsinger (2001) describes how we need to go 'beyond the basics' of pain assessment, a part of which involves recognizing the multidimensional aspects of a pain episode in order to prevent inappropriate application of opioid regimens such as the WHO three step ladder (Fainsinger, 2001).

Fainsinger (2001) states that although measures such as verbal or numerical scales are used to assess a patient's pain we need to understand the multidimensional perspective of pain as problems can arise by simply following guidelines such as increasing a patient's opioid for pain relief if they report severe pain as that has led to many reports of side effects such as myoclonus, hallucinations, agitated delirium and seizures, all of which will amplify pain and suffering rather than relieving it (Bruera and Pereira, 1997).

Fainsinger further provides examples of the types of sense making of pain syndromes that are necessary such as differentiation of neuropathic and incidental pain syndromes and as well as the need to understand the propensity of terminally ill patients to become dehydrated and have reduced kidney function, which leads to build up of opioid metabolites and symptoms such as myoclonus and delirium, which may be incorrectly interpreted as pain causing further increased opioid doses (Fainsinger, 2001).

Fainsinger (2001) points out that although some patients describing their pain as 8/10 might be accurate from a physiological perspective, others may mean "My back hurts a bit but I feel absolutely awful about my circumstances. I cannot cope with anything. Are you smart enough to hear my message?" (Fainsinger, 2001). Cohen et al. (2004) describe a similar concept by stating that we need to understand the meaning of symptoms, as distress and anxiety are sometimes described as symptoms. Patients may exhibit characteristics associated with depression, despair or anxiety with signs and symptoms that are nonexistent (Shvartzman et al., 2003). Going beyond the basics of pain assessment includes understanding the context of a pain episode such as identifying the differences between distress due to symptoms such as pain, and distress due to existential or psychosocial reasons (Payne, 2000).

#### **2.1.6.2 Practice Support Opportunities for Pain Management**

Although there is consensus pain management protocols such as the World Health Organization three step ladder that have been reported as effective at managing cancer pain, it has also been reported that the ladder failed to provide sufficient relief to 10–20% of advanced cancer patients with pain (Ahmedzai, 1997). Others have criticized the

ladder as being too mechanistic or cookbook and not recognizing individual uniqueness (Twycross, Harcourt and Bergl, 1996).

A critical part of pain assessment is ensuring that it leads to effective management. Gordon and Dahl (2004) state although there have been many efforts at enhancing pain assessment and documentation such efforts have not been extended to pain management. Areas in pain management that have been identified as deficient include access to non-drug techniques for pain relief and assessment of contributory psychosocial issues of pain (MacDonald et al., 2002); lack of knowledge of pain medications and adjuvant therapies, and ambivalence and discomfort about dealing with the practical implications/meaning of pain's subjectivity (Lasch 2002). A 2005 review of the educational needs of palliative care nurses in Quebec found that managing emotional impacts and emotional needs of the dying patient, understanding issues around personal autonomy and dying person's rights, and the use of nonpharmacological interventions for pain were among the top ten identified educational needs (Fillion , Fortier and Goupil, 2005).

Allard et al. (2001) state that education and support for pain management must help pain to be made more 'visible' and also must provide clinicians the necessary tools for changing their pain management practice. Lasch (2002) details the need for an interactive component to pain management as clinicians (especially students learning pain management) need to be steered in the correct direction. Lasch (2002) states "If they're not told to focus on it (multiple aspects of pain management), they don't".

However the challenge is developing approaches for making pain more 'visible' given the subjective nature and individual uniqueness of pain. One way of making pain more visible is linking conceptual models about pain (such as the Pincus and Morley SEMP) and empirical clinical cases, and then developing tools to incorporate such material into practice settings to provide clinicians the support needed for changing of pain management practice. To date there are no such tools available in palliative care.

### **2.1.6.3 Common Language Between Patients and Clinicians**

One of the opportunities for practice support is to promote a common language for severe pain as one of the biggest challenges to a common understanding of pain is the lack of a common language to promote such a common understanding. Torke et al. (2004) emphasize that pain management has both pharmacologic aspects of managing pain as well as the means to effectively communicate with a patient in pain. Although a clinician needs to know all the contributions to pain including physiological and social factors, Merskey (2005) wonders how a physician is to know all those things considering that clinicians and patients use different language to describe pain. Engel (1980) has stated that knowledge about a patient's pain needs to be negotiated between the patient and clinician implying the need for common understanding between clinicians and patients. Williamson et al. (2005) add that when a bodily cause of pain is evident it is easier for a patient and clinician to come to concordance about the pain. But they further emphasize that absence of "evidence" of pain is not evidence of absence of pain, but rather a failure of language Williamson et al. (2005).

But in order to deliver practice support to promote a common language about pain we need a means of understanding how pain presents and is described from all perspectives including physical and psychosocial. We then need a way of incorporating such a common language into clinical practice.

#### **2.1.6.4 Reflective Practice**

The concept of reflective practice refers to a process that starts when a clinician encounters a phenomenon that is outside their current knowledge such as an unexpected outcome in a case (Schon, 1983). The process of reflection in action beings where the clinician defines the problem and the dynamics associated with it, decisions to be made and the means of making the decisions. Schon (1983) also describes reflection on action that occurs as a reconstructive mental review that provides an opportunity to learn from the earlier processes.

Reflection in practice has been described as a vehicle for learning by intertwining practice and theory (Schon, 1983). There is evidence that reflective practice can enhance

decision making and learning in palliative care by transforming abstract theory into knowledge that is familiar to clinicians and grounded in the workplace (Smyth, 1992; Greenwood, 1998). Specific areas where reflective practice has been described as useful is in dealing with ethical dilemmas (Tishelman et al, 2004), which is an important component of palliative care. Encouraging clinicians to engage in reflection in practice can help establish connectivity between theory and practice.

Reflection on practice has been described as particularly important to health care clinicians who work with the terminally ill as there is a cumulative effect on ones self from being in the presence of so many who suffer (Vachon 1995; Vachon 2000). Working with patients in severe pain presents a specific example of a situation that is difficult on clinicians and where care of one's self through self reflection is needed.

The challenge is to incorporate reflective practice into clinical settings to encourage clinicians to self reflect. Clinicians acknowledge the need for self reflection but it is just one more thing to do in practice settings that are already pressed for time. With respect to self reflective practice Cooke presents a set of questions to encourage self reflection and a set of strategies to encourage self care one of which is keeping a journal (Downing, 2006). Although the theory and rationale around reflective practice has been well researched there are few empirical studies that provide tools for doing reflective practice (such as access to journals or logs) and then assess the effect of providing ongoing access to such tools.

### **2.1.7 Computer Based Tools for Palliative Severe Pain Management**

Although fields such as chronic disease management (Hoffmann, Russell and Mckenna, 2004; Balas et al., 2004) and intensive care have been quite active in the development of computer based tools there has been much less development of such tools for use in palliative care. Most computer based tools for pain management in palliative care are for collecting assessments. Such systems include PAINReportIt (Wilkie et al., 2003), an electronic extension of the McGill Pain Questionnaire (MPQ) and a PDA based acute pain management system (APMS) developed at Queen's University in Ontario that

records pain scores, medications and adverse effects from the medication (VanDenKerkhof et al, 2003).

Although the above pain assessment tools facilitate assessment and documentation of data, which is what they are intended to do, they do not provide guidance details such as how to conduct the assessment, interpret the assessment results or manage the pain. A comment from a physician using the APMS was that although it enhanced data collection for research and audit purposes it did not provide the supporting resources such as assessment tools or templates to carry out a more comprehensive assessment (VanDenKerkhof et al, 2003).

## **2.2 Health Informatics**

### **2.2.1 Information Management**

Shortliffe (2001) states that a large percentage of a health professional's activity is information management, which includes tasks such as obtaining information about a patient, reading scientific literature and devising strategies for patient care. Tools that facilitate information management can range from systems that provide data to focus attention and help support decisions (but the ultimate interpretation of how to apply the data is left to the clinician) to systems that obtain patient specific data and perform an inference in the data to provide patient specific recommendations such as through a care plan (Shortliffe, 1989).

But information needs to be managed effectively as it is a key element in the decision making process (Hurtado and Parets, 2001). Simply providing access to information will not necessarily enhance decision making or problem solving and will more likely cause types of information overload such as cognitive overload, knowledge overload and communication overload (Eppler and Mengis, 2004). Contributing factors to information overload are the information itself (quantity, intensity and quality), the person receiving, processing or communicating the information, the tasks or processes that need to be completed using the information and the information technology and how it is used to manage information (Eppler and Mengis, 2004).

The complex relationship between information and problem solving has been identified through a set of 5 propositions of human problem solving (Newell and Simon, 1972).

1. Human problem solving is information processing.
2. Information processing is dependent on the characteristics of the problem solver and the task.
3. There are individual differences in problem solving.
4. Different tasks require different information processing.
5. The nature of the task and intelligence of the problem solver determine problem-solving behavior.

Zeng and Cimino (2001) extend Newell and Simon's five propositions by proposing different views of data as a means of dealing with information overload. Views can help provide the information needs of different users as well as help focus attention to certain aspects of the data. (Zeng and Cimino, 2001). Information views have been applied extensively to information retrieval from medical records such as concept oriented (heart), source oriented (lab, diagnostic imaging) or time oriented (certain dates) views (Zeng and Cimino, 2001). However one overall challenge to developing concept views is how to make sense of the concepts themselves. Concept views require a method for developing the views and an understanding of how information needs to be presented to facilitate problem solving. Currently there is no comprehensive method for making sense of the concepts and relationships in a domain area to develop views such as problem solving methods around information retrieval. Data-concept links need to be inferred, established or otherwise created and ways by which such linkages are acquired, modeled, stored, maintained, and utilize such information are still issues for investigation (Zeng and Cimino, 2001).

### **2.2.2 Informatics Based Practice Support**

It has long been recognized that a gap exists between clinical information that could be used for practice support and means of implementing that information. In the above

section the problem of information overload was explored and that problem highlights why simply putting forward information is not an effective solution. Waitman and Miller (2004) offer a number of suggestions for how to enhance the presentation of clinical information for use in practice including making available reference and supporting material and ancillary information relevant to clinician's thought processes that support their attempts to follow information. In fact Waitman and Miller (2004) emphasize that clinicians often take a 'show me' stance and therefore do not only want a recommended intervention but also detailed steps involved in its implementation.

Informatics based solutions provide one means of structuring and formalizing information to facilitate data analysis and information retrieval, both of which are necessary to develop applications such as practice support tools. Examples of informatics based solutions are decision aids, which have been shown to reduce information processing demands and promote communication and comprehension of domain knowledge (Ruland, 2004) and tools such as on line search engines and case base retrieval databases that have proven helpful for managing information (Davenport and Prusak, 1998).

Bakken (2001) proposes that an informatics infrastructure is needed to support evidence based practice. The infrastructure includes three types of informatics based solutions: standardized terminology and structures; informatics competencies such as supporting the retrieval and application of information to a particular task; and the use of informatics solutions such as data modeling and establishment of decision making techniques to enhance problem solving. Although Bakken is correct that such an informatics infrastructure is necessary, the challenge is how to make sense of practice settings to understand the information and terminology needs and how those needs are applied to processes such as problem solving so that informatics based solutions can be developed.

Another aspect of applying information for practice support is structuring the information so it fits the appropriate context. Knowledge takes information one step further in that it involves the articulation and characterization of information so that it can be applied

within a particular context. (Van Elst and Abecker, 2002). Section 2.2.1 described the need for information management but knowledge also needs to be managed. Knowledge management (KM) is concerned with the representation, organization, creation, acquisition, use and evolution of knowledge (Jurisica, Mylopoulos and Yu, 2004). However to build technologies for KM we need to further our understanding of how individuals, groups and organizations use knowledge and how we can build tools that facilitate the delivery of knowledge to the user.

### **2.2.3 Ontologies**

Ontologies represent a type of informatics based solution that provides a means of structuring and representing the knowledge of a domain area, which then enables that knowledge to be applied to development of artifacts such as information systems (IS) (Evermann, 2005). Since the 1990's Ontologies have gained popularity as a means of structuring knowledge that can allow a shared and common understanding of a domain (Studer, Benjamins and Fensel, 1998). In the context of IS research an ontology is formally defined as 'a specification of a conceptualization that is designed for reuse across multiple applications' (Chandrasekaran, Josephson and Benjamins, 1999). In lay terms an ontology in the context of IS can be defined as a description of the concepts and relationships in a domain area.

Weber (2003) describes ontologies as relevant to the IS field in that they are the best base for building theories about IS representation phenomena (Weber, 2003). With regard to knowledge management Van Elst and Abecker (2002) describe ontologies as having a major purpose of enabling communication and knowledge reuse between different actors by finding an explicit agreement on common ontological commitments (which basically means having the same understanding of a shared vocabulary).

However, ontologies are not programmatic representations but rather are intended to be conceptual representations of a domain and thus free of technical specifications (Edginton et al., 2004). Further, ontologies are not intended to be merely vocabulary nor taxonomy but rather ontologies have been described as serving multiple purposes

including a schema for knowledge bases, controlled vocabulary to drive searching and navigation through large collections of documents to facilitate organization of knowledge (Noy and Klein, 2004) and an explication of implicit details and systemization of knowledge (Mizoguchi, 2003). Three ways ontologies can be used in IS design are as a benchmark to evaluate models used in systems development, to provide a set of concepts to model systems and to reason about their characteristics, and finally to define the meaning of information and knowledge that will be available through an IS (Wand and Weber, 2004).

Because ontologies can represent concepts, relationships and the processes that act on the concepts, there are different ways of structuring ontologies to represent different types of knowledge. One distinction that is sometimes seen in the literature is the separation of domain and task ontologies (Mizoguchi et al., 1995; Studer, Benjamins and Fensel, 1998). Domain ontologies represent the knowledge about a domain area as well as constraints that are applied to the structure and content of the domain knowledge (Van Heijst, Schreiber, and Wielinga, 1997). Task ontologies describe the inherent problem solving structure such as defining the goals or tasks that must be achieved during problem solving (Mizoguchi, 1995).

#### **2.2.4 Problem Solving Methods**

Problem solving methods are an informatics based solution that works complementary to an ontology. Whereas ontologies provide the structure of the concepts and relationships around a domain area (domain ontology), and the high level tasks of the domain (task ontology), problem solving methods provide the reasoning process of a knowledge-based system (KBS) in an implementation and domain independent manner (Benjamins and Motta, 1998). Fensel and Motta (2001) formally define problem solving methods as a task oriented systemization of a field. Studer, Benjamins and Fensel (1998) characterize problem solving methods as:

- A method that specifies which inference actions have to be carried out for achieving the goal of a task.

- A method that defines one or more control structures over these actions.
- Knowledge roles that specify the role that domain knowledge plays in each inference action. These knowledge roles define a domain-independent generic terminology. There are two types of roles: static roles describe the domain knowledge needed by the problem solving method; dynamic roles form the input and output of inference actions.

For example 'diagnosis' would be represented in the task ontology whereas a problem solving method would define specific means for achieving a diagnosis such as a decision tree or heuristic algorithm for matching signs or symptoms (Studer, Benjamins and Fensel, 1998).

Much of the existing research on problem solving methods has revolved around developing methods that can be reused across applications. Fensel and Motta (2001) point out that it is possible to reuse problem solving methods for different domains (i.e. medicine or books) or tasks (i.e. selection or diagnosis).

While reusability has definite advantages it also limits the amount of domain specific knowledge that can be applied to a problem solving method. Further most problem solving method research has developed a method that performs a single task such as heuristic classification or matching and that limits its usability where problem solving may be a continuous process or set of tasks.

### **2.2.5 Existing Ontology and Problem Solving Method Based IS Development**

There has been some application of ontologies to IS research in healthcare with much of the work revolving around implementation of clinical guidelines. One such example is the EON<sup>2</sup> project developed at Stanford University (Musen et al., 1996). EON guideline model presents an extensible set of ontologies covering different aspects of concepts and relations that are needed for encoding clinical practice guidelines and clinical protocols in a form suitable for generating patient-specific recommendations (Musen, 1998). Another

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<sup>2</sup> EON is not an acronym but rather is the name of a Greek god

example of an ontology based system is the GASTON framework described by de Clercq et al (2001). Similar to EON, GASTON uses ontologies and problem solving methods to create guidelines to solve clinical problems such as recommendation of medication for blood pressure or to determine eligibility for clinical trials. Aside from clinical guidelines, other ontological approaches in healthcare have included modeling operating room workflows and decisions (Hajdukiewicz et al. 2001) and patient monitor alarms in intensive care wards (Torralba-Rodriguez et.al, 2003).

### **2.2.6 Summary of Literature Review and Associated Challenges**

The literature review has described the need for adequate pain management, presented the challenges to providing severe pain management and also identified some areas where practice support for severe pain management would be beneficial. The research challenges that come out of the palliative care section include one, the need to find methods for making sense of the complexity of palliative SPM, two, identifying ways to provide practice support to help clinicians manage that complexity and three, we need a way to bring the richness of conceptual models of pain and palliative care into practice settings to allow them to enrich clinical practice by helping make pain more 'visible'.

Informatics based solutions such as ontologies and problem solving methods present a means of enhancing SPM by providing the means of modeling knowledge of the SPM domain and how problems are solved within the domain. However, the methodological issues around ontology development is there remains few studies around how to develop an ontology in a domain area that conceptualizes the reasoning and information definitions necessary of the domain while still being empirically based. A further challenge how to extend such conceptual models into IS design. Wand and Weber (2004) state that ontologies are relevant to IS design as ontologies represent the world as perceived by a group of humans and our IS will only be as good as our ontologies. The challenge arising from that statement is that we need enhanced approaches to obtain and articulate knowledge about a domain area such as SPM so it can be formalized into an ontology. A similar challenge arises in that although problem solving methods have been successful when applied to specific problems we need the means of representing

problem solving methods as algorithms that can provide practice support to a continuum of practice. The need to enhance our ability to formalize knowledge about a complex domain area into an ontology and set of problem solving methods that model the practice support requirements of a domain area is one of the motivations for this research.

Further methodological challenges are expressed by Green and Rosemann (2000) who state that there is little theoretical or conceptual guidance for how to apply IS knowledge to the design of IS tools such as the computer based tool developed in this research. Further, Van Heijst , Schreiber and Wielnga (1997) point out that to use ontologies for tasks such as knowledge management they must be imbedded in a methodology. The challenge from both of the above citations is to identify a suitable methodology for capturing the requisite knowledge from a domain area, making sense of and applying that knowledge to ontology and PSM development and then implementing the ontology and problem solving method as IS tools. That challenge provides the motivation for this research as it uses a Grounded Theory-Participatory Design guided methodology to capture and code data around SPM to inform development of IS based solutions. Those IS solutions are then implemented as a computer based practice support tool for palliative care.

## **Chapter 3 – Research Methods**

### **3.1 Basis for Research**

Although there has been much research on palliative pain there is limited research on severe pain, particularly around providing practice support for enhancing severe pain management that supports the complete spectrum of assessment, interpretation and management. However such research is necessary as chapter two identified the importance of adequate severe pain management as well as the barriers and challenges that prevent it. This study draws on the need to better understand severe pain and the complexity contained within it so that we develop supporting material to enhance severe pain management. Expert clinicians use a hybrid of knowledge that contains experience and intuition developed through years of practice. However if we are to formalize that knowledge to allow it to become practice support material we need a means of unpacking, making sense of that knowledge and then classifying and codifying it to provide the basis of practice support material. This study achieves such formalization by using a grounded theory guided method with three palliative data sources to develop a set of informatics based solutions that provide structure, vocabulary and navigation to the severe pain knowledge. That knowledge was then implemented in the form of a computer based practice support tool for SPM.

### **3.2 Research Methods**

This dissertation uses four methodologies: two methods are used as a hybrid grounded theory – participatory design (GT-PD) guided method, the third method is prototyping and the fourth method is usability testing. Each method is described in the forthcoming sections followed by a discussion of the rationale of why those four methods were chosen over other methods.

### **3.3 Grounded Theory-Participatory Design Guided Method**

The Grounded Theory-Participatory Design (GT-PD) guided method uses the principles of traditional GT but it diverges from traditional GT. The method also uses aspects of PD

to acquire the data for GT coding. Traditional GT and PD methodologies will be described followed by a description of the GT-PD guided method used in this dissertation.

### **3.3.1 Traditional Grounded Theory**

GT was developed for the purpose of studying social phenomenon from the perspective of symbolic interactionism, which is the study of construction, maintenance and change of social institutions. (Glaser and Strauss, 1967). GT emerged from the works of Glaser and Strauss in the 1960's to challenge the view that qualitative research only produced descriptive case studies and could not be applied to theory development (Glaser and Strauss, 1967).

### **3.3.2 Data Collection and Coding in Grounded Theory**

GT is a general methodology for developing theory that is ground in data that has been systematically gathered and analyzed. GT can be used with different methods for collecting data, which can include participant observation, in-depth structured interviews and focused and directive interviews. (Bowers, 1988). Likewise, there are different categories of data sources including field data (observations and interview data) existing artifacts such as operating or policy manuals and research literature. Regardless of the methodology used to collect the data and the types of data sources used, GT involves three cycles of coding the data: open coding, axial coding and selective coding. (Strauss and Corbin, 1990). Strauss and Corbin (1990, p. 57) describe coding as "the operations by which data are broken down, conceptualized, and put back together in new ways". The codes are generated and validated through a process called constant comparison, where data sources are continuously compared against each other in order to both create new codes and validate and refute existing codes. Constant comparison involves four stages: comparing incidents applicable to each category, integrating categories and properties, delimiting the theory and writing the theory (Glaser and Strauss, 1967). Each of the three stages of coding is completed when theoretical saturation is reached, defined as the point at which no further codes or relationships emerge from the data. The three types of

coding from the Strauss and Corbin GT method are described briefly (Strauss and Corbin, 1990).

- **Open Coding** – Open coding involves the initial analysis of the data. The initial coding of the data requires detailed analysis of the data, which can take place in a very detailed analysis such as line by line or more holistic phrase by phrase or sentence by sentence analysis. Line by line analysis is the most time consuming but also the most generative in terms of codes and is recommended for initial coding of data. Codes are names or labels given by the researcher to events activities, functions, relationships, contexts, influences, and outcomes. Proper open coding is important as the codes that arise from open coding form the basis for later aggregation into concepts (or core codes) in axial and selective coding. Strauss and Corbin (1994) emphasize how the open coding process while procedurally guided, is fundamentally interpretive in nature and must include the perspectives and voices of the people whom they study (Strauss and Corbin, 1994).
- **Axial coding** – Axial Coding extends the initial level concepts and categories from open coding by establishing connections in new ways between categories and sub-categories (Strauss and Corbin, 1990). Strauss and Corbin stress the importance of using a model in the form of a ‘paradigm model’ during axial coding for reassembling fractured data. The coding paradigm has 6 components to it: causal conditions, phenomena, context, intervening conditions, action/interaction strategies and consequences (Strauss and Corbin, 1990). (Strauss and Corbin, 1990); Page 97) describe the paradigm model “*In axial coding our focus is on specifying a category (phenomenon) in terms of the preconditions that give rise to it; the context (its specific set of properties) in which it is embedded; the action/interactional strategies by which it is handled, managed, carried out; and the consequences of those strategies.*”. The coding paradigm provides density and precision to the GT by making explicit connections between categories and sub-categories (Strauss and Corbin, 1990).

- **Selective coding** – Selective coding involves the establishment of a core category or central phenomenon and linking all other categories to the core category, again using the paradigm model. Glaser details a number of core category criteria including: being central, reoccurring frequently and connections with other categories comes quickly and richly (Glaser, 1978). The idea is to create a single storyline around which everything else is draped. All categories are related to the core category and the relationships are validated and refined. At the conclusion of selective coding all the categories are integrated together and a GT is established.

GT differs from other research methods in that data gathering and analysis are done as a continuous cycle, as the initial data gathering and analysis cycles influences later cycles. Most other research methods follow a more linear path and gather most if not all of the data before proceeding to analysis. Eisenhardt describes a number of advantages from the cycle of constant data gathering and analysis including giving the researcher a head start in data analysis and providing flexibility in data collection as the researcher has freedom to make adjustments during the collection process, should the theory development process warrant such adjustments (Eisenhardt, 1989).

One aspect of the Strauss and Corbin method that has been criticized in the research community is their use of a coding paradigm that acts as a framework for developing GT codes. Glaser believes that the coding paradigm ‘forces’ theory rather than allowing it to naturally emerge from the data through constant comparison (Glaser, 1992). Research using GT has also been critical of the coding paradigm. Sarker, Lau and Sahay (2001) found it too constricting and Urquhart (2001) reports practical problems using coding paradigm within the GT coding process. In contrast to the above studies where the authors at least attempted to use the coding paradigm, other studies have chosen not to include it including Eisenhardt (1988) and Orlikowski (1993). However it should be noted that not including the coding paradigm has not impacted the quality of the research as the Orlikowski (1993) paper was awarded Management Information Systems Quarterly Best Paper award of 1993.

### **3.3.3 Application of Grounded Theory In Practice**

Although the roots of GT were developed through studying phenomena within sociology, GT has been used in a number of disciplines including education and nursing. GT has also been used as a methodology for studying information systems in practice as described by Orlikowski (1993), Baskerville and Pries-Heje (1999) and Sarker, Lau and Sahay (2001). Of particular relevance to this dissertation are two GT projects in health informatics. Sjoberg and Timpka (1998) used GT for theory development of a hospital systems design project while Ash et al. (2003) used GT for evaluation of a physician order entry system. It is significant to note that other studies have adapted the GT method as was done in this research and did not completely follow GT in the traditional sense. Baskerville and Pries-Heje(1999) and Timpka (1998) used aspects of the GT method in combination with other methods. The three GT coding cycles was a common piece to be extracted from the GT method and combined with other research methods (for example Baskerville and Pries-Heje(1999) combined GT coding and action research) as it provides a systematic approach to coding data.

### **3.4 Participatory Design (PD)**

The goal of participatory design (PD) is not only to design a product but rather to ensure the usability and utility of the product by engaging end users in design (Shrader, Williams, Lachance-Whitcomb et al., 2001). Participatory design first originated in Scandinavia to allow software developers and users of the software to collaboratively develop and refine new technologies (Spinuzzi, 2005). Participatory design is a way to understand knowledge by doing and to make sense of the traditional, tacit and often invisible ways that people perform their everyday activities (Spinuzzi, 2005). The object of study in participatory design is the tacit knowledge developed and used by those who work with technologies (Spinuzzi, 2005). There are two guiding principles of PD: democracy of participation in all aspects of the design and strong and effective participation (Shuler and Namioko, 1993).

PD focuses on research to bridge the divide between research and practice by engaging researchers and practitioners to value the knowledge, experience and expertise of all involved (Shrader, Williams, Lachance-Whitcomb et al., 2001). In effect, PD becomes a mechanism for researchers and practitioners to learn through interaction with one another. PD has been shown to be a particularly useful method for user requirements analysis such as for IS design. Traditional approaches to requirements analysis (such as document reviews or interviews) often fail to elicit true user needs, because many of these needs are hard to articulate and may be implicit, as part of a shared understanding among users (Gennari et al., 2005). A participatory approach, particularly one that engages multiple users and data sources has been shown to bridge the gap between explicit requirements and real user needs and to bring to light some of the unspoken culture of the work setting (Gennari et al., 2005). Developers of PD state that those two types of knowledge (explicit and tacit) must be bridged with each type being valued by all involved in the research (Spinuzzi, 2005).

There are three basic stages to participatory design research: initial exploration of work, discovery process and prototyping (Spinuzzi, 2005). Initial exploration involves designers familiarizing themselves with how users do their work including workflow, routines and teamwork; discovery process involves formalization and understanding of priorities of the workplace and involves the feedback of several users, and prototyping develops technological artifacts to meet the needs of the workplace as identified in the previous two phases (Spinuzzi, 2005).

The PD method has been used successfully in health informatics design and development projects including (Timpka and Sjoberg, 1995; Sjoberg and Timpka, 1998; Hartswood et al. 2003; and Gennari et al., 2005). Participatory design was chosen as a method for this study because it has been shown to be valuable for helping users to articulate information system needs, particularly needs that are implicit. Gennari et al. (2005) point out that there is often a gap between what users say they need and what they actually need and they found participatory design useful for getting users to articulate all their needs in order to close that gap.

### **3.5 GT-PD Guided Method**

During this research the GT coding paradigm was also found to be too generic and at times not compatible with the context of the data from the data sources used in this study. However it did not seem appropriate to exclude the coding paradigm since it is a component of Strauss and Corbin's method. Further I agree with Strauss and Corbin in the concept of a coding paradigm and that it can help structure the data by providing a common reference for the codes to evolve around.

In order to stay as consistent as possible with the traditional GT method (such as using a coding paradigm) but to also have the GT method best serve the research the use of GT has been altered into a method called a grounded theory-participatory design (GT-PD) guided method. As described in section 3.3.1 traditional GT is a research method for coding data to develop theory but it does not specify where the data comes from. What was done in this research was use PD as a supplementary method to collect the data for GT. The extensive user involvement of PD (described in section 3.5) helped ensure that the data used for GT coding was a rich representation of SPM. In fact the GT-PD relationship was very complementary as the active involvement of the participants through PD enabled the participants to articulate needs and problems that need to be solved during SPM.

An example of the complementary nature of GT-PD is that I was able to acquire and adapt a palliative care SPM model to act as the coding paradigm. Rather than using the Straus and Corbin Coding Paradigm, which was previously described as problematic because of its generic nature, I used a palliative care SPM model that emerged through the participatory nature of the research. The palliative care SPM model used for a coding paradigm is the paper based clinically applied pain information tool (CAPIT) that is described in section 4.7.1.1.2. Using GT coding I was then able to extend and enhance the SPM model through the richness of the concepts and relationships gleaned from the GT. PD's emphasis on interaction with the participants also enabled me to obtain a rich empirically derived vocabulary of palliative SPM. The extension and enrichment of the

data became the basis for the user requirements of the computer based version of CAPIT developed during this research.

I acknowledge that my use of GT differs from traditional GT in that I have changed how I acquired and use the coding paradigm as well as tagging on PD as a supplementary research method. In that context I am referring to my use of GT as a GT-PD guided methodology to acknowledge the fact I am not using GT in the traditional sense but rather adapting it to serve my research.

### **3.6 Prototyping**

Prototyping was used as the research method during the construction phase for design of the computer based version of CAPIT. Prototyping is a method that is used for rapid development of computer systems where the system is developed through multiple iterations called prototypes. Prototyping is part of iterative user-centered design because it enables designers to try out their ideas with users and to gather feedback (Preece et al, 1994). The main purpose of prototyping is to involve the users in testing design ideas and get their feedback in the early stage of development, thus to reduce the time and cost. Prototyping is an efficient and effective way to refine and optimize interfaces and other computer tools through discussion, exploration, testing and iterative revision (Rudd, Stern and Insesee, 1996).

There are different types of prototyping depending on the stage of completion of the prototype (Rudd, Stern and Insesee, 1996). Low fidelity prototyping includes brainstorming and rough or in progress versions of interface designs. Low fidelity prototypes are very fast to design and allow early testing of system interfaces for feedback. Medium fidelity prototypes include more refined versions of interfaces and heuristic evaluation such as screen mock ups. Medium fidelity prototypes enable more comprehensive evaluation than low fidelity prototypes and allow users to actually test screens or interfaces on a computer to evaluate the flow of screens through the system. High fidelity prototypes include working systems that enable field and usability testing to be done. High fidelity prototypes are often developed using a programming language such as Visual Basic or

using CASE tools which enables development of a functional system in a short time period (Leone, Gillan and Rauch, 1997). Aside from different types of prototyping described above there are also different ways prototyping can be applied to IS design. Two such approaches are 'throw away' and evolutionary prototyping. 'Throw away' prototyping develops a basic prototype system in order to discover and understand user requirements after which the prototype is discarded and another systems development method is used to build a working system (Chen and Huang, 2002). Evolutionary prototyping develops an initial prototype that is then refined through a number of evolutions to produce a working system (Wu and Lin, 2000).

The value of prototyping to enable rapid development and feedback of IS in healthcare has been demonstrated by Gennari et al., 2005; Dornan et al., 2005 and Holzinger 2004. Gennari et al. (2005) point out the value of prototyping as enabling rapid capture of design requirements leading to a short time period to develop functional prototypes. In particular the rapid turnaround time of prototyping enables additional design ideas generated during the prototyping to be incorporated into subsequent revisions.

The prototype computer based CAPIT developed in this dissertation is a high fidelity prototype as it is a working system that enables users to do usability testing. Prototyping was selected as the methodology for design of the computer based CAPIT because the fast turnaround time in prototyping allows development of a computer tool while still probing at design approaches and understanding user needs. The version of computer based CAPIT used for usability testing was the third version of the prototype and it included substantial changes from versions one and two based on feedback from both health informaticians and palliative clinicians. Prototyping helped the computer based CAPIT to become more functional both from clinical and informatics perspectives.

### **3.7 Usability Testing**

The usability testing conducted in this dissertation draws on theories of healthcare IS usability testing described in a methodological review by Kushniruk and Patel (2004). Usability of a computer system can be defined as the capacity of the system to allow

users to carry out their tasks safely, effectively, efficiently and enjoyably (Preece et al, 1994). Usability testing refers to the evaluation of information systems that involves testing of participants who are representative of the target population performing representative tasks as they use the system (Kushniruk, Patel and Cimino, 1997).

Usability testing encompasses both ease of use of the system (screens, placement of text, navigation) as well as usefulness of the material in the system, which in this study is how well does the material provide practice support for palliative severe pain management. The duality of both ease of use and usefulness is consistent with the concept of 'usefulness' testing as described in the software development literature. It is important to acknowledge that the term usability may have a different meaning in some computing science literature where it refers to aesthetic details such as navigation and screen layout and does not consider the usefulness of the material. The term usability testing within this dissertation is drawn from the IS definition that considers both ease of use of the system and usefulness of the material.

Kushniruk and Patel (2004) describe nine phases to usability testing outlined as follows:

1. Identification of evaluation objectives – Objectives can range considerably and can include assessment of system functionality and usability, input for refinement of emerging prototypes, evaluating the effects of a system on decision making and assessing the impact of a new technology on clinical practice and workflow
2. Sample selection and study design – Testing subjects should be representative end users of the system being designed. Study designs can vary and can be within group or between group types of designs.
3. Selection of representative experimental tasks and contexts – Testing can range from laboratory settings to naturalistic settings in an actual clinical environment. For laboratory settings it is common to use testing cases or scenarios that are representative of how the system would actually be used.
4. Selection of background questionnaire – A questionnaire may be given before or after testing to obtain information about the subjects experience in health practice or with computer systems.

5. Selection of evaluation environment – Testing environments can range from laboratory settings to clinical settings such as the ward where the system is being developed for.
6. Data collection through video and audio recording of thought processes – Subjects are encouraged to think aloud or verbalize their thoughts while performing usability tasks. Both the computer screens and audio spoken by the tester are recorded.
7. Analysis of process data – The recordings from phase 6 are transcribed and coded using a coding scheme to identify usability problems. Coding categories that have been applied for health information system studies include information content, problems in navigation, comprehension of text and graphics and overall system understandability.
8. Interpretation of findings – Data can be summarized in a number of ways including time to complete tasks, task accuracy and frequency and classes of problems encountered.
9. Iterative input into design – Usability results are integrated into system design and testing may be repeated to assess impact on usability.

During usability testing all user-computer interactions are typically recorded such as by video recordings of the computer screen (Kushniruk and Patel, 2004). Audio recordings are also commonly recorded such as by using the ‘think aloud’ protocol where the users verbalize their thoughts as they use the system. The recordings are transcribed and analyzed using a coding scheme. The coding scheme contains two types of coding categories. First it codes user-computer interactions such as information content (whether the computer tool provides too much information, too little, etc.), comprehensiveness of graphics and text, problems in navigation, and overall system understandability (e.g., understandability of icons, required computer operations and system messages) (Kushniruk and Patel, 2004). Second, it codes cognitive processes that are done during the task.

Usability testing has shown to be an affective means of evaluating healthcare IS as illustrated by Kushniruk et al. (2005).

### **3.8 Rationale for Selection of the Four Research Methods**

The four research methods were chosen because each one makes a distinct contribution to the capture of knowledge, development of a prototype system and evaluation of that system. The four separate methods encompass systems design, development and evaluation and in that sense they are similar to other system development methodologies such as soft systems methodology, which is an action research based systems development method (Checkland, 2000), or evolutionary prototyping. However a goal of this study was to emphasize the context and content of how the system would be used in order to capture and model the detailed practice support requirements for palliative SPM. Berg introduces a concept called the sociotechnical approach for HIS design that refers to the need to understand the interrelationship between the system and the social environment and context of how it is used (Berg, 1999). However Berg himself admits there is no defined sociotechnical approach but rather it comes from balancing the technical and social aspects of a HIS (Berg, Aarts and van der Lei, 2003). Thus methods were desired that would emphasize a focus on content and context to allow contextualization of aspects of the sociotechnical approach.

The soft systems and evolutionary prototyping methods follow a cyclical pattern of problem analysis followed by systems analysis, development, evaluation and feedback, with each phase of the cycle getting relatively equal amounts of time. Because this study focused on content and context to draw out the detailed practice support requirements for SPM, a development method was desired that would enable more time for the capture and organization of knowledge, which involved pushing the actual prototype development to the later phases of the study design. Therefore the soft systems and evolutionary prototyping methods were not an ideal fit for this study.

The use of principles of GT as one of the research methods was for two reasons. First, in order to mitigate concerns about implementing technology into palliative it is imperative

that design and implementation of technology, such as computer based practice support tools be done with consideration of the content and context of palliative practice. The detailed analysis and coding within GT allowed the researcher to obtain that level of detail regarding content and context as the researcher spent significant time both discussing pain management with clinicians as well as observing and documenting pain management on the clinical ward. Those multiple sources of palliative practice allowed the researcher to triangulate the data sources and validate the findings that were developed in this study. Second, although Musen has described ontologies and problem solving methods as defining a theory for the knowledge to solve a task (Musen, 2002), informatics based ontology work done to date has primarily been more concerned with building the ontological model and not explicitly describing how the theory behind the ontology was derived. In order to capture knowledge about the content and context of palliative SPM and provide a means of applying theory to ontology development the GT-PD method was derived. PD provided the means of interacting with the users to capture different data sources and GT provided the methodological rigor to not only build the ontology from an empirical grounding but also trace the ontology back to the concepts and categories from which it was derived. Once the ontology and problem solving methods were developed prototyping was then used to develop the prototype computer based practice support tool. However the largest percentage of time was spent on the GT-PD method to capture and understand the content and context of practice support for palliative SPM.

Usability testing was chosen for this study because it provides a way of obtaining a rich set of evaluation data in a short period of time, which enables the usability results to be cycled into further system design iterations. In that sense usability testing is a good fit with the participatory design and prototyping methods used in this study. The study spent a lot of time articulating and modeling user practice support requirements and therefore it made sense to select a method that allowed evaluation of those detailed practice support requirements. Other evaluation methods that have been used extensively in health informatics include a randomized control study or questionnaire based evaluation (Kushniruk and Patel, 2004). However an acknowledged shortcoming of both of those

methods is they focus on the outcome of how the system is used and not the process and context of how it is used. Further although those methods may indicate that a system does not meet expectations they do not provide extensive details about why the system does not meet expectations. Usability testing evaluates the actual processes and tasks that are done while using the system and the video and audio recording enables detailed analysis to be done on what aspects of the system were well received by the users and what aspects were not well received.

## **Chapter 4 – Research Approaches**

This chapter describes the research questions and objectives, the study design and three phases of the study design; and the study site, participants and data sources used in the study.

### **4.1 Research Questions and Objectives**

The overall objectives of this dissertation are to gain an understanding of the information and processes in palliative SPM, to formalize that understanding into a set of informatics based solutions, and finally to implement the informatics based solutions as a computer based practice support tool.

The research questions of this dissertation are as follows:

1. How can we capture and organize knowledge to extend existing work on development of ontologies within the context of SPM?
2. How to represent problem solving methods as a series of tasks that provide a continuum of practice support for SPM?
3. How and to what extent can a set of informatics based solutions (ontology, problem solving methods and vocabulary) be implemented as a computer based practice support tool for SPM?
4. To what extent does the computer based tool provide practice support for SPM?

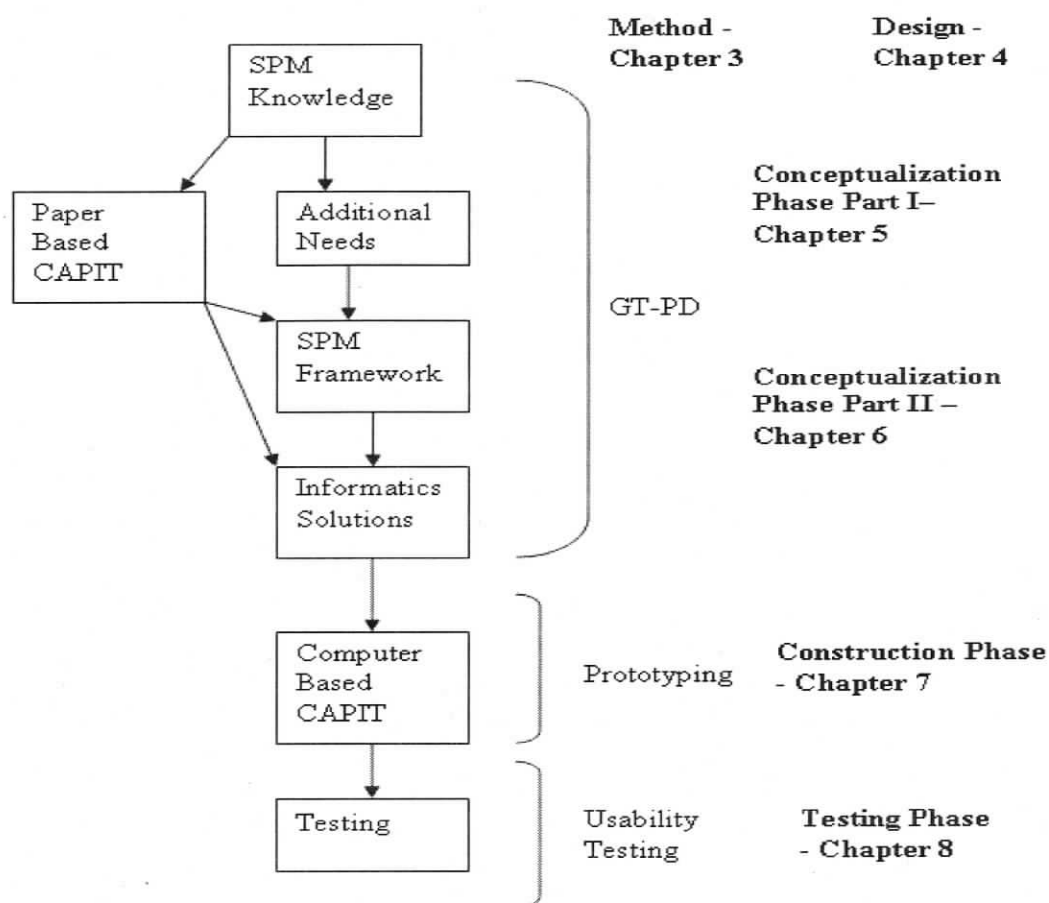
The research objectives to answer the above questions are:

1. To use a grounded theory-participatory design method to obtain and code three palliative data sources into concepts and relationships to make sense of the information and processes used in palliative SPM
2. To formalize those concepts and relationships into a set of informatics based solutions consisting of an ontology, set of problem solving methods and empirically derived vocabulary for SPM.
3. To implement the ontology, problem solving methods and vocabulary as a computer based practice support tool for palliative SPM

4. Perform usability testing in order to test the ability of the computer tool to provide practice support

#### **4.2 Overview of Study Design**

This study was done in three phases: conceptualization, construction and testing. Figure 5 shows a model of the overall study design and indicates where each of the three phases fits within the design. This chapter then discusses each phase in detail. As seen from Figure 5 the three phases flow in a logical fashion for realizing the objectives put forth for this study. The conceptualization phase was done in two parts. Part I applied the GT-PD guided method to the three Palliative data sources (PDS) to develop concepts and categories to make sense of the problem domain of SPM and to understand the additional requirements needed to enhance the paper based CAPIT. Part II used those additional requirements to develop the informatics based solutions. The construction phase used the prototyping method to implement the informatics based solutions as a prototype computer based CAPIT. The testing phase involved usability testing of the computer based CAPIT.



**Figure 5.** Research design for the study showing the relationship to the methods described in chapter 3. The three phases of the study: conceptualization, construction and testing are detailed in sections 4.3, 4.4 and 4.5 respectively.

### 4.3 Conceptualization Phase

The conceptualization phase captured knowledge around SPM from three palliative data sources (PDS): practice experience, patient charts and research literature. The knowledge capture in the conceptualization phase was done in two parts.

Part one of conceptualization used the knowledge from the three PDS to define the problem domain of palliative severe pain management (SPM), the challenges and issues in SPM, a current solution to overcome the challenges and issues in the form of a paper

based Clinically Applied Pain Information Tool (CAPIT) and additional requirements that would make paper based CAPIT more usable.

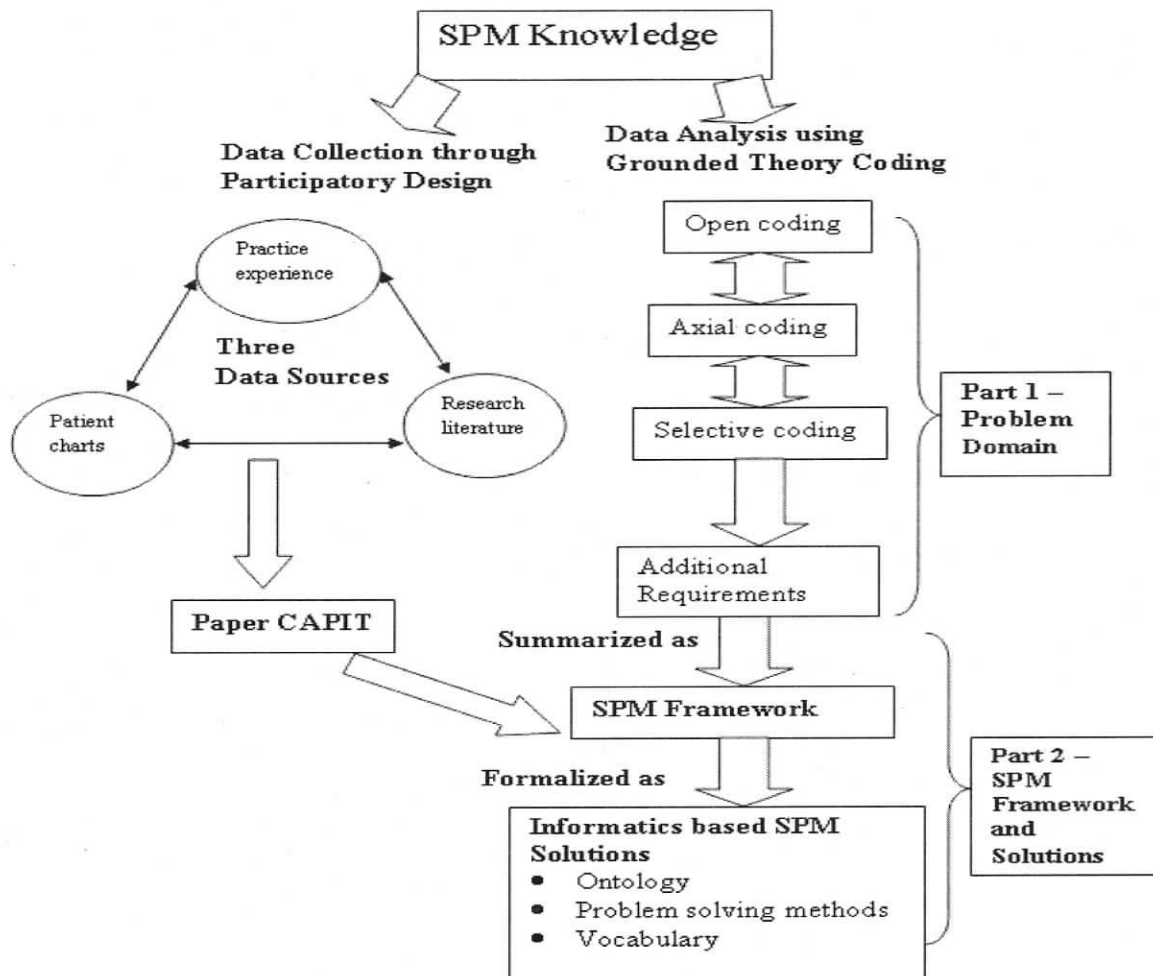
Part two of conceptualization developed a conceptual SPM practice support framework and a set of informatics based solutions for making sense of palliative SPM. The SPM practice support framework was developed through the GT-PD guided method. The SPM practice support framework extends the paper based CAPIT as the paper based CAPIT was the starting point for the development of the SPM but the SPM practice support framework extends the paper based CAPIT by using GT-PD to articulate additional requirements needed as part of SPM. Additional requirements include practice support requirements such as the types of problems that need to be solved, processes that need to be supported and information that needs to be managed in order to enhance SPM.

The SPM practice support framework was then formalized into a set of informatics based solutions for SPM consisting of an ontology, a set of problem solving methods and an empirically derived vocabulary. The ontology represents the overall structure and navigation whereas the problem solving methods represent ways of presenting the additional requirements in order to provide practice support for SPM. The vocabulary is an empirical representation of the terms used in palliative SPM.

The initial GT-PD data collection and analysis cycles involved the practice experience and patient chart data sources, as patient charts and practice experience represent palliative clinical practice, which were logical starting points for development of the GT framework. Once that framework was developed the research literature was incorporated into the study as areas were identified where research literature could inform the study. The research literature was therefore used to substantiate and enhance and not to directly develop the theory or model.

Figure 6 details the conceptualization phase of the study and illustrates the data collection and analysis for the two parts of conceptualization. As illustrated in figure 6 the data collection and analysis in the conceptualization phase followed a cyclical pattern (shown

by the two way arrows in the top of figure 6), which is consistent with how GT is done. As data were collected and analyzed they often identified concepts that would facilitate further data collection and analysis, either to verify and strengthen or refute the results of earlier data analysis.



**Figure 6.** Conceptualization phase of the study showing the two parts of conceptualization

#### 4.4 Construction Phase

The construction phase used the prototyping methodology to implement the informatics based solutions from the conceptualization phase into a computer based CAPIT. The development of the computer based CAPIT was done in rapid fashion to enable feedback about the computer tool to be sought and included in future revisions of the tool.

The construction phase consisted of three tasks. The first task is implementation of the informatics based solutions into a technical view. That provided a view of how the conceptual informatics solutions translate into the computer based CAPIT. That technical view included the representation of the ontology as database tables with the vocabulary becoming data elements within the tables. It also describes how the data elements and the relationships between them become the means of implementing the problem solving methods. The technical view is a back end or 'under the hood' view of the system.

The second task is to develop the user interface view for the computer based CAPIT, which consists of developing the forms, rules, reports and interfaces that the user sees when they interact with the system. For example the database relationships becomes the basis access to data elements and the problem solving methods become rules, queries, screens and the means of navigating through the database content. The vocabulary becomes the terms the user queries on to access data and also enters in a patient case. The interface view is the front end view of the system as seen by the user. Part of the user view also includes a description of how the knowledge that is contained within the computer based CAPIT is balanced. That involves ensuring that the screens and forms are manageable from a user perspective and that the knowledge contained within the system is easy to access and use.

#### **4.5 Testing Phase**

The testing phase involved usability testing of the computer based CAPIT. Testing was conducted with five representative users of the tool, three physicians and two nurses. The three physicians and two nurses practice in palliative care and are experienced in severe pain management. Therefore when they used the computer based CAPIT they were not learning about severe pain such as a novice clinician would but rather they are testing how well the computer based CAPIT provides practice support.

Four testing questions were developed that were offshoots of the research questions from section 4.2 and provide specific details about the testing phase and what specific aspects

would be measured. The four testing questions are described below showing how they relate to the research questions.

1. Does the computer tool contain appropriate content? - Tests research question #1 about how to capture and organize knowledge about SPM to extend existing work on ontology development. The content of the computer tool is based on data obtained through the GT-PD method that was formalized into an ontology?
2. How well does the computer tool fit within the workflow of the users? – Tests research question #2 about how to represent problem solving methods as a set of tasks that provide ongoing practice support and looks at whether the tasks in the problem solving methods fit with workflows.
3. How useful and usable is the computer tool? – Tests research question #3 about how and to what extent can the informatics based solutions be implemented as a computer based tool. The features of the tool are technical implementations of practice requirements of SPM, some of which involve subjective perceptions of a patient's pain. This question tests how well SPM practice can be implemented as a technical computer based tool.
4. How helpful are the problem solving methods at providing practice support – Tests research question #4 by asking a number of questions about specific features of the problem solving methods such as how helpful are the case building feature, differential diagnosis feature, checklist for fundamental considerations, reminders, supporting information, reflective practice logs and ability to print reports to include in the patient chart.

The testing involved the user reading three cases of a patient who presents with severe pain and then completing a series of tasks that provide practice support for the cases. The three cases were developed by two of the palliative care physicians who were involved in development of the paper based CAPIT, but were not involved in the testing of the computer based CAPIT. The cases were developed to be similar in terms of information content and complexity. Each case outlines a scenario where a patient presents with severe pain and describes the details about the pain episode as well as any other medical

information (such as diagnosis or medications) that the physicians felt was relevant to the case. Following completion of the three cases a set of interview questions were asked to gain insight about the computer based CAPIT and the extent to which it provided practice support for palliative SPM. Appendix B contains the testing cases and tasks for each case as well as the interview questions that were asked after completion of the cases.

After the testing was completed the think- aloud data and interview results were coded according to a coding scheme that was adapted from Kushniruk and Patel (2004). Descriptive statistics were used to summarize the data from the coding scheme drawing on previous work by Kushniruk, Patel and Cimino (1997) who showed that evaluation involving video analysis provides a rich source of data and a considerable amount of information (approximately 80% of usability issues) may be obtained from a small number of subjects (e.g. three or four in a group). Descriptive statistics were used to present some of the results such as identifying what percentage of problems were due to navigation problems, understanding system messages or the inability to access needed information. The nature of the data from the usability testing is such that it informs the iterative design of the computer tool and the data was not sought nor intended to be subject to statistical validation.

#### **4.6 Study Site**

All clinical aspects of this study took place at Victoria Hospice Society, Victoria, British Columbia, Canada. Victoria Hospice Society (VHS), which has an integrated hospice palliative program with a 17 patient hospice unit and a community based palliative service with a 24/7 palliative response team, home care and bereavement service. VHS averages about 800 patients each year for both its inpatient and community services. Approximately 80% of VHS patients have a cancer diagnosis. All the clinical aspects of the research such as the grounded theory sessions (including collection of the practice experience and patient chart information sources) were conducted at VHS.

#### **4.7 Participants**

The units of operation for this study were participants. Participants supplied the practice experience data as well as patient cases from the chart audits. Three types of palliative care clinicians took part as participants in this study: physicians, nurses and counselors.

All the palliative participants (physicians, nurses and counsellors) who took part in the research are palliative care specialists. The physicians have undergone specialist palliative care residency training and the nurses and counsellors have undergone a palliative care training course through Victoria Hospice.

Given the fact that collection of the data in this study had active involvement of the researcher it is at times necessary to refer to myself in the dissertation. In such instances I refer to myself as 'the researcher'.

#### **4.7.1 Physicians**

A total of six physicians took part in the study. Two physicians were extensive contributors involved in all three phases of the study. It should be noted that although those two physicians helped with the design of the testing phase they did not take part in the testing themselves. One of the physicians has been in full time palliative care for 25 years and is currently medical director of a local hospice. That physician took part in consensus meetings but was not involved in qualitative observation and documentation on the clinical ward. The second physician is a full time palliative care physician who has been practicing in palliative care for ten years. That physician took part in consensus meetings, was the exclusive source of qualitative observation and documentation on the clinical ward and also performed some of the retrospective chart audits.

Of the remaining four physicians, one was involved in the conceptualization phase and three were involved in the testing phase. No physician who was involved in either the conceptualization or construction phase was used as a testing subject.

#### **4.7.2 Nursing Staff**

Nursing staff were involved in the conceptualization and testing phases of the study. whereas counselling staff was only involved in the conceptualization phase. Five nurses were involved in the research, three were involved in conceptualization and two were involved in testing. The nursing staff was represented both by nurses who work on the unit and nurses who are part of the Palliative Response Team (PRT) and spend much of their time delivering care to patients at home. The different perspectives between unit and PRT nurses provided valuable insights on requirements for the design of the computer based CAPIT. No nurse who was involved in conceptualization was used as a testing subject.

#### **4.7.3 Counsellors**

Counsellors were involved in the conceptualization phase of the study. Four counsellors were involved in the study.

#### **4.8 Data Sources**

Three palliative data sources (PDS): practice experience, patient charts and research literature, were used to supply data for the grounded theory sessions that took place within this study. A significant component of the practice experience data (observing and documenting patient care) and the patient chart data source involved being in contact with confidential patient information. Prior to obtaining access to either of those data sources ethical approval was sought and received from both the University of Victoria and the Vancouver Island Health Authority.

The use of three data sources collected by different means provides confirmation of results from this study. An example of confirmation of data sources can be seen from the practice experience source. Practice experience consisted of two data sources: consensus meetings and clinical observation. Consensus meetings involved developing the paper based CAPIT and using GT-PD for identifying additional requirements to it through meetings with physicians, nurses and counsellors. Triangulating the two sources of practice experience provided confirmation of the data as I was able to compare what emerged from the consensus meetings with what was observed on the ward.

Each of the three data sources and details of how they were obtained is described below.

#### **4.8.1 Practice Experience**

Practice experience, representing clinical practice on palliative pain management in day to day situations was obtained in two ways: consensus meetings and clinical observation and documentation. The two types of practice experience provided validation for the data that was extracted. The consensus meetings included conversations with participants regarding how pain is managed whereas the qualitative observation and documentation provided insight on how pain is actually managed on the clinical ward. A significant portion of the practice experience data was audio recordings of discussions, meetings or interviews with palliative care clinicians or clinical observation sessions with palliative care clinicians. Audio recordings were transcribed into text format by the researcher.

##### **4.8.1.1 Consensus Meetings**

The researcher participated in weekly meetings at VHS from May 2003 until July 2004. The meetings involved physicians, nurses and counselors, which ensured that different approaches to palliative pain management were represented. A total of 75 hours were spent in consensus meetings.

The consensus meetings produced two data sources that were used in the study. The first data source was the paper based CAPIT. The second data source was the raw transcriptions of the meetings that produced the additional requirements used to develop the GT framework.

##### **4.8.1.1.2 Paper Based Tool**

The paper based tool, called CAPIT for 'Clinically Applied Pain Information Tool' was a collaborative effort from this study and its development involved all the participants described in section 4.7. The paper based CAPIT originated from a palliative care physician participating in this research who recognized the lack of a system for differentiating occurrences of why a palliative patient may report having severe pain. The

physician felt that it would be important to distinguish the presentation and management of severe pain for occurrences of pain that were primarily driven by a physical etiology, such as a patient with bone metastases that develops pain from being repositioned on their bed, from pain that is more driven by 'total' pain aspects such as a patient unable to come to terms with their imminent death or is distraught about leaving a young family behind. Aside from using specific data elements such as signs and symptoms to classify severe pain occurrences the physician further reasoned that there are additional factors such as disease trajectory, ethical principles of decision making and ethnic or cultural factors that must also be considered when deciding how to manage a patient's pain.

In early 2003 two palliative care physicians used their practice experience to identify 11 categories of why a patient may report severe pain and began to identify the symptoms, signs, interpretations and strategies for relief that would be seen within each category. The next task was to refine each of the 11 categories, which involved revising the signs, symptoms, interpretations and strategies for relief. The refinement of the paper based CAPIT was when the researcher first got involved with the study and he had a role in refining the paper based CAPIT. Details about the refinement of the paper based CAPIT is presented in chapter 5 as part of the domain description and current approaches for managing severe pain.

#### **4.8.1.1.3 Raw Transcripts**

The transcripts produced data that were used in GT coding to develop concepts and categories which contributed to the development of the informatics based tools (ontology, problem solving methods and vocabulary) from this study.

The SPM practice support framework that comes out of the consensus meetings was a triangulation of the two data sources as it is informed by the data within the paper based CAPIT but is enriched by the additional details that came out of discussion during the meetings. During the consensus meetings it was not uncommon to identify supporting information or an additional process that would enhance the paper based CAPIT by

supporting workflow and those became the basis for the GT framework that extended the paper based CAPIT.

#### **4.8.1.2 Participant Observation and Documentation**

From January-April 2004 the researcher gathered data on palliative care practice on the clinical ward of Victoria Hospice Society. The observation and documentation was a form of participatory design in the study. However it should be noted that while on the ward the research only involved observation and collecting field notes thus the researcher was not involved in any aspects of care delivery. My role as researcher was strictly to observe and document how pain was managed in a clinical setting. The initial observations were general in nature and gradually shifted towards more specific and focused observations until a point of theoretical saturation was reached (Adler and Adler, 1994). The participatory nature of the observations came once care delivery was completed, as to ensure the documentation was as accurate as possible, the researcher conducted follow-up interviews with the appropriate clinicians to clarify existing documentation or obtain further detail about an observation.

The observations involved spending full days (i.e. both morning and afternoon work practices) shadowing a palliative care physician, which allowed the opportunity to observe a number of aspects of palliative care delivery including morning chart reviews, patient consults, family consults and interdisciplinary medical rounds. Although the main objective was to observe the management of pain, a secondary objective was to gain an overall understanding of palliative care and clinical workflow. Pain management occurs in the context of overall palliative care and an episode of pain both affects and is affected by the patient's other symptoms and aspects of care. The clinical observations were also an important source of information for development of the informatics based tools as they allowed me to understand how practice evolves and how information flows through the clinical ward in support of that practice. A total of fifty hours were spent doing qualitative observation and documentation.

#### **4.8.2 Patient Charts**

Retrospective chart audits were done at VHS. The retrospective audits were done in two phases and the data from the audits were used to inform the development of the paper based CAPIT as well as the informatics based solutions from the conceptualization phase of the study. A stand alone computer based tool was developed to allow data entry and analysis of the audit data. The phase one audit was initially done on paper and then entered into the computer tool whereas the phase two audit was inputted directly into the computer tool.

The two chart audit processes are summarized here and detailed in appendix A. The phase one audit was done in March 2003 on 44 cases of patients who experienced an episode of 10/10 pain during a stay at VHS between March of 2000 and August of 2002. The audit was meant to determine the level of congruence between the episodes of pain from the charts and the 11 categories of severe pain. The phase two audit was done in February 2004 by a physician and a nurse on 44 cases of patients who experienced an episode of 8 or 9/10 between March of 2000 and August of 2002. There was no overlap of patients between the two audits.

Combining the results of both chart audits gives the following percentages with respect to the category of severe pain occurrences based on the 11 categories from the paper based CAPIT:

	<b>Totals (8, 9 &amp; 10/10)</b>	
1. Lack of understanding of scale	1	1%
2. Sudden medical crisis	12	15%
3. Visceral spasm or colic	7	9%
4. Opioid neurotoxicity	3	4%
5. Titration pain	12	15%
6. Incident pain	26	32%
7. Neuropathic pain	6	7%
8. 'Total' pain	11	14%
9. 'Plea' for relief	1	1%

10. Drug seeking addictive behavior	1	1%
11. Dementia or delirium	<u>1</u>	<u>1%</u>
	<b>81<sup>3</sup></b>	<b>100%</b>

#### 4.8.3 Research Literature

The literature review was done on the medline, psychINFO, and Web of Science databases. The search terms were palliative pain, palliative pain management, pain assessment, and severe pain. Manual searches were also done of each of the 11 categories of severe pain from the paper based CAPIT. The literature search was done as an iterative search conducted over time. Other research literature such as journal articles were also incorporated into the study as deemed appropriate by the clinicians participating in the study. The cumulative search retrieved 30 pieces of literature that became the official literature reference listing for paper based CAPIT.

Other research literature included textbooks on palliative care. In particular all of the practice support information such as for assessments or management of severe pain that became the content for the computer based CAPIT was taken from the textbook *Medical Care of the Dying* (2006) by Downing. Part of the validity of the supporting information used in both the paper and computer based CAPIT was that the information came from the *Medical Care of the Dying* Textbook. For example supporting information on short acting opioids as part of management of incident pain came from the analgesics chapter of the textbook.

#### 4.8.4 Analytical Techniques

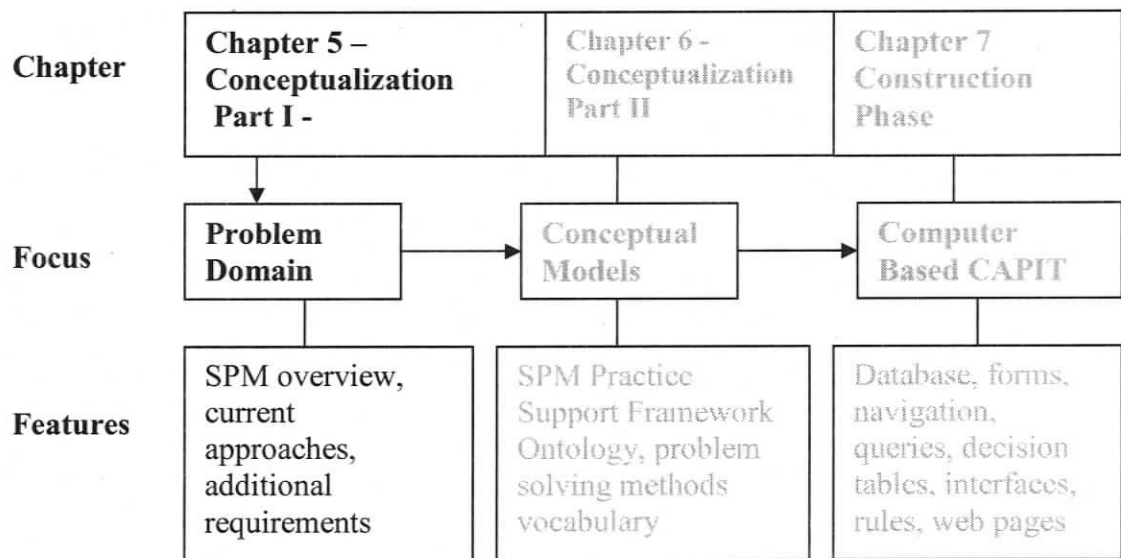
All text documents including consensus meetings, ward observations, chart audit data and research literature were transcribed into Microsoft Word and entered in ATLAS.ti© qualitative analysis software, which was the computer program used to assist with analysis and management of the data.

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<sup>3</sup> Although 88 charts were audited there were 7 charts where it was not possible to identify one primary cause of the pain

### Chapter 5 – Results - Conceptualization Part I - Problem Domain

This chapter provides part I of the conceptualization phase, which focus on the problem domain of palliative severe pain management (SPM). The conceptualization presents an overview of the SPM domain and challenges and issues within the domain, current solutions to overcome the challenges and issues in the form of a paper based Clinically Applied Pain Information Tool (CAPIT) and finally additional requirements that would make paper based CAPIT more usable. Figure 7 is a results diagram that shows this chapter in relation to chapter 6 (conceptualization part II) and chapter 7 (construction phase) in order to illustrate how the chapters flow from one to another.



**Figure 7.** Diagram showing flow of results between chapters 5, 6 and 7

#### 5.1 Overview of Severe Pain Management

From a high level perspective the overall process of SPM is represented by a linear set of processes consisting of assessment, interpretation and implementation of a management strategy as described by a physician in the quote below. The physician describes how SPM uses a set of three steps of assessment of signs and symptoms, an interpretation of what is going on in the case and the establishment and implementation of a strategy to

deal with the severe pain report. The physician also points out that the linear steps are a process that is done all day long.

*One specific driving element may be this and if so it may have certain symptoms, which is what patient's say to us, it would have certain signs, which is what we observe and based on those things we would come up with a definitive or probable interpretation of what's going on and based on that some general strategies of how we are going to deal with it.....We do this, we all do this every 5 minutes all day long, we're assessing, we're interpreting we're deciding on a strategy and we're implementing it...Physician #1*

However just taking SPM in the context of the above quote gives it a false simplicity. Not only do the three linear steps have complexity within them but there are other aspects that need to be considered. The quote below from a physician points out how severe pain has some 'unique' aspects to it and is really a synthesis of things.

*...At the same time with respect to severe pain there are some unique aspects to look at ... I think part is physical assessment, part is observation, part of it is what they share and part is intuitive....it's a synthesis of things... Physician #1*

For example the physician articulated that although a strategy of emergency stacking of opioid can easily be the perceived tendency for managing a report of severe pain, there are in fact differences in how severe pain presents and subsequently how it needs to be managed.

*The tendency can easily be, the patient says I've got 10/10 pain, so I better start emergency stacking....the concept is there has to be something done immediately and in a very aggressive way....but wait a minute, aren't there differences?....Physician #1*

Capturing and organize knowledge to make sense of those differences is a key aspect of this research. In the literature review it was pointed out that there is a need to differentiate etiologies of severe pain to help understand difficult pain problems in order to prevent inappropriate administration of opioids. The literature also described the need to go beyond the assessment and understand the overall perspective of a patient's pain.

It was also emphasized during the research that strategies for severe pain are not just implemented purely based on signs, symptoms and interpretations but rather the unique and individual nature of each report of severe pain must be considered.

*For any severe pain we need to consider the context, meaning and impact – you don't just knee jerk or cookbook approach – It's wait a minute who is this person?...Physician #1*

So although severe pain management consists of a set of three steps of assessment, interpretation and implementing a strategy there is in fact much added complexity that supports those steps.

## **5.2 Paper Based CAPIT**

This section describes the paper based Clinically Applied Pain Information Tool (CAPIT) that was introduced in section 4.2. The structure of CAPIT is shown in figure 8. CAPIT contains 11 categories of why a patient may report severe pain. Each of the 11 categories is listed according to a set of symptoms, signs, interpretations and strategies. The paper based CAPIT also contains a set of fundamental considerations that are used across all categories of pain and are meant to provide a holistic means of looking at a report of severe pain. The fundamental considerations include concepts such as the need to look at the disease trajectory, context, meaning and impact, as well as the need to consider ethical decision making principles when making decisions about developing a strategy to manage severe pain.

Clinically Applied Pain Information Tool (CAPIT) for Severe Pain				
Categories of Severe Pain (NRS 7-10/10)	Symptoms	Signs	Assessment & Interpretation	Strategies for Relief & *Considerations
1. Lack of understanding of scale				
2. Sudden medical crisis				
3. Visceral spasm or colic				
4. Opioid-induced neurotoxicity				
5. 'Titration' pain				
6. Incident pain				
7. Neuropathic pain				
8. 'Total' pain				
9. 'Plea' for relief				
10. Drug-seeking addictive behavior				
11. Dementia or delirium				

**\* Fundamental Considerations**

- Disease trajectory and functional status
- Ethical context
- Resource access/limitations
- Location of care
- Impacts/context/meaning of pain for the patient and surrounding family/team
- Ethnic/cultural
- Individual uniqueness
- Limits of any pain scale
- May be multiple categories in one patient

**Figure 8.** Illustration of the components (11 categories of severe pain and fundamental considerations) of CAPIT (Downing, 2006).

The paper based CAPIT was developed at a local hospice from May 2003-July 2004. Although the development of the paper based CAPIT was already in progress when this research started it was refined during the study using the three PDS (practice experience, patient charts and research literature) that were described in the research design (chapter 4). The refinement of paper based CAPIT took place over a 14 month period (May 2003 – July 2004). Figure 9 shows the incident pain category from the paper based CAPIT. Appendix C shows the paper based CAPIT in its entirety.

Categories of Severe Pain (NRS 7-10/10)	Symptoms	Signs	Assessment and Interpretation	Strategies for Relief and Considerations
6. Incident pain	<ul style="list-style-type: none"> <li>• Intermittent severe pain related to one or more activities or procedures</li> <li>• Pain subsides shortly after action</li> <li>• Probably comfortable except during precipitating physical factor</li> <li>• Often pain is recurrent and predictable</li> <li>• Patient is usually fearful of activity or precipitating event</li> <li>• Can locate and describe pain accurately</li> </ul>	<ul style="list-style-type: none"> <li>• Severe pain directly related to one or more specific actions</li> <li>• Patient may become rigid, tense, resistive or yell out during incident</li> <li>• No evidence of acute medical crisis</li> <li>• Delirium not present (unless compounding factor) although patient may be very agitated and restless during pain episode</li> </ul>	<ul style="list-style-type: none"> <li>• Type and quality of pain is specific to the actual etiology e.g. bone pain with movement or position change; bowel care; dressing change</li> <li>• True incident pain is predictable, both to onset and duration. It is a subset of breakthrough pain (BTP) but requiring a different approach</li> </ul>	<ul style="list-style-type: none"> <li>• Preemptive use of short or ultra-short acting opioid i.e. once incident pain is identified, then focus on use in prevention</li> <li>• Modify action or procedure if possible to reduce pain intensity</li> <li>• Additional adjuvant supports such as distraction, hypnosis, imagery, music</li> <li>• Use short-acting sedation with analgesic if necessary</li> <li>• Goal is to ensure baseline opioids are sufficient to cover rest pain and to reduce severity level of incident pain to mild or no pain over next several 'incidents'</li> </ul>

**Figure 9.** Incident Pain category from CAPIT

### 5.3 Scenarios of How CAPIT Is Used

Two clinical scenarios will be presented that illustrate how the paper based CAPIT is used. The scenarios are a patient presenting with total pain and incident pain. Both scenarios originate from the same starting point. A patient has reported having 8, 9 or 10/10 pain and a nurse has gone to get a physician. The physician immediately goes to the patient's room to deal with the severe pain report. The scenarios illustrate how the physician uses paper based CAPIT to understand the signs and symptoms the patient has, come up with an interpretation based on the signs and symptoms and finally a strategy to manage the pain.

#### 5.3.1 - Total Pain Scenario

As the physician walks into the patient's room he immediately looks at how the patient is positioned and how they are behaving. The patient is lying still on the bed and does not appear to be in obvious extreme pain. The patient looks overwhelmed and tired than and there is no outward evidence of an acute medical crisis. The patient turns to acknowledge the physician when he enters the room and the physician notes the patient does not appear to grimace or grab any part of their body as an indicator of discomfort. The physician asks the patient about their pain and the patient responds that their hip hurts and they feel 'lousy' and the pain is 'horrible'. The physician asks where the pain is located and the patient responds 'all over'.

The following quotations describe how the physician uses information from the paper based CAPIT to decipher the clues from the above scenario to make sense of the patient's pain. The first step of the linear SPM process is assessment of signs and symptoms but the quote below describes how assessment of 'total pain' can be difficult as patients have difficulty articulating the pain.

*I wonder if one of the symptoms of total pain is people really having difficulty articulating what it is?...like I don't know if it's easy....I think to some degree it's easy to kind of identify physical pain but I think when you have people who have a sense that they're depressed or feeling helpless they often don't know what labels*

*to use for it...I think part of the clues for me include that they're overwhelmed or they have an inability to articulate a source for their pain....Counsellor #3*

In terms of symptoms a counsellor points out that patients may have trouble describing the specifics about their pain and just say they feel 'lousy'.

*I know sometimes you ask people and they just say they feel lousy...they can't say any more...Counsellor #4*

In fact one sign of total pain that has been described is that it presents differently than the 'flight or fight' look that is commonly seen in acute pain etiologies. A physician describes below how the patient may present as stunned, depressed or confused or irrational as outlined in the paper based CAPIT.

*What we see is they are not in obvious extreme pain, meaning that 10/10 extreme burning pain, we're not seeing the physical pain, in fact they may have that chronic pain facies..stunned depressed looking....their behavior may appear confused or irrational....Physician #1*

The interpretation draws attention to the fact that there is more to this pain than just a physical pain.

*The interpretation is we begin to see this picture as more than the pain in the hip.....the proportionality is different from titration pain....the suffering is predominating the physical pain...Physician #1*

The strategies for total pain from the paper based CAPIT include dealing with both proportions of the pain. That includes managing the physical pain but also managing the psychosocial proportion of the pain.

*If we're saying that this severe pain is actually total pain, or more driven by total pain, we certainly want to improve the physical pain, so we need to deal with that hip pain properly as it is a driver, we need to perform a thorough psychosocial assessment in all domain – use tools for clinical depression over more reactive depression...Physician #1*

A physician points out that total pain is a different type of pain than physical pain and it is possible to get a good sense of the difference between physical and total pain.

*If total pain is driving the 10 then we know their hip hurts a bit but what is driving it more is the other aspects – fear, burden – this is painful to feel a burden, that's true but it's a different type of pain, we can't quantify the different amounts, but we can get a good sense of the difference...Physician #1*

A challenge from that statement is how to develop practice support tools to help residents, or novice staff to be able to get a 'good sense of the difference' in order to make sense of the different proportionalities of pain a patient may be experiencing. Sections 1.3-1.5 of the literature review described how symptoms such as anxiety and depression may be non-existent. Further section 1.6 of the literature review described how we need to be able to make pain more 'visible' in order to get at the subjective aspects of a patient's pain.

### **5.3.2 Scenario #2 - Incident Pain Scenario**

In the second clinical scenario the physician enters the room and as the patient turns to acknowledge the physician he appears uncomfortable, grimaces and holds his left leg with his hand. Based on the signs and symptoms the physician believes the provisional diagnosis is 'incident pain'. However coming up with that diagnosis required a lot of consideration about different aspects of pain. The following quotes illustrate two physicians detailing out how incident pain is assessed, interpreted and managed.

The paper based CAPIT describes how incident pain presents and how it looks different from other categories of pain.

*If their issue for severe pain is incident pain as a separate cause than they would be comfortable (other than during the triggering incident) otherwise it would be a titration pain or something else....Physician #1*

The information contained in the paper based CAPIT then guides the clinicians as they look at signs and symptoms, which include how the pain looks, whether a medical crisis is present and how the patient presents cognitively and behaviorally.

*Severe pain directly related to one or more direct actions, no evidence of a sudden medical crisis, delirium not present unless compounding, although patient may be very agitated and restless during incident....Physician #1*

*In terms of signs that person can become rigid or flinch.... Physician #2*

*What we're saying is the severe pain is related to this (incident) they become this (rigid, tense, resistive or yell out) but there is no evidence of a sudden medical crisis... Physician #1*

In fact some of the signs and symptoms that are assessed are used as part of a differential diagnosis to rule out other categories of pain.

*You still may examine the abdomen at a time other than the painful action... Physician #2*

*The rigid abdomen and visible fracture we see in sudden medical crisis will be absent here?....Researcher*

*That's right... Physician #1*

Once the clinician has completed assessment of signs and symptoms he or she proceeds to an interpretation and finally to a management strategy as outlined in the paper based CAPIT.

*Interpretation - often due to movement related bone metastasis but the type and quality of pain is specific to the actual etiology....true incident pain is recurrent and predictable, a subset of breakthrough pain...strategy – preemptive short acting opioid, modify action or procedure, the goal is to ensure baseline opioids cover rest pain and have them comfortable other than when the incident is occurring... to maintain general comfort..... Physician #1*

As in the ‘total pain’ scenario from section 5.2.1 there are a number of factors that need to be considered in order to determine that incident pain is the driving cause of pain. The above transcribes describing incident pain contains a lot of knowledge about severe pain management as they have assessed behavioral, cognitive and onset signs of pain as well as differentiating incident pain from titration pain and from a sudden medical crisis. They have also made reference to breakthrough pain and identified a management strategy as preemptive short acting opioid. A clinician may require supporting information about some or all of those references.

#### **5.4 Requirements to Enhance CAPIT**

The previous two sections illustrate the complexity of palliative SPM and although the paper based CAPIT is a comprehensive knowledge base of SPM there were a number of requirements identified during its development that would enhance it and make it more usable. Those requirements add another layer of complexity and became the design specifications for the computer based version of CAPIT. The relationship between the paper and computer based CAPIT is the paper based CAPIT is starting point for the

computer based version. However the computer based version incorporates the complexity of both the paper based CAPIT and the additional requirements around context and content that would make the paper based CAPIT more usable. The interactive nature of the GT-PD method helped to draw out the details of those requirements, which are described in this section.

#### **5.4.1 Fit with WorkFlow of Clinical Practice**

One of the overarching additional requirements to the paper based CAPIT is that when it is implemented as a computer tool it needs it will need to be developed into a format that is usable within the context of clinical practice. The quote below from a physician describes how much of the knowledge contained within CAPIT is implicit to an experienced physician and that raises the challenge of how to structure that knowledge so it makes sense to people who use it considering that they may not be experienced at SPM.

*These reaffirm things that I consider after all these years, these are things I do without even thinking about and a lot of experienced people do...what you are trying to do is come up with an educational tool for people who don't think of these things automatically...the challenge is to come up with a form that people actually use...Physician #1*

The above quote implies the need to understand the context of how computer based CAPIT could be used as there will be a number of implicit processes that must be articulated if it is to fit with the flow of clinical practice. For example in the description of the total pain scenario in section 5.2.1 one of the quotes describes how it is possible to get a sense of the difference between severe pain that is driven by total pain elements as opposed to physical pain elements. To provide practice support for SPM those details need to be formalized so they can become content of the computer based CAPIT.

With respect to fitting within workflow a nurse describes below that how much benefit they get out of the computer tool will impact how it gets used.

*I don't want to use the term user friendly..but how much benefit we get out of it will certainly impact how it gets used...Nurse #1*

Another nurse pointed out that although the computer tool needs to fit within the context of nursing workflow it will only be one part of that workflow that includes drawing up medications, charting and other processes.

*When you design this tool I think you need to keep in mind a general principle or just a fact is as nurses it's a little bit different for us as we're the ones who do the physical things like get the narcotic keys, draw this (medication) thing up so we need to make time for that (using the computer tool) within what we're doing..Nurse #3*

Therefore it is not just a matter of understanding how SPM occurs in order to support those processes but also where SPM fits in the overall work practices of the clinicians who will be using computer based CAPIT. The concept of practice support arose from the need to fit the computer based CAPIT into the overall flow of practice that includes activities directly related to SPM but also supplementary to it.

#### **5.4.2 Supporting Information**

Supporting information is required to provide a 'show me' or 'help me do this' functionality to computer based CAPIT. During a consensus meeting where the paper based CAPIT was being discussed a physician made a comment on how links are needed to assessment tools or strategies to help with SPM.

*We don't see the links here (in the paper tool) but throughout pointing to other assessment tools that exist, how do we help assess this better? What are strategies that are helpful for this person within the context that there is a physical pain as well...Physician #1*

For example in the two scenarios in sections 5.2.1 and 5.2.2 references were made to 'chronic pain facies', differentiation of suffering and pain, tools to screen for clinical depression and pre-emptive short acting opioids. Each of those references has supporting information available about them and a clinician may need such information to manage the pain episode.

A physician describes below how although the paper CAPIT launches off on signs and symptoms the assessment of a patient can involve other details which are not contained in the paper CAPIT.

*Not coming back to the severe pain tool (paper based) specifically but a lot of places that the tool launches off of are signs and symptoms and I was wondering about going back to if we were able to examine a patient in severe pain or reported in severe pain, it can still be more than just the bedside examination, what are some of the things we do in examining a patient? ...Physician #2*

Depending on a clinicians' level of experience they may need access to supporting information about the other things that are done in examining a patient. Supporting information also enhances many of the management strategies in paper based CAPIT such as for titration pain where the strategy is to titrate or rotate the patient's current opioid or for a 'Sudden medical crisis' where the strategy involves stacking a patient's opioid.

Another example of supporting information is knowledge of 'total pain'. Total pain is a vital aspect of palliative care and there are a number of references to it in the paper based CAPIT. However total pain is a complex concept and therefore clinicians may need more than just a reminder to consider it. The computer based CAPIT also needs to make available supporting information in case a more in depth understanding of all the pieces of total pain is required. The complexity of total pain is articulated below by a physician.

*When I think of total pain I think of those seven P's (physical, personal..) and all those subpieces caught in here..... it's a number of things, physical pain, intellectual pain...emotional pain... spiritual pain and bureaucratic pain so when someone is in total pain we all realize it is very complex...Physician #1*

But complexity is part of the reality of SPM and therefore part of practice support is helping to manage that complexity. For example clinicians of different expertise will be using computer based CAPIT and may require supporting information about some of the concepts contained such as the complexities of total pain or how to rotate an opioid.

### **5.4.3 Charting and Communication**

The need to support charting was described by clinicians, particularly nurses, as a necessity because data entry is an integral part of practice. Nursing staff questioned how useful just having the paper CAPIT on a computer would be? One nurse in fact admitted that she probably would not use computer based CAPIT if it was simply implemented in its current format as it would not be practical to use within the nursing workflow.

*I'm puzzled as to where you are going to use the tool... how would you use that tool if you walk in the house and there's a patient in 10/10 pain and you have the tool on a computer?...Nurse #2*

*Well I probably wouldn't use the computer..realistically...Nurse #3*

The need for the computer tool to support charting was described as a solution to help fit the computer based CAPIT into the workflow. The paper based version of CAPIT is independent of a specific patient case but an enhancement from the computer version would be the ability to have it specific to a patient by developing a patient case.

*Is there a way to predict when a patient may have pain? ....have it fine tuned to that patient like these are the areas we know they have pain, I'm thinking about having the background knowledge...finding a way to have it specific...Nurse #2*

At that point I intervened and asked if the tool would be helpful if it could bring up data from previous pain episodes in a summarized form so it could be used at the time of the current pain episode.

*I think when you have it ahead of time specific to each patient and come on and go through the chart and see what's happened to each patient...have they had incident or neuropathic pain etc..but that's not using it at the time of the severe pain...Nurse #2*

*Would that knowledge help? ...a printout in the chart of what types of pain have they have had..when the pains came on, information on context of the pain episode. etc....would that possibly help your thinking at time of an incident when it comes on...Researcher*

*Absolutely – we take in the history - if you knew they didn't have pain until now – that was important to know – but I also think afterwards it (severe pain tool) is also excellent to go through -okay what happened here and to look at it afterwards...Nurse #2*

*So really you need the information... the tool needs to present info before to help with the incident and record after the incident what was done, how was it treated, what were the circumstances, what was the impact, what meds were given....Researcher*

Therefore one enhancement is the need to support charting as part of the practice workflow amongst clinicians.

Part of the need to support charting also relates to communication. During a GT-PD session a nurse provided a clinical example of a patient who was suffering from severe pain of which part was due to a physical etiology and part was due to the psychosocial issues from the patient losing autonomy over her life because of the progression of her disease:

*Knowledge of the patient is another thing as I know what is going on with this women and all the different parts, if I were a new staff member coming on and walking into her room, that's going to be more difficult as not everything gets passed on, you can't pass all that knowledge on to the next new person coming on...Nurse #2*

As the above quote points out all the knowledge about that patient does not get passed on to all staff members. For example it is one thing to have clinicians look at and consider the fundamental considerations as part of a patient's case but it is more valuable if the details are charted as part of a patient's case. Providing the means for doing such charting will allow it to become part of day to day practice to ensure all aspects of a patient's case are documented and communicated.

A nurse further articulated how having the tool document data may help organize the facts about a patient's pain so the report to a physician could be more complete and organized, which will enhance nurse-physician communication.

*That comes in handy just before you call the doctor because if you can get all your information together it makes it so much easier particularly if you have the doctor on the other end of the phone to get all your cookies in one bag so to speak and talk to the doctor...you can give them complete information and get your orders and life goes on pretty quickly but if you have incomplete information... it doesn't go as well...Nurse #3*

Therefore an enhancement to the computer tool is that it needs to enable development of a severe pain case for a patient so data about a severe episode can be recorded and charted thus enhancing communication.

#### **5.4.4 Diagnostic Support**

Part of paper based CAPIT is a column called interpretations. During a GT-PD session it was articulated that an interpretation encompasses two types of diagnosis. The diagnosis concept came out during an exchange between two physicians where one physician asks for clarification as to what an interpretation actually means.

*What do we mean by interpretation?...Physician #2*

*...Well I suppose interpretation would be both your differential diagnosis and your provisional diagnosis, so it's based on signs and symptoms from your assessment so then you're saying the interpretation...this, this and this are the issues....Physician #1*

The two different types of diagnostic reasoning (differential and provisional diagnosis) are different and have different information requirements. Differential or provisional diagnoses are two ways of getting at a definitive diagnosis, which is the type of pain that is actually causing the patient's severe pain episode.

Aside from general types of diagnosis (provisional, differential and definitive) a specific type of differential diagnosis emerged during the GT-PD sessions in the form of the need to differentiate between pain driven by a physical etiology and pain driven by total pain. As detailed in the total pain scenario in section 5.2.1 a complication to total pain is the fact that it has an aspect of physical pain caught up within it as well and because the physical pain is often a trigger for total pain it is vital that physical pain be assessed and managed appropriately.

Although the clinicians acknowledge it is not practical to be able to identify what proportion of pain is physical and what is total pain it is possible to get a sense of what is driving the pain. The differentiation of physical and total pain is discussed in the set of quotations below where a physician and counsellor discuss how it is possible to get a sense of the difference between physical and total pain.

*In my view total pain needs a physical part, we certainly spoke to the proportionality issue regarding total pain, the stronger element to the pain you are feeling in total pain is emotional, financial, spiritual issues with some physical pain as opposed to some other pains where there is a physical intensity with elements of other issues... Physician #1*

*Maybe that's the point of contention, some people are saying it's not reasonable to identify proportionalities when it comes to total pain as it's all melded together ...Counsellor #1*

*Yeah, we won't know those actual numbers, the issue is it is at 10 and the question is from the 11 categories what is the thing driving the 10?, if total pain is driving the 10 then we know their hip hurts a bit but what is driving it more is the other aspects – fear, burden – this is painful to feel a burden, that's true but it's a different type of pain, we can't quantify the different amounts, but we can get a good sense of the difference...Physician #1*

A challenge from that statement was how to develop practice support tools to help palliative care clinicians to be able to get a 'good sense of the difference' in order to make sense of the different proportionalities of pain a patient may be experiencing. Sections 2.1.6.1 of the literature review described how symptoms such as anxiety and depression may be non-existent. Section 2.1.6.2 of the literature review described how we needed to be able to make pain more 'visible' in order to help gain an understanding of the subjective aspects of a patient's pain.

#### 5.4.5 Management of Complexity

SPM is complex in that it often is not only a matter of managing one type of pain but rather multiple types of pain, including total pain. In the two scenarios in sections 5.2.1 and 5.2.2 it was illustrated how although a patient may have one type of pain such as incident pain there is still a need to consider multiple categories of pain to confirm the diagnosis. As the quote below indicates that can get very complex and a way is needed to manage that complexity.

*Complexity comes in that although we have 11 categories, a particular patient may have 2 or 3 of them at one time.....in some of our categories, we have to recognize the complexity as total pain was suggested that it's not a category but a filter – all categories may have an element of total pain ...if it walks you through a pathway it can get very complex...Physician #1*

Understanding the navigation that is necessary for SPM is critical because navigation is a large part of providing practice support to manage that complexity.

However all navigation is not the same but rather it must be defined in the context of the specific process it is supporting. For example the two types of diagnostic reasoning described in the previous section both involve navigation but they have different navigational requirements. Provisional diagnosis requires navigation at the component level meaning that a clinician needs to be able to drill down within the provisional diagnosis task. Although the drilling down may bring up new information, such as additional diagnostic information, it is still within the same category of pain. Differential diagnosis requires navigation at the system level in that you navigate across different pain categories. Navigating from a pain category to an information linkage such as an assessment tool is yet another type of navigation. The computer tool needs to be able to navigate between categories of pain as necessary as well as providing access to practice support resources as necessary.

Part of managing complexity is drawing attention to particular aspects of SPM through reminders. In the quote below a physician describes how a reminder becomes an enhancement to the SPM process because it reminds clinicians about factors related to a diagnosis or a strategy.

*The enhancement comes from if you walk through a couple of strategies and have you now considered this or this or blah blah...those things enhance your judgment because they act as a reminder and then you have to sort it out..yes,no or maybe..... it's enhanced your judgment because it has reminded you of some things...Physician #1*

A nurse describes below how computer based CAPIT could be enhanced with reminders to ensure completion of particular aspects of SPM. She pointed out how reminders can enhance communication with a physician as they will draw her attention to particular aspects of SPM to ensure she has thought of this or that, which she describes as what she gets when she is on the phone with a physician discussing a patient's pain episode.

*It may be a good back up check, I think as a check system, a guide once the initial stuff is over ...it's the thing oh did I think of this? Or did I think of that?, which is often what I get when I'm on the phone with the doc...did you do this?... just something I can use to see if my assessment was complete...Nurse #3*

Providing reminders such as that a sign or symptom from one category of pain is also present in another category will help the clinician to navigate between the two categories and enhance the SPM processes and communication within those processes.

#### **5.4.6 Ensuring Assessment of Total Pain and Fundamental Considerations**

During development of the paper based CAPIT it was presented at conferences and to palliative care clinicians for feedback and part of the feedback that was received was concern that CAPIT would slot someone into a category of pain and ignore other categories.

*That was the worry of people that we would put someone into total pain and dismiss the physical pain, or put them in visceral colic or spasm and ignore the fact they have severe total pain...Physician #2*

One way of addressing the above situation is to use the fundamental considerations, one of which says that a patient may have multiple categories of pain. Clinicians emphasized that the fundamental considerations should be considered at all times but it is particularly important to consider them when making a diagnosis or before implementing a management strategy.

*Should fundamental considerations be added when we are doing an interpretation or a strategy....or both... Nurse#2*

*....both....Physician #2*

*It gets applied the whole time, when you walk in the room, while you are assessing and later while interpreting what is going on, it is a never ending process of cross checking...Physician #1*

The importance of the fundamental considerations was described in section 5.2.2 where a physician articulated that SPM is not a knee-jerk or cookbook approach but rather reflections need to be made about 'who is this patient' and what are the unique properties about their case. A counsellor added to that discussion and described how total pain is a factor in all pain and can be present even if a patient does not outwardly describe or present with distress or anxiety. That emphasized the need to always assess for the presence of total pain.

*Total pain is an overarching piece and when we're talking about other (physical) types of pain the other stuff (total pain issues) becomes invisible... Counsellor #3*

Therefore a requirement is that information about the fundamental considerations and total pain needs to be accessible during SPM but there also needs to be checks and reminders to ensure that people actually assess and record those elements into the patient case.

#### **5.4.7 Team Development**

One of the things that were emphasized in the consensus meetings is that SPM requires an interdisciplinary team perspective.

*We recognize in palliative care the need for a team approach, especially when caring for aspects of total pain....Physician #2*

However that that is not always possible as the clinician dealing with the severe pain report may be a family doctor or home care nurse in a remote area where there is no immediate access to a team. But it was described by a counsellor in the quote below that the team aspect still needs to be emphasized so that clinicians who are by themselves do not say 'I don't have a team so I can ignore that part of SPM'.

*You need to emphasize the need for a team approach so you don't say I don't have a team so I can ignore that....Counsellor #3*

Although a team approach is an important consideration a physician articulates how in some situations there simply is no access to a team. But in those situations the pain tool can become a source of team resources for a clinician.

*Sometimes with resource limitations you can't, there only is the family doctor or homecare nurse, but in complex pain the fundamental considerations (in CAPIT) are what other resources can help with this.....Physician #1*

Further it was pointed out that a computer based CAPIT could actually have linkages to electronic resources to provide access to counseling and other team resources.

*If we're talking electronically it may be connecting them with the Canadian Virtual Hospice website, so if there isn't a counsellor in your area it may be making the connection for support...either directly as in Victoria as we have direct counselling or PRT department but not everyone has that so if you are resource limited what are some strategies to take...Physician #1*

Therefore a requirement is to ensure that a team perspective on pain is considered and also that resources for promoting a team environment are available in case a clinician does not have direct access to a team.

#### **5.4.8 Continuum of Care**

Continuum of care is a consideration that emphasizes the need for the tool to support severe pain management work practices both in the immediate management of the pain but also in a management continuum that may take place over days or weeks.

A nurse describes how ongoing strategies, such as strategies for total pain, must be a part of the tool in order for it to be useful as palliative SPM resource.

*I'm thinking of total pain which is part of this tool and you don't treat that with a quick injection either so there's certainly parts of it (palliative severe pain management) that do not lead themselves to in the moment 10/10 pain.— that total pain is ongoing all the time so it's not like we walk in and say 'oh my god she's in total pain I'm going to give this', [if the computer tool worked like that] it wouldn't be useful because it's ongoing...Nurse #2*

That exchange helped draw out a design issue that was not known previously to the researcher and emphasized the fact that palliative severe pain management is not a one time thing but rather a continuous process that must be supported. Using the tool as a one time event is not supportive of nursing practices. The documentation aspect of previous severe pain episodes was subsequently added to the design requirements.

As with management of the pain, clinicians also described how the assessment and diagnostic processes can also be ongoing. In the quote below a physician points out that the ‘thinking piece’ of the tool needs to support an ongoing way of providing care.

*Part of pain assessment is not just a one time examination and therefore you have an answer, it's often a process over a number of hours or days. So whether you have or you will need to build that in to that thinking piece...Physician #2*

A physician describes below about the intertwined process of SPM and how it is important to keep track of what has been done for a patient in case and implementation does not work and the process needs to be done again.

*It's an intertwined process , if an implementation does not work than you would need to look at why it is not working and perhaps I have missed something and go back through the whole loop again...Physician #1*

Therefore the tool must support a continuum of care, which includes both immediate and ongoing aspects of severe pain management. SPM is very much an ongoing and dynamic process that needs to be constantly reconsidered in light of what has already been done with this patient. Further many of the management strategies have short and long term solutions and it is imperative that the full range of solutions be made available to a clinician.

#### **5.4.9 Vocabulary and Definitions**

Given the complexity of severe pain and the fact that signs and symptoms can make reference to any part of the body there are a number of potential ways of describing a patient's severe pain report. However using a common set of terms will help promote consistency for describing severe pain reports but also allow use of accepted terms. During a consensus meeting a clinician asked for a reminder about what ‘allodynia’

meant and after a physician described it he noted that computer based CAPIT could be enhanced by having links to such definitions.

A physician describes in the quote below how what the paper based CAPIT has been doing is giving clinicians 'language' to describe what is happening with patients in severe pain.

*What it is doing already is giving language to better describe what is happening with their patients, they're asking questions about these categories when giving feedback to other care clinicians whether charting or doing physician orders and they have a better understanding as they describe what we can do to help this person with severe pain....Physician #2*

The importance of language cannot be overemphasized as it was described in both the literature review (section 2.1.5.1 ) and in the total pain scenario (section 5.2.1) that patients with total pain and the components of it such as depression often have difficulty articulating about their pain. Therefore an enhancement to computer based CAPIT is to provide examples of language to describe total pain to help clinicians recognize when total pain may be present.

The need to understand the vocabulary of SPM is important for the development of computer based CAPIT. Computer based CAPIT is meant to enhance communication and charting amongst clinicians and thus the vocabulary needs to contain terms that are used in day to day practice.

#### **5.4.10 Learning and reflections on Practice**

Part of SPM involves learning and reflecting from your severe pain case to enhance future severe pain management. Because of the complexity of SPM it will be learned in an iterative fashion and thus there is a need to ensure that clinicians have the chance to reflect upon what they have learned. The quote below from a nurse describes how she

believes CAPIT could have value as a check system as one of the things that worried her most when she started out was would she be able to react fast enough to severe pain.

*As a check system, a check, a check and balance.....you know I have to say that I think that of all the things when nurse are new on the ward....I think one of the things that worried me most about severe dyspnea, severe pain, severe hemorrhaging was would I react fast enough? Would I do the right thing and as a teaching tool if we had strategies like this and would implement them so we could go over it could be an amazing thing for the comfort level of new nurses on the floor....Nurse #3*

But because clinicians using CAPIT may encounter so much information they need to be able to document and reflect upon what they have learned so that they can take what they have learned to practice and enhance their abilities to manage SPM.

In the quote below a nurse describes how a hospice nurse is required to demonstrate knowledge about total pain.

*With pain management the first thing a hospice nurse is supposed to do is demonstrate knowledge of the concept of total pain.....Nurse #1*

But it has been illustrated extensively in this dissertation that total pain is complex and a nurse is not likely to fully retain the depth of knowledge of total pain just by reading it over once or twice. Allowing clinicians to reflect and make log entries about their SPM experience will enhance learning about SPM and its many complexities.

Although the need and value of engaging in reflective practice was described in section 2.1.6.4 a challenge is that clinicians need the means of engaging in reflections but also direction on what to reflect upon.

One aspect of reflections that came out of the GT-PD sessions is the need to consider an ethical basis when making decisions about severe pain.

*...Someone in severe pain do we ignore what the patient wants? What the family wants and let the doctor just do what he wants? No, ethics comes into play and in fact it's very important...Physician #1*

However another physician acknowledged that sometimes because of the urgency to quickly manage an episode of severe pain ethical considerations are not always given their due diligence.

*Perhaps the intensity of the pain pushes us through ethics more quickly than we need to...then we should be, and sometimes the urgency pushes us to the place of action without necessarily looking at ethical aspects...Physician #2*

Therefore an enhancement is to provide clinicians with the information needed for ethical reflection and the tools to facilitate ethical deliberations to ensure that ethical considerations are given their due diligence.

Another aspect about reflective practice occurs after dealing with a severe pain report and relates to self care and awareness for clinicians. Severe pain is certainly difficult for the patients and families to witness but it is also difficult for the staff to witness. Managing one's own suffering is important for the well being of clinicians and during a consensus meeting it was pointed out that one strategy in CAPIT needs to be help for clinicians to engage in reflective practice in order to manage their own suffering.

*What is the context of the pain, not only for the patient but also for those around the patient including the family and team caring for the person...Physician #2*

*You know for strategies I wonder if there doesn't need to be a strategy for students self awareness, you know I think that's a big strategy, fundamental to all of this is the need to know where your suffering begins and ends....Counsellor #3*

*Right, attention to effect on ourselves.....Physician #2*

*Self awareness...Counsellor #3*

*It's really a reflective practice.....Nurse #4*

An enhancement to CAPIT is to provide a clinician material to promote reflective practice such as on ethical considerations, team development or self awareness as well as the means to capture the reflections over time such as through a journal or log. Capturing reflections will enable a clinician to look back at reflections over time to see how the reflections have impacted their practice but will also allow the development of a case base of reflections that could be used for teaching.

### **5.5 Summary of Conceptualization Phase Part I – Problem Domain**

This chapter presented two clinical scenarios to demonstrate the complexity of SPM, presented a current approach to SPM in the form of the paper based CAPIT and then described ten additional requirements that emerged from the GT-PD sessions that would enhance CAPIT and provide it more functionality. The ten additional requirements are as follows:

1. Fit with workflow of clinical practice
2. Supporting Information
3. Charting and Communication
4. Diagnostic Support
5. Management of Complexity
6. Ensuring assessment of total pain and fundamental considerations
7. Team development
8. Continuum of care
9. Vocabulary and definitions

## 10. Learning and reflections on practice

Those ten requirements get at the practice support needs of SPM and help provide a rich understanding of what is needed to support SPM at the moment of pain but also what processes and information are needed leading up to and after the moment of pain. The requirements become the basis for the informatics based solutions described in chapter 6 and are then implemented in chapter 7 as a computer based version of CAPIT.

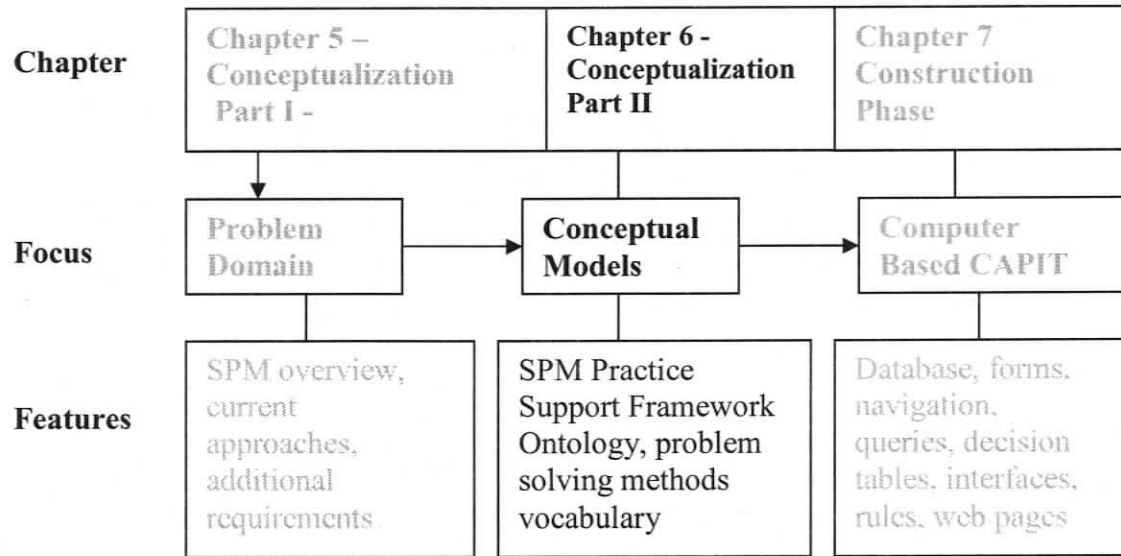
## **Chapter 6 – Results – Conceptualization Phase Part II – Conceptual Models**

Chapter 6 is part II of the conceptualization phase. Given the complexity of the results in this chapter it is structured into six sections. The first section is an overview of part II of the conceptualization phase. The second section describes the SPM practice support framework that acts as the overall framework for the results of this dissertation. The third section details the ontology and how it was developed. The fourth section describes the problem solving methods. The fifth section describes the vocabulary. Section six concludes the chapter with a summation of the results.

### **6.1 Overview of Conceptualization Phase Part II**

Figure 10 shows the results diagram that was first introduced in chapter 5. As figure 10 shows the conceptualization phase part II chapter is the intermediate chapter between chapter 5, which described the problem domain of severe pain management and chapter 7, in which the results from the conceptualization chapter are implemented as the computer based severe pain tool. As figure 10 shows the focus of this chapter are the conceptual models that formalize the data from the problem domain description in chapter 5. The conceptual models consist of an SPM practice support framework and a set of informatics based solutions consisting of an ontology, set of problem solving methods and empirically derived vocabulary.

All of the results presented in this chapter, the SPM practice support framework and the three informatics based solutions, have been developed using the results obtained from the GT-PD sessions as described in chapter 5.

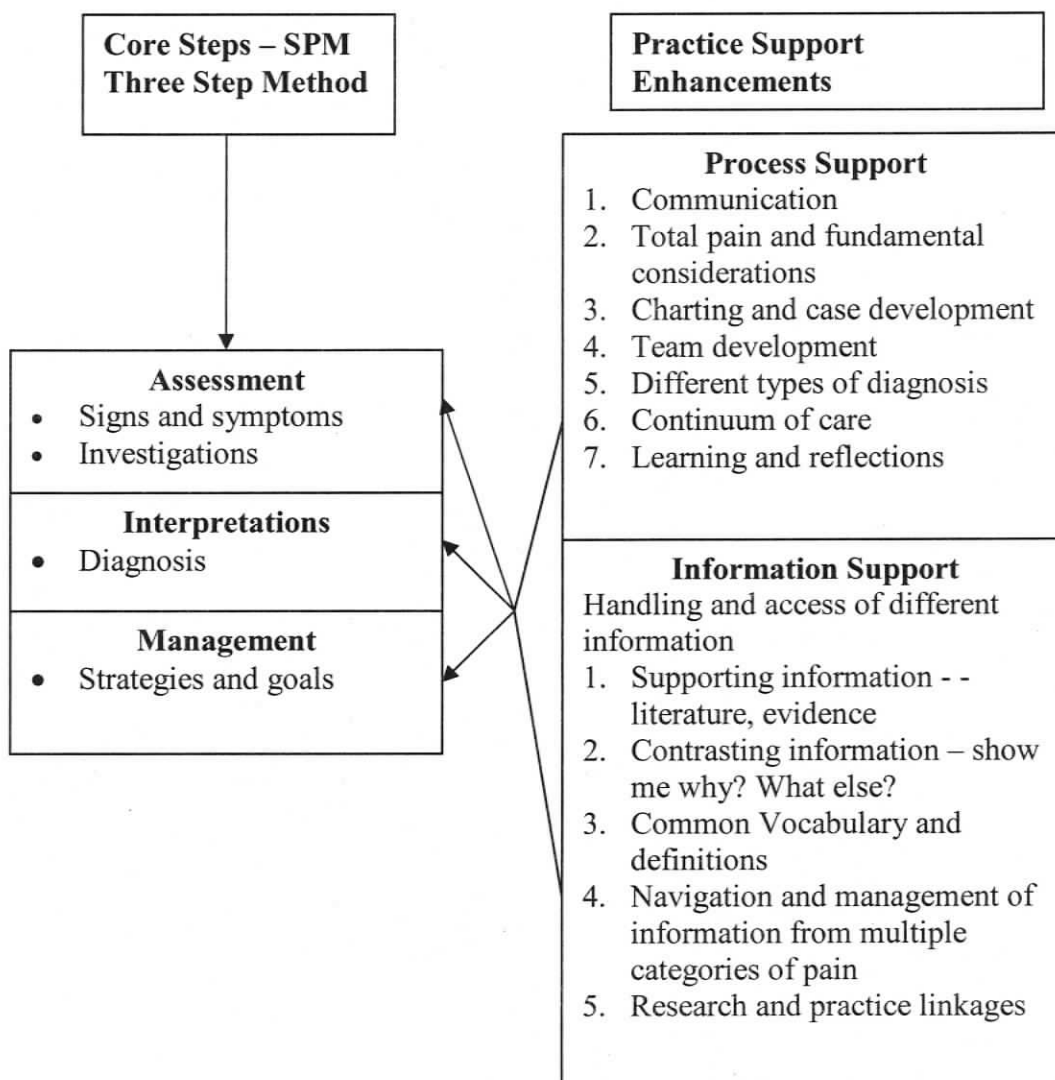


**Figure 10.** Results diagram of the conceptualization part II and how it connects to chapters 5 and 7

The remainder of the chapter provides details about the development of the SPM practice support framework and the three informatics based solutions.

## 6.2 SPM Practice Support Framework

This section describes the development of the SPM practice support framework (figure 11). As figure 11 shows the SPM practice support framework has two parts to it. The left side of the framework shows the core SPM steps (assessment, interpretation and management) to ensure those are reflected in the framework. The right side shows the practice support enhancements that can help sharpen the core SPM steps. The practice support enhancements are derived from the list of additional requirements from the previous chapter.



**Figure 11.** SPM practice support framework illustrating the three core SPM steps (assessment, interpretations and management) and practice support enhancements to those steps

The two parts of the SPM practice support framework, the core SPM steps and practice support enhancements are described below.

### 6.2.1 Core Steps – SPM Three Step Method

The core steps, called the SPM three step method are assessment, interpretation and management (strategies and goals). Those three steps were described in the quote in

section 5.1 as processes that clinicians do all day as part of practice and those steps correspond to the terms in the paper based CAPIT. Assessment is where signs and symptoms are obtained; interpretation establishes a diagnosis of what is the driving cause of the severe pain episode; and management determines appropriate strategies for managing the severe pain episode.

### **6.2.2 Practice Support Enhancements**

Although the three SPM steps can be found in any palliative care textbook the contribution from the SPM practice support framework are the practice support enhancements to the SPM steps. The practice support enhancements are derived from the ten additional requirements presented in conceptualization phase I but there are some elaborations to the enhancements that warrants presenting them as distinct from the additional requirements. Two types of elaborations are described below.

First in reviewing the additional requirements it was determined that there were two main categories of practice support needed: process and information support. The rationale for the two categories is that in order to provide practice support for SPM we not only need to define the processes that are done and the information that supports those processes but also the relationships between the processes and information. Identifying a process done as part of SPM (i.e. a diagnosis) without the necessary information to support that process (i.e. signs and symptoms) will not provide practice support.

Second, the different types of process and information support enhancements are represented somewhat differently from the ten additional requirements. One of the additional requirements is fit with workflow of clinical practice. There is no specific type of process support called workflow but rather workflow support is a part of many process support enhancements. Likewise one of the additional requirements is supporting information but when all the different types of information were reviewed it was determined that there are in fact many types of information that support different processes. Therefore the information support enhancement differentiates supporting

information, contrasting information and research and practice linkages as those are different information types and are used to support different processes.

Table 1 shows the relationship between the ten additional requirements and the process and information supports from the SPM practice support framework. The left column is the ten additional requirements and the top column refers to the process and information support from the SPM practice support framework (PS1 = Process Support #1, IS1 = Information Support #1 etc.) Table 1 shows how some of the additional requirements are part of multiple process or information support enhancements and it also shows the relationship between the processes and information.

**Table 1.** Relationship between the ten additional requirements and process and information practice support enhancements

	PS1	PS2	PS3	PS4	PS5	PS6	PS7	IS1	IS2	IS3	IS4	IS5
1. Fit with workflow of clinical practice	✓		✓	✓	✓	✓		✓	✓		✓	
2. Supporting Information								✓	✓			✓
3. Charting and Communication	✓		✓							✓		
4. Diagnostic Support					✓			✓	✓		✓	
5. Management of Complexity					✓			✓	✓		✓	
6. Holistic care		✓									✓	✓
7. Team development	✓		✓	✓				✓		✓		
8. Continuum of care	✓		✓			✓						
9. Vocabulary and definitions	✓		✓	✓							✓	
10. Learning and reflections on practice							✓			✓		✓

The two categories of practice support enhancements are described below:

### 6.2.2.1 Process Support

Process support identifies enhancements to specific processes done as part of SPM. The process supports are:

1. **Communication** –Effective communication needs to be promoted such as between a physician and nurse such as during assessment. Communication of knowledge about a patient is also needed to support the ongoing care of a patient
2. **Holistic care and fundamental considerations** – The fundamental considerations and total pain were identified as two components that need to be considered every time an episode of severe pain is managed regardless of what category of severe pain the patient may be having.
3. **Charting** – Ensuring that all requisite data is charted about a severe pain episode including physical and psychosocial data.
4. **Team development** – A team perspective needs to be considered for each severe pain episode even in instances where no team is available.
5. **Diagnosis** – The interpretation aspect of paper based CAPIT was articulated as being both a provisional and differential diagnosis, which are two ways of getting at a definitive diagnosis. Differential and provisional diagnoses represent different approaches to clinical reasoning and thus require different support. It was also identified how clinicians need to be able to distinguish between pain driven by physical etiologies and pain that is driven by total pain issues.
6. **Learning and reflections** –It was described how computer based CAPIT could be helpful for helping students and new staff (nurses and physicians) to learn about SPM. The requirements also described how reflective practice is an important part of SPM. The reflections can be about the current patient case (a progress note for a case), about aspects of the case (such as ethical decision making) or about the clinician themselves and how they have been impacted through witnessing patients in severe pain (self reflective practice).
7. **Continuum of Care** – Reflects the fact that SPM is not a one time occurrence and communication and effective development of severe pain cases are needed to support ongoing patient care.

### 6.2.2.2 Information Support

Information support refers to the different types of information that needs to be available to support the processes of SPM. Each type of information support is described below.

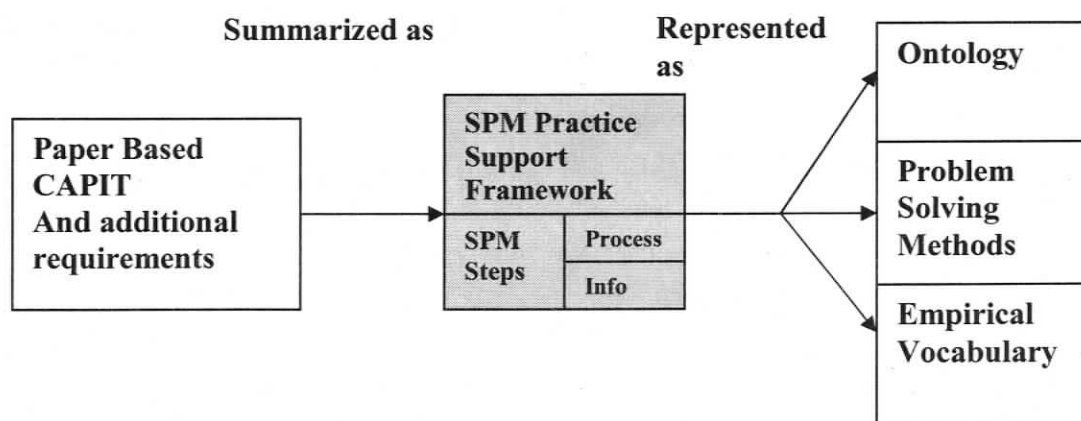
1. **Supporting Information** - Given that many of the aspects of SPM have further levels of detail there can be a lot of imbedded complexity. A number of aspects were described as important in managing a severe pain episode including ethical models of care, conceptual models from the literature and details about total pain. Many of the features of the severe pain tool refer to tasks such as doing an assessment, performing a differential diagnosis or titrating an opioid and those tasks have detailed descriptions about how they should be done. Supporting information provides a 'Show me how' or 'help me do this' functionality.
2. **Contrasting information** – Contrasting information is used to provide information to help with an interpretation. Contrasting information answers questions such as what else in cases where a sign or symptom may be found across multiple categories of pain or how to differentiate amongst two or more categories of pain
3. **Navigation** – Navigation is needed to provide the means of moving through the information in order to support the core SPM steps and helping to connect the steps. When patients have multiple categories of pain, each of which has its own assessment, interpretation and management it can get very complex and therefore support and navigation for the process is necessary. Navigation also is necessary for helping a user to access appropriate supporting information, but again the navigation needs to be done so it supports the user and does not overwhelm them

4. **Common Vocabulary** – Part of enhancing SPM is providing a common vocabulary to communicate about pain episodes so that clinicians have a common understanding about the terms. The common vocabulary needs to enhance communication between clinicians but also needs to help clinicians make a patients pain more visible.
5. **Research and Practice Linkages** – Provides information about conceptual models and the means of illustrating how those models can be used to make patient cases more visible

### **6.2.3 Relationship of SPM Practice Support Framework to Problem Domain and Informatics Based Solutions**

Figure 12 shows the SPM practice support framework as the anchor point for the conceptualization results of this study. The SPM practice support framework is an enhanced representation of the paper based CAPIT through GT coding of the three PDS described in section 4.8. The contribution from the GT coding was that it helped to draw out and articulate the practice support needs of palliative SPM.

As described in chapter 3 (section 3.2.3) the paper based CAPIT was used as the coding paradigm for GT coding. What that means is that the requirements and practice support enhancements are ways of extending the functionality of the paper based CAPIT. The paper based CAPIT contains signs, symptoms, interpretations and strategies and the SPM practice support framework enhances the way the paper based CAPIT is used by providing practice support.



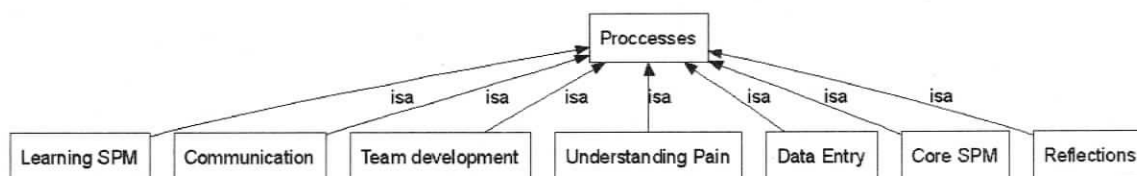
**Figure 12.** SPM practice support framework as the anchor point of conceptualization results from this study

The informatics based solutions are internal representations of the SPM practice support framework. The ontology describes what concepts are used in SPM and the relationship amongst those concepts, the problem solving methods describe when and how the concepts are used for different types of problem solving and the vocabulary describes the language used in SPM.

### 6.3 Ontology

The ontology is a formal representation of the concepts and relationships from the SPM practice support framework such as establishing names and relationships for the concepts contained within the SPM practice support framework. Formal representation from an ontology perspective provides depth of detail about what concepts are used in palliative SPM and how those concepts relate. The depth of detail elaborates on the SPM practice support framework, which only presents concepts at a functional level. For example the process support 'charting' from the SPM practice support framework is conceptual and does not provide details about what is charted to develop a severe pain case. The ontology provides that level of detail. The problem solving methods discussed in the next section become the means of navigating through the ontology and linking the processes with the information in order to facilitate problem solving.

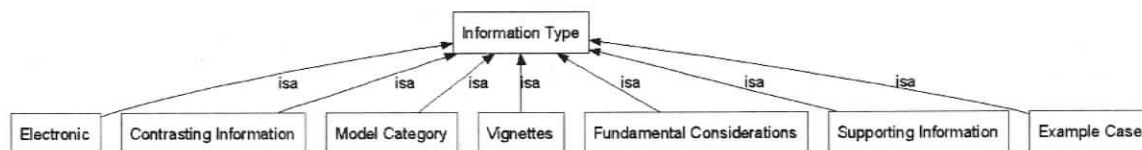
Figures 13 and 14 show high level views of the processes and information types within the ontology.



**Figure 13.** Ontological view of the processes in palliative severe pain management

In mapping Figure 13 back to the SPM practice support framework (figure 11) it can be seen that some of the ontology concepts are variations of the SPM practice support framework terms and have different names. The charting process from the SPM practice support framework has been placed within the data entry ontology concept. That was done because although charting is a large part of data entry there are also other types of data entry such as a reflective note. Therefore in keeping with ontology design principles the more general term data entry was used to enhance the ability to share the ontology in other settings. Similarly the total pain and fundamental consideration types of process supports from the SPM practice support framework have been placed with the understanding pain ontology concept. Understanding pain was chosen as a general term to refer to the need to look at the complete picture of a patient's pain in order to understand all facets of the pain. The understanding pain term makes the ontology more general and shareable because fundamental considerations are a very specific term to the site where the study was done. Other centres may use different approaches for understanding pain and a general term allows them to plug in their own local variation.

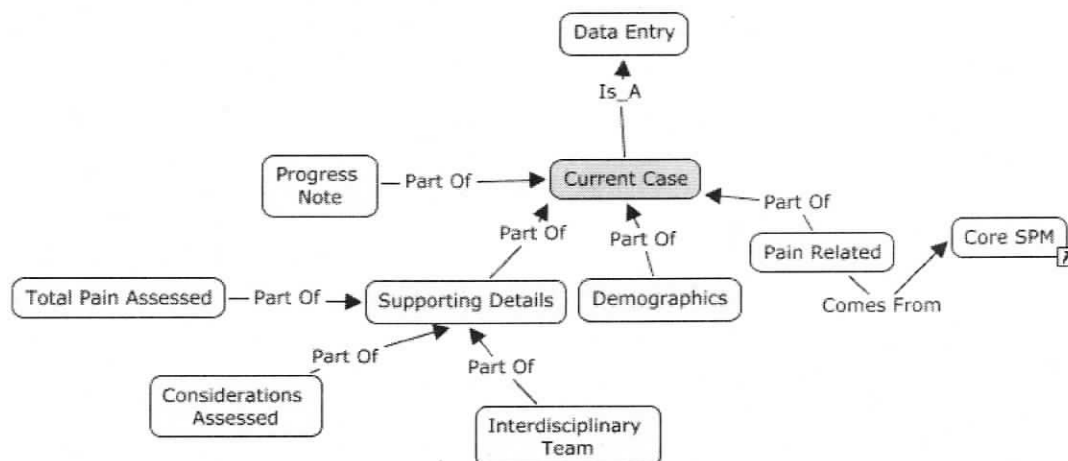
Finally there is no explicit ontology concept called 'continuum of care', which is part of the SPM practice support framework. Continuum of care is represented through other concepts such as communication and data entry as a type of data entry is progress notes as a way of documenting ongoing care for a patient.



**Figure 14.** Ontological view of the information types in palliative severe pain management

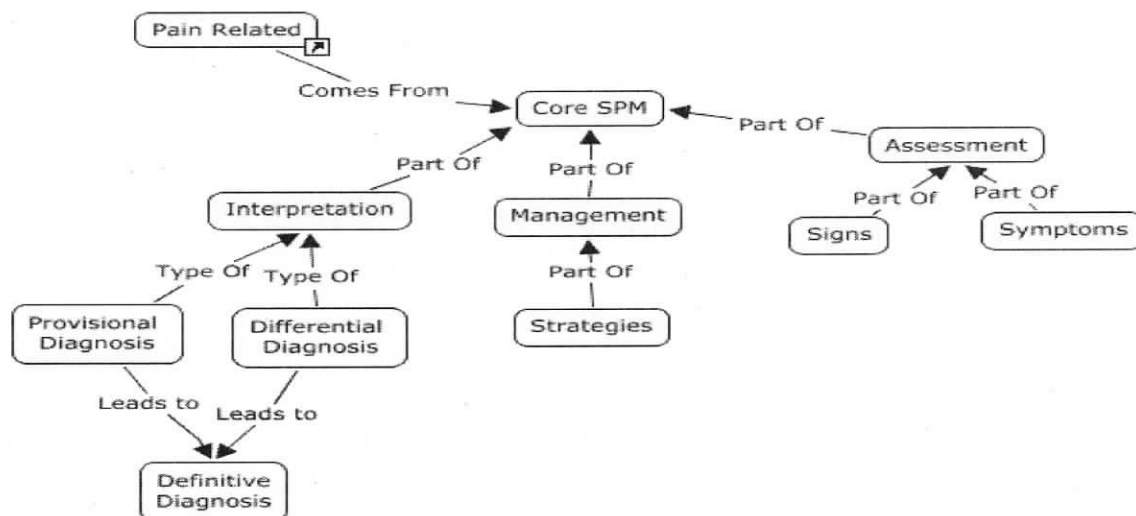
As with the process supports there is also some variation of the information types in the way they are represented in the ontology compared with the information support piece of the SPM practice support framework. The supporting and contrasting information ontology concepts come directly from the SPM practice support framework. The other information types are specific elaborations of information types. Electronic refers to electronic data such as websites, model category is a model severe pain category from the paper based CAPIT; vignettes are narratives about aspects of SPM and example cases are historical severe pain cases.

An extended view of parts of the ontology can be seen in figures 15 and 16. Figure 15 shows a hierarchy of the data entry process and figure 16 shows a hierarchy of the core SPM process. Figure 15 shows that part of the formalization of the SPM practice support framework was development of an ontology concept called current case that encompasses three concepts: pain related, supporting details and demographics. The supporting details concept is further broken down into three sub-concepts: consideration of interdisciplinary team, assessment of fundamental considerations and assessment of total pain. Figure 15 also shows the relationship between the data entry and core SPM processes as the pain related data from the current case is derived through the core SPM process.



**Figure 15.** Expansion of the data entry process to show the current case concept

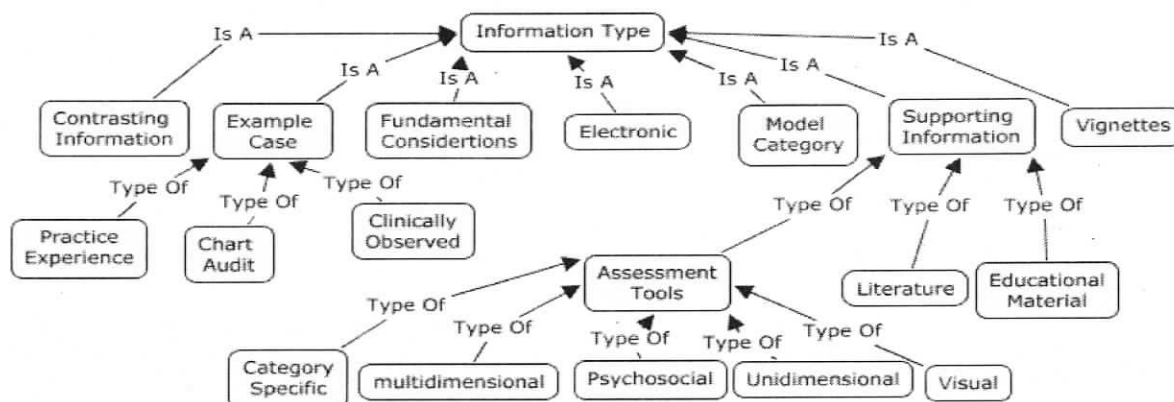
Figure 16 shows the Core SPM concept that contains the three core SPM steps but also extensions to the steps. For example the interpretation concept actually consists of two sub concepts, differential and provisional diagnosis and those two types of diagnosis lead to a definitive diagnosis.



**Figure 16.** Expansion of the core SPM process

Figure 17 shows the information type concept and its associated subconcepts. The information types represent the summation of the information gathered from this research and are used to support the processes from figures 13. The information type concept contains a range of information including patient cases, research literature, electronic

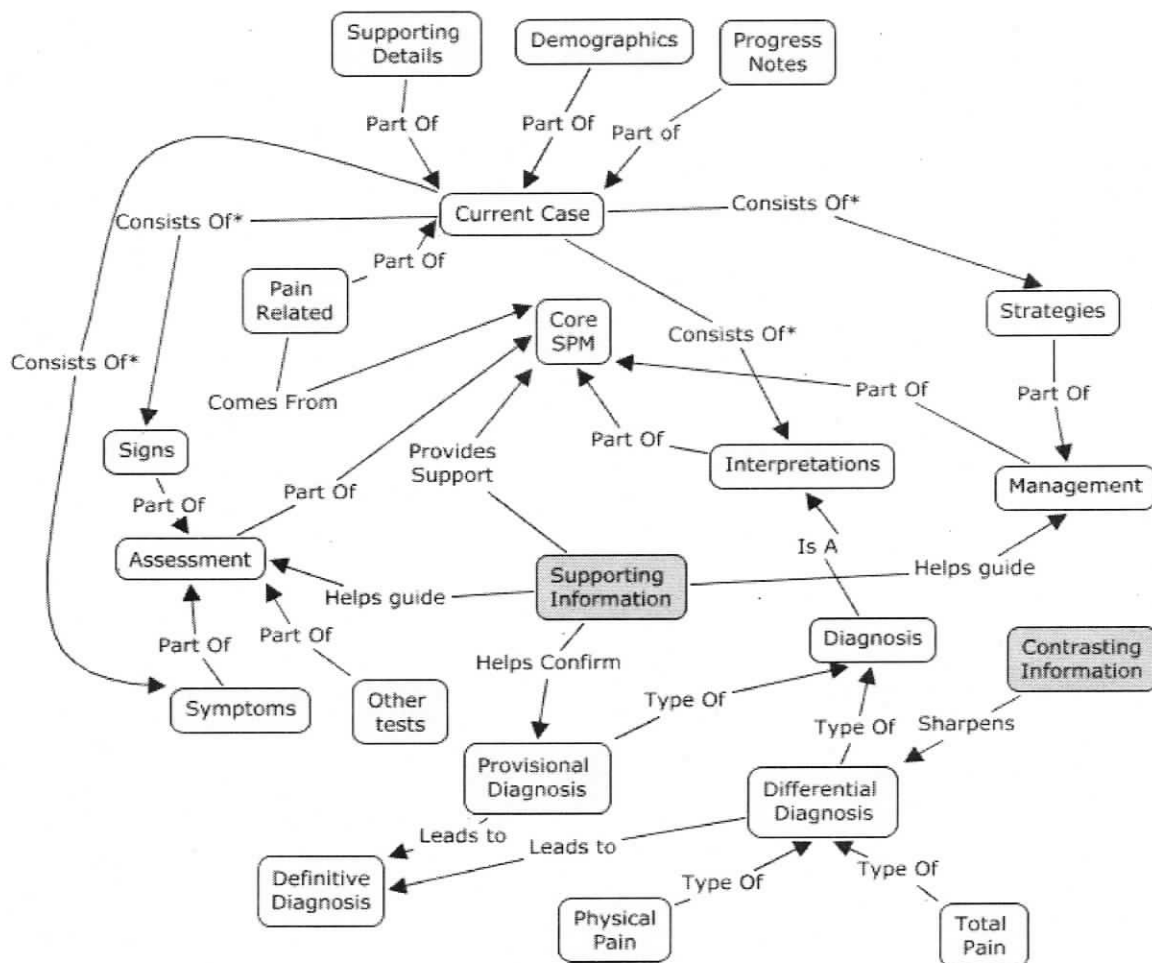
linkages to websites and subjective narratives as vignettes. The key aspect is managing the information so it is available at the right time to support the process where it is needed.



**Figure 17.** Information type concept and subconcepts

### 6.3.1 Relationships between ontology concepts

Part of the utility in displaying the SPM domain in ontological format is displaying the relationships between the concepts as it helps to define and illustrate how the ontology concepts relate to one another. In particular the relationships illustrate how the SPM processes interact with the information types in order to carry out a process, which helps define what information needs to be available to support the process. A detailed example of the relationships between ontology concepts is shown in figure 18, which expands upon the current case concept from figure 15 and illustrates the processes and information of the pain related data of the current case. The supporting details, demographics and progress notes concepts of the current case are shown but not expanded out into detail in order to keep the diagram readable. Figure 18 illustrates that the pain related data of a current case comes from the core SPM processes but also establishes the cardinality between the concepts. For example the 'consists of' relationship that links the current case to the Core SPM concepts has an asterisk beside it to indicate that it is a one to many relationship in that a current case can have many Core SPM concepts (signs, symptoms, interpretations and strategies).



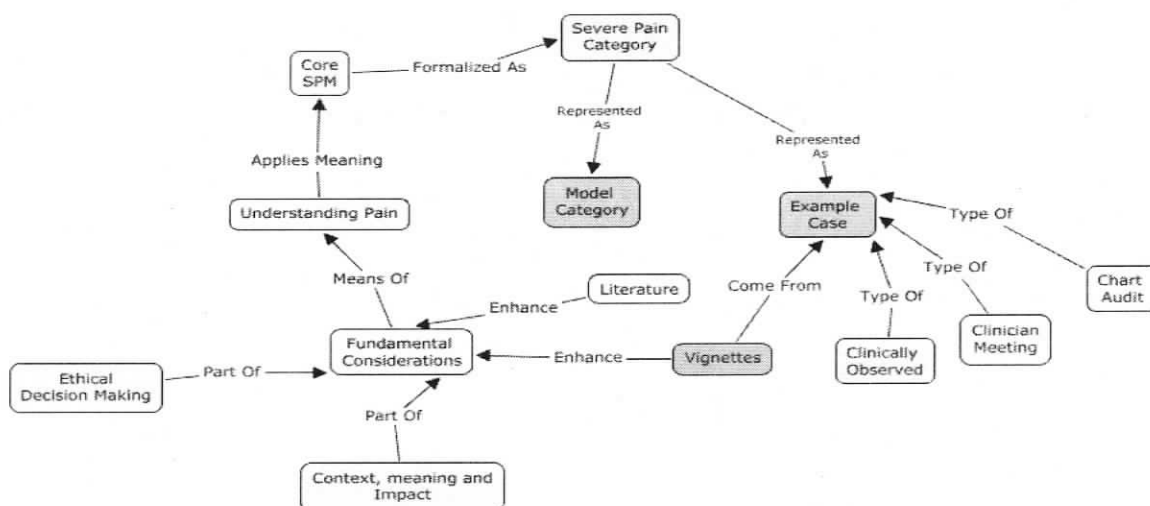
**Figure 18.** Expansion and relationships of the current case concept including linkage of two information types (in gray boxes)

Figure 18 also illustrates an expansion of the differential diagnosis concept that has two types of differential diagnoses, a physical pain differential diagnosis and total pain differential diagnosis.

Finally, figure 18 shows how two of the information types are used to provide support to the Core SPM processes. The information type supporting information 'helps guide' the assessment and management processes. The two diagnostic processes, differential and provisional diagnosis also have relationships with information types as differential diagnosis (distinguishing between two or more categories) has a 'sharpens' relationship with contrasting information whereas provisional diagnosis (confirming a category) has a

'helps confirm' relationship with supporting information. The different information needs of a provisional and differential diagnosis support the different navigation requirements in that a differential diagnosis needs cross category navigation (via contrasting information) to differentiate between pain categories whereas a provisional diagnosis requires information to drill down within a category (via supporting information) to help confirm a pain category.

A final example of the relationship between the ontology processes and information types is shown in figure 19. A current case contains pain related data derived through the Core SPM processes. However the data is not organized randomly but rather is formalized to give it structure. The core SPM data are formalized as severe pain categories and a category is represented as either a model category or an example case. Model categories represent the categories from the paper based CAPIT and are a consensus of what data a severe pain category should have. Example cases come from empirical severe pain cases. These empirical cases come from the three palliative PDS described in section 4.8 via chart audit, meetings with clinicians or clinical observations. Using the model categories as a means of formalizing the cases is an important aspect of information handling and will be described in the case management problem solving method.



**Figure 19.** Relationship between the Core SPM and understanding pain process and information types (in gray shaded boxes).

Figure 19 also illustrates the ontology relationships and information used by the understanding pain process. The understanding pain process will be described in the next section as part of the case management problem solving method.

#### **6.4 Problem Solving Methods**

The problem solving methods are internal ways of bundling the processes and information support from the SPM practice support framework in order to accomplish specific tasks. Put another way the problem solving methods are different ways of using the information and process concepts from the ontology and thus the problem solving methods are the means of navigating the ontology.

Three problem solving methods: case management, quality improvement and reflective practice were developed. Each problem solving method is described as a series of tasks and in some cases sub-tasks in order to illustrate the multiple parts of practice support provided through each problem solving method.

##### **6.4.1 Case Management**

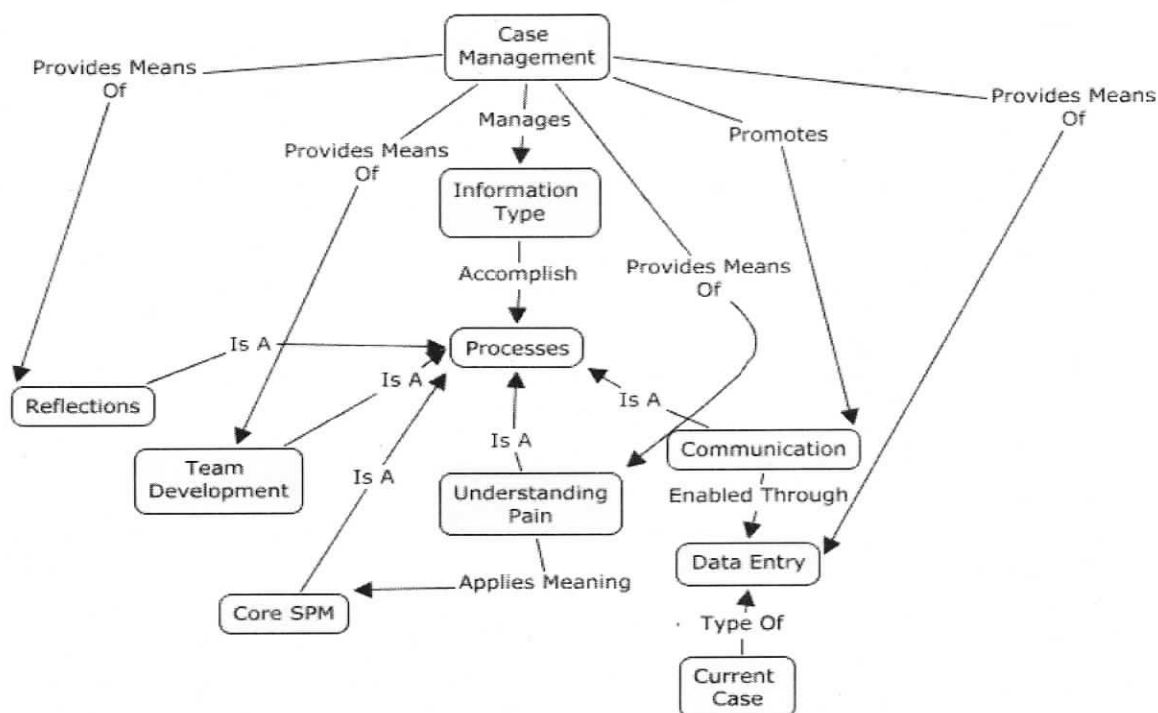
Case management is a problem solving method that helps the user to move forward through the process of SPM. The specific tasks and subtasks of the case management problem solving method are as follows:

1. Enables CAPIT to develop and manage a patient's severe pain case. Data can be entered into the case to bring it to the level of detail of the model cases. Example cases can also be viewed based on similarity with the current case and additional data elements can be entered to enrich the current case to the level of the historical cases. The current case can be printed out as a report that can be placed in the patient's chart to ensure that data about a patient's case is communicated to other staff members. Progress notes can be made about a case to support ongoing care.
2. Promotes use of a common SPM vocabulary and also enhances charting and communication around SPM through data entry. The common SPM vocabulary

also enhances the diagnosis process as it enables retrieval of SPM categories based on signs and symptoms

3. Manages the various types of information that can be presented about a severe pain category. For example each severe pain category can be drilled down (via supporting information) or viewed across categories (via contrasting information).
4. Guides the user through the overall flow of SPM to develop the patient case, perform a diagnosis, retrieve information related to the case, and finally to close the case. Part of that guidance is providing navigation and management of complexity for viewing of multiple categories of pain.
5. Helps manage the complexity of information such as providing checklists to promote completion of tasks. A checklist is provided for tasks such as fundamental considerations, total pain assessment, consultation with the interdisciplinary team and consideration of ethical aspects of care to promote completion of the tasks. Also provides the means of doing reflective practice by engaging the user various types of reflective practice by providing the means of documenting of reflective notes.
6. Provide means of 'Understanding Pain' – The 'Understanding Pain' concept enhances CAPIT by providing the means of understanding the individual uniqueness of a report of severe pain.

Figure 20 shows the case management problem solving method and how there are two ways the six case management tasks described above are achieved. The first way is handling of the ontology concept 'information type' to provide information handling around SPM. The second way is to provide the means of completing the processes outlined in the ontology including interdisciplinary team development, reflections in practice, data entry, communication, understanding pain and the core SPM processes. The learning SPM process from figure 13 is part of the reflective practice problem solving method and is not shown in figure 20. Also figure 20 does not show expansion of the information type concept but that detail is provided in figure 17.

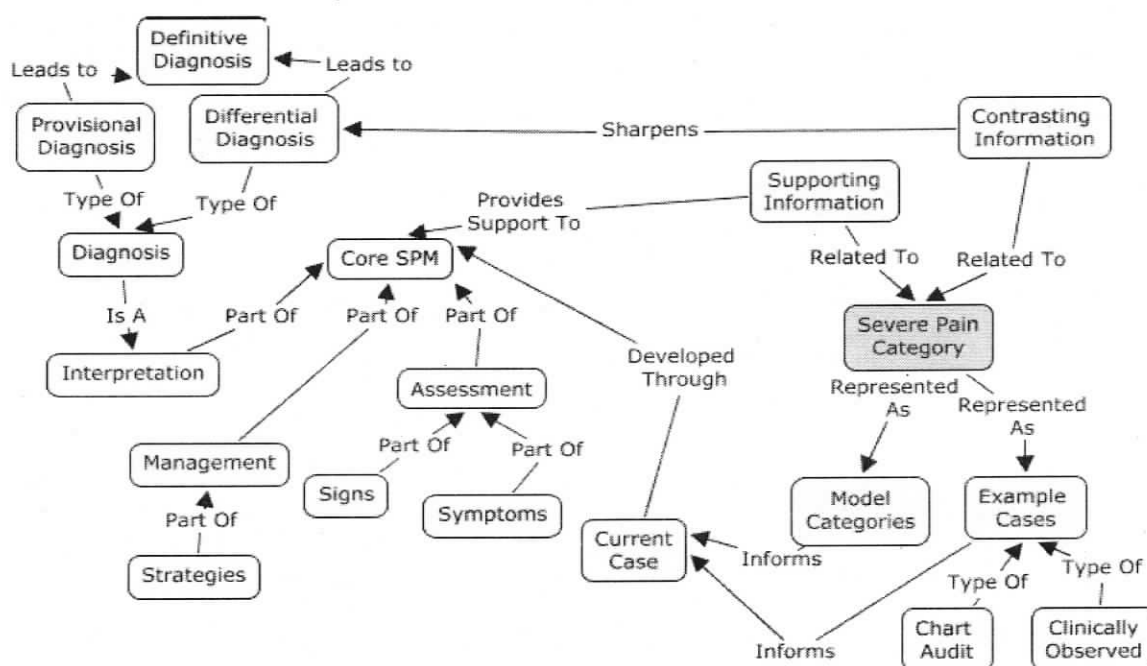


**Figure 20.** Case Management problem solving method

The next two sections describe the two ways of achieving the case management tasks.

#### 6.4.1.1 Case Management – Information Handling

A specific example of how the case management tasks are achieved through information handling is shown in figure 21. The case management problem solving method categorizes the different information types so they can be retrieved to support different processes. As shown in figure 21 the information types are linked according to the category of severe pain (shown in gray), which enables supporting or contrasting information to be retrieved according to the severe pain category the information is needed for. For example one type of supporting information is an assessment tool used to assessing signs and symptoms as part of the core SPM process of assessment. However some assessment tools are category specific such as observational tools being used for patients with dementia or delirium who may not be able to describe their pain verbally. Thus a specific assessment tool needs to be retrieved when querying the two categories of pain (opioid induced neurotoxicity and dementia or delirium) where a patient may not able to verbally describe their signs and symptoms.



**Figure 21.** Information handling for strategic retrieval of information

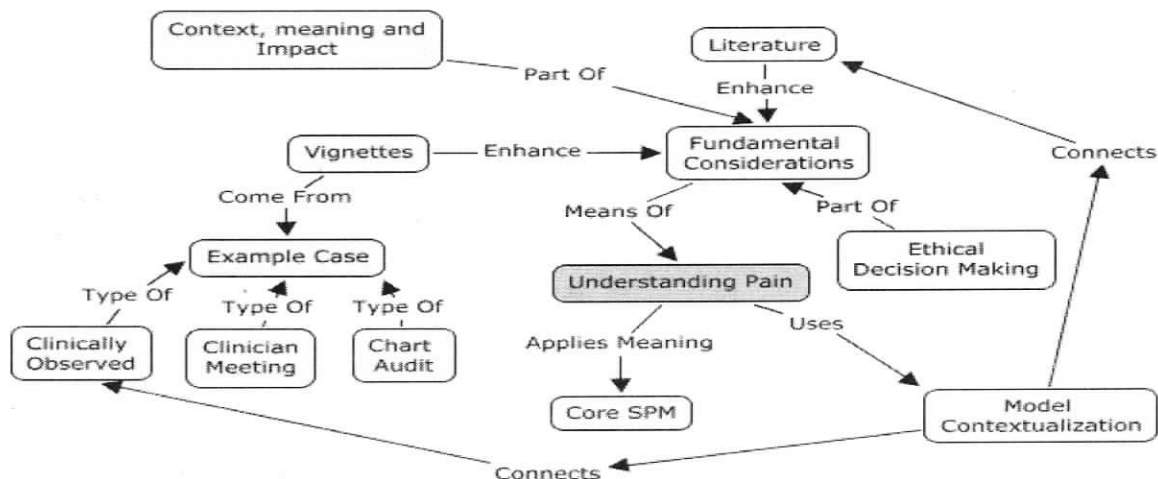
#### 6.4.1.2 Case Management – Completion of Processes

The second way the tasks of the case management problem solving method are achieved is by providing the means of completing the processes from the ontology including interdisciplinary team development, reflections in practice, data entry, understanding pain and the core SPM processes. Case management does that by providing items such as checklists to ensure completion of fundamental considerations, assessment of total pain and consultation with an interdisciplinary team, provides access to electronic resources about interdisciplinary teams if no team is available and research-practice linkages to enhance understanding pain. Reflective practice is encouraged by providing material for reflection as well as tools for developing reflective notes both for both reflections in and on practice. The means for doing data entry of the core SPM processes are through assessment forms and charting documents, both of which enhance communication around SPM.

The case management problem solving method also provides the means of understanding pain, which is a formalization of the requirements to always check the fundamental

considerations and assess for the presence of total pain in each severe pain episode. The understanding pain process and its relationships are shown in figure 22. Overall the understanding pain process applies meaning to the signs, symptoms, interpretations and strategies of the core SPM processes. Applies meaning refers to the need to consider the core SPM processes within the individual context of a patient case. A large aspect of how case management provides the means of understanding pain is through research-practice linkages. Two specific research-practice linkages will be described. First is a feature of understanding pain called model contextualization, which illustrates how the conceptual Schema Enmeshment Model of Pain (SEMP) presents as a real patient case. Model contextualization shows how different enmeshment patterns of the three schemas (pain, illness and self) would present in different patient cases. Model contextualization can help a clinician make sense of the unique severe pain case they are currently managing such as showing why the illness and self schemas may become enmeshed.

A second part of the understanding pain process is information handling that establishes linkages between the information types such as research and practice in order to bring empirical examples to abstract theory. Understanding pain provides a set of clinical vignettes that helps put empirical context to some of the conceptual terms such as the terms from the fundamental considerations. The vignettes are subjective narratives that describe particular aspects about fundamental considerations (such as context, meaning and impact) in the context of a patient case and help to give empirical grounding to the fundamental considerations. For example one vignette describes how a 'temporal' circumstance related to a pain report such as a missed family reunion can shed light on the context, meaning and impact of the patient's pain and give a better idea of all the circumstances around why that patient is reporting severe pain.



**Figure 22.** Understanding pain process

#### 6.4.2 Quality Improvement

Quality improvement (QI) is a problem solving method that supports the SPM processes by helping the user to look back to make sure that certain aspects of SPM have been done. The case management problem solving method provides the means of assessing the fundamental considerations, assessing for the presence of 'total pain', considering the need for an interdisciplinary team in all severe pain episodes and charting a severe pain case. QI works complementary to the case management problem solving method in that case management provides the checklists for fundamental considerations or check box for total pain assessment and QI ensures that the checks are actually done. QI also provides rules and reminders to draw attention to particular aspects of SPM such as during an assessment or diagnosis in order to help with charting a severe pain case.

The specific tasks of the QI problem solving method are:

1. Fundamental considerations are monitored to ensure they are checked off in each pain episode and if they are not it needs to be brought to the clinician's attention
2. Data entry has mandatory and optional fields so to ensure that requisite data is collected for each severe pain episode to ensure that data is communicated to different staff. If a current case is designated as 'confirmed diagnosis' without any

signs or symptoms being the clinician needs to be alerted to the fact that the case has no data

3. A clinician needs to check off or view material on interdisciplinary team approaches to SPM to ensure a team perspective is considered in each SPM case.
4. 'Total pain' check box needs to be checked off prior to closing the patient case or else a reminder needs to be provided about the need to consider total pain in all cases
5. Reminders are used to support the assessment, interpretation and management processes of SPM to raise attention to key considerations while doing those processes. An example of a reminder is drawing attention to additional information about a category such as supporting or contrasting information

#### **6.4.3 Reflective Practice**

Reflection practice is the third problem solving method and it complements the case management and QI problem solving methods in that it encourages a clinician to reflect on what they have learned and/or experienced while using computer based CAPIT. The reflective practice problem solving method draws on the literature in section 2.1.6.4 and encompasses two types of reflections: reflections 'in' practice and reflections 'on' practice.

Reflections in practice are made while a clinician is going through the process of SPM. Reflections in practice can be related to a patient case, such as a reflection about the context of a patient's case, a reflection about ethical considerations, or a reflection about something that a clinician may have learned while using computer based CAPIT to develop their case.

Reflections on practice are done after the clinician has finished managing their SPM case. Reflections on practice help a clinician to summarize their thoughts about the case they have developed but they also enable the clinician to engage in self reflective practice to deal with their own suffering.

The learn SPM feature of the reflective practice problem solving method is an information handling function that allows a user direct access to the educational material without having to go through the process of building a patient case and having alerts and reminders pop up while viewing material.

Part of the reflective practice problem solving method also helps to draw attention to how a clinician managed a severe pain episode by providing a log of activities they performed while using computer based CAPIT. For example the log shows how many times each of the core SPM steps (assessment, interpretation and management) were done, which enables a clinician to see how they did while managing their case. The log also enables them to do a check of how complete their charting is as they can compare data entered for the patient case with their log activities. The log also indicates how well the QI features were adhered to such as showing when they did not check off all the fundamental considerations while viewing a category of pain and if they ignored the reminder to check fundamental considerations.

The specific tasks of the reflective practice problem solving method are as follows:

1. Automatically logs activities in CAPIT such as doing a differential or provisional diagnosis, when data are added to a case or when supporting or contrasting information is viewed. That enables users to look back at what they did while using CAPIT such as what types of assessment or diagnostic activities did they do? Over time that can help establish SPM practice norms for managing different types of SPM cases
2. Has a mode designated as 'Learn SPM' by which users can directly access the educational material in CAPIT. That gives a user direct access to educational material related to SPM so they can review the material, make reflective notes on it and incorporate theory into their current case to help link theory and practice
3. Promotes both reflection in and reflection on practice.
  - a. Reflection in practice allows development of a reflective journal while using CAPIT that enables reflections to be made about the current SPM

case or something the user may have learned while using CAPIT.

Examples of reflection in practice are providing the means of doing ethical deliberation about a case to promote attention to and deliberation of ethical considerations about a severe pain case. Reflections in practice can also include deliberations on interdisciplinary teams to encourage use of interdisciplinary teams in SPM

- b. Reflections on practice are made after using CAPIT to encourage users to reflect about their own suffering and how they have been affected by witnessing palliative severe pain patients.

### **6.5 Vocabulary**

One of the contributions from the GT-PD approach was the establishment of an empirical vocabulary around palliative severe pain management. Development of a practice support tool such as computer based CAPIT requires a vocabulary to drive the data entry such as charting but also to retrieve data such as querying on signs or symptoms to retrieve a severe pain category. Although it is advantageous to use existing standard vocabularies (such as International Classification of Disease or Systematic Nomenclature of Medicine) as that facilitates sharing of data across care centres a vocabulary must also be representative about how users talk in day to day practice.

Part of conceptualization is to illustrate how the vocabulary was obtained using the GT-PD method and how the vocabulary is used for communication about SPM. The discussion of the vocabulary in this chapter looks at the 'clinical talk' around SPM. That includes a look at some of the terms used in discussing SPM, what common themes come out of those terms and how the terms are used within the specific context of SPM. The discussion of the vocabulary in the construction chapter goes one step further and looks at the extent that the vocabulary is represented in selected controlled medical vocabularies as well as illustrating how the terms contribute to systems design of the computer based CAPIT.

Vocabulary is an important aspect of SPM as many of the additional requirements and problem solving methods that were developed require an effective vocabulary. For example charting, communication, diagnosis and writing reflections about a case all require a well articulated vocabulary. Yet it is important that the vocabulary be reflective of how clinicians talk about SPM as the vocabulary is the means of communication. A physician describes below how one of the things that the paper based CAPIT is doing is giving common language around severe pain.

*what it is doing already is giving language to better describe what is happening with their patients, they're asking questions about these categories when giving feedback to other care clinicians whether charting or doing physician orders and they have a better understanding as they describe what we can do to help this person with severe pain....Physician #2*

Table 2 shows an example of how about how language is used. It shows examples of data sources and how the GT was used to establish codes that became the basis for both the ontology concepts but also the language for the ontology concepts.

**Table 2.** Grounded theory coding of 'clinical talk' leading to empirical vocabulary

<b>Data Source</b>	<b>Data or quote</b>	<b>Open Coding – Initial Concepts and Categories</b>	<b>Axial Code – Revised concepts and categories</b>
Practice Experience – Physician#2	A patient reporting 10/10 pain had just been admitted to the ward for their first respite stay and reported 10/10 pain immediately after being admitted. After the patient was put in his room, given a chance to acclimate and settle down, his pain was reassessed and had changed to 3/10	New environment, first respite, change in patient situation, anxiety, temporal event	Understanding Pain-Context -
Patient Chart – details from chart	The following are some of the data elements collected from charts: Disease - Palliative Performance Scale (assessment of functional	Aspects of pain assessment – different dimensions – pain, disease, intervention, cognition	Assessment– signs, symptoms, disease trajectory

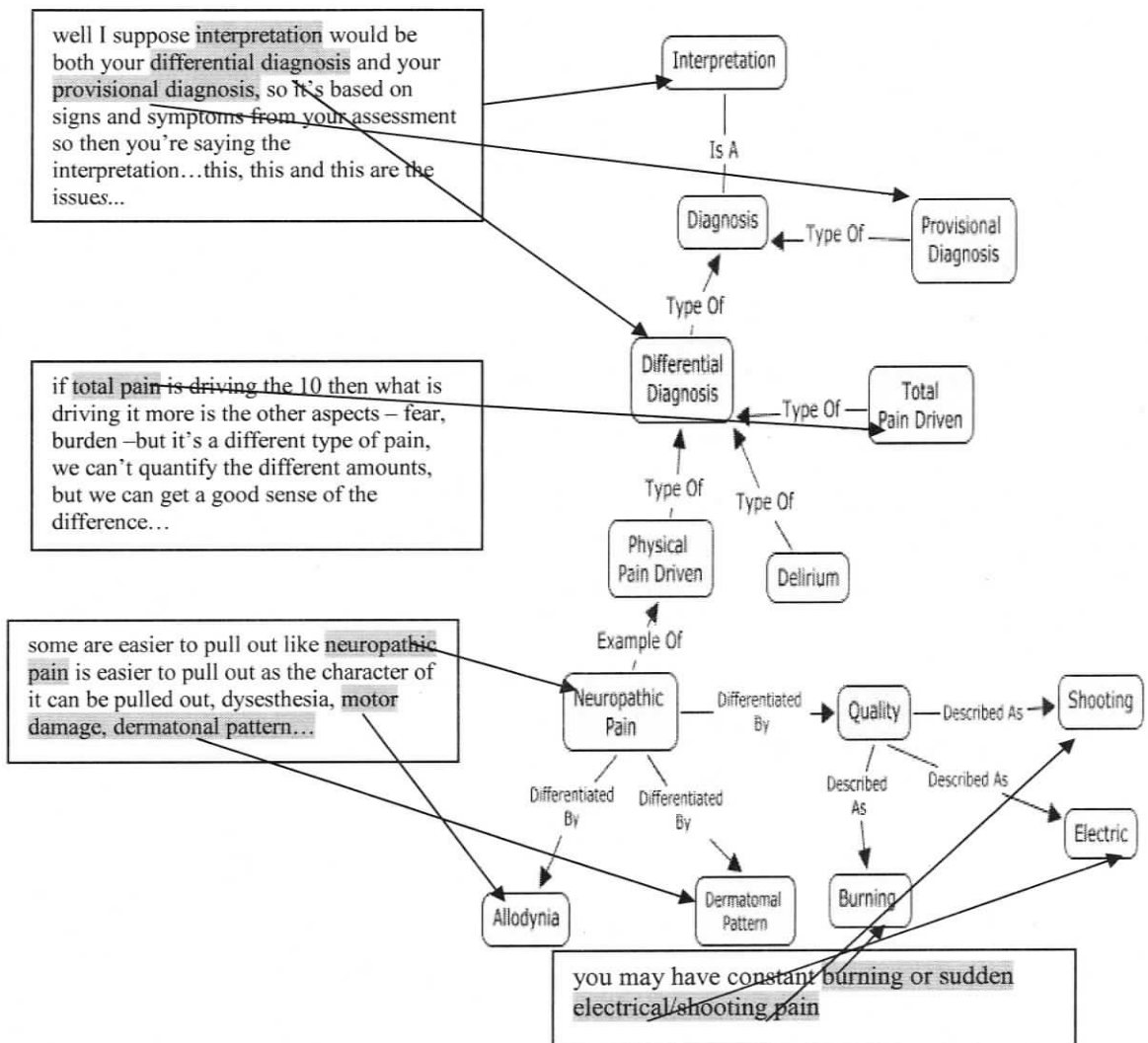
Data Source	Data or quote	Open Coding – Initial Concepts and Categories	Axial Code – Revised concepts and categories
	<p>status), diagnosis Pain - Location/description/quality of pain, onset of pain, comparison to previous pain Behavioral Signs- positioning, patient agitation Cognitive signs – confusion, delirium Interventions – opioid, adjuvant and non-pharmaceutical,</p>	<p>Many different signs – behavioral, cognitive – all part of assessment</p> <p>Different types of management – opioid, non-opioid, drug adjuvant, non drug adjuvant</p>	<p>Management -</p>
<p>Research Literature – from Pincus and Morley (2001)</p>	<p>“ .. enmeshment model proposes that the particular aspects of the self schema that are disrupted by pain determine the focus of enmeshment and the cognitive and emotional consequences of it”</p>	<p>Components of pain assessment – pain defined by space, time and sense Need for understanding the focus of enmeshment</p>	<p>Understanding pain through enmeshment</p>
<p>Practice Experience</p>	<p>Knowledge of the patient is another thing as I know what is going on with this women and all the different parts, if I were a new staff member coming on and walking into her room, that’s going to be more difficult as not everything gets passed on, you can’t pass all that knowledge on to the next new person coming on</p> <p>I think when you have it ahead of time specific to each patient and come on and go through the chart and see what’s happened to each patient...have they had incident or neuropathic pain. Etc.</p>	<p>Inadequate communication, need for better charting to enhance communication</p> <p>Need for charting of severe pain episodes, ahead of time and specific to patient</p>	<p>Case development</p> <p>Workflow – charting is a need</p>
<p>Practice Experience</p>	<p>How would you see a patient...how would the delirium look different if they were neurotoxic as opposed to having an underlying bladder infection? What would look</p>	<p>Differentiation of categories, presence of different signs – different diseases (neurotoxic vs. bladder infection)</p>	<p>Diagnosis – differential diagnosis</p>

Data Source	Data or quote	Open Coding – Initial Concepts and Categories	Axial Code – Revised concepts and categories
	<p>different to you?...Physician #2</p> <p>I think the difference would be they would have more of a pain component (in neurotoxicity) and have signs of hyperextendability like myoclonus or hyperreflexia....physician #3</p>	<p>Differentiation of delirium</p>	<p>Specific differential diagnosis – delirium based</p>
Practice Experience	<p>some are easier to pull out like neuropathic pain is easier to pull out as the character of it can be pulled out, dysesthesia, motor damage, dermatonal pattern.....Physician #3</p>	<p><u>Differentiating pain</u>, character as diagnostic tool, mix of pain types</p>	<p><u>Diagnosis - differential Assessment</u> – character, pattern,</p>
Practice Experience	<p>perhaps the intensity of the pain pushes us through ethics more quickly than we need to...and sometimes the urgency of the family seeing the person suffering pushes us to the place of action without necessarily looking at ethical aspects.....</p> <p>for strategies I wonder if there doesn't need to be a strategy for students self awareness, I think that's a big strategy, fundamental to all of this is the need to know where your suffering begins and ends</p>	<p><u>Considerations for reflection</u> - Ethical considerations, lack of time for proper ethical deliberation</p> <p><u>Reflections</u> – how are we impacted by witnessing severe pain</p> <p><u>Self reflection</u> – strategy for attention to ones self</p>	<p><u>Reflections – self reflective and reflections about the case</u></p> <p>Self reflective practice</p>

The GT codes that came out of the clinical talk such as the examples in the above table give language to the ontology concepts. Four examples are provided, three of which articulate the ontology concept differential diagnosis and one that articulates part of the fundamental considerations and how they provide a means of understanding pain.

The first example involves the vocabulary used in doing a diagnosis. One of the quotes articulated how an interpretation is really both a provisional and differential diagnosis.

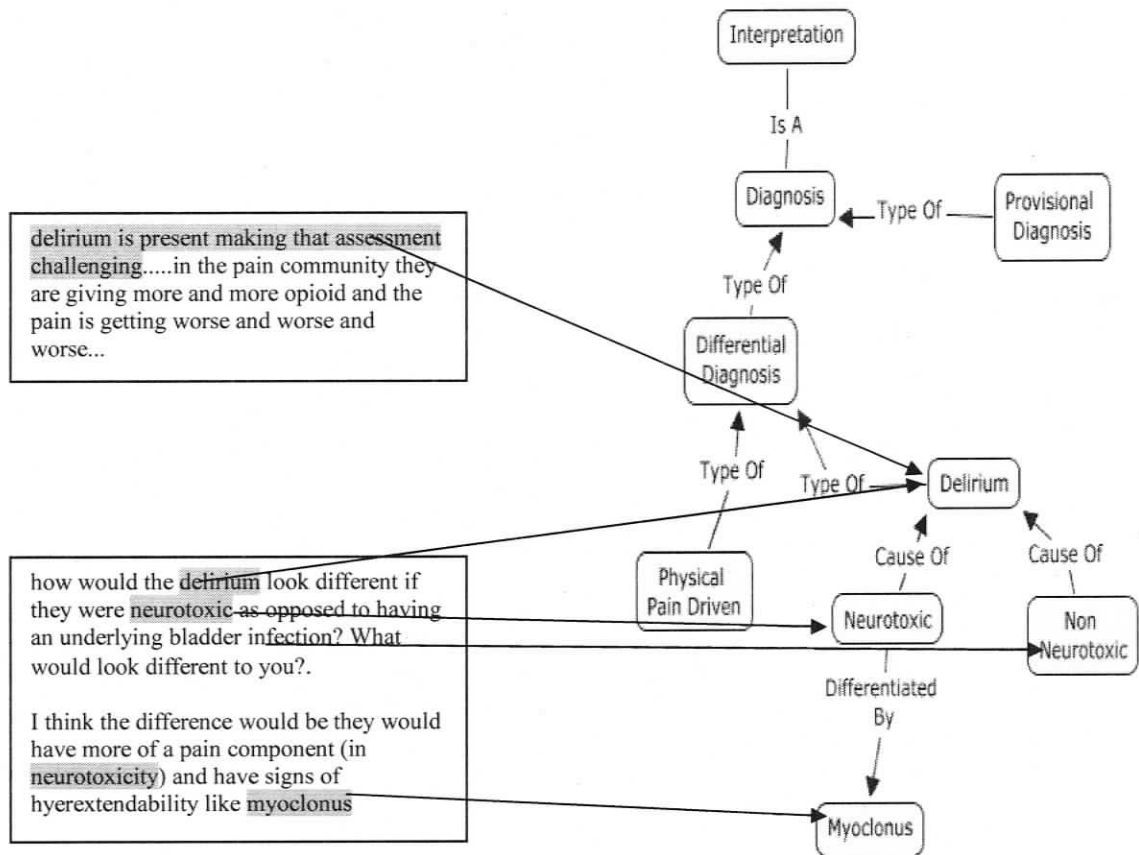
Figure 23 shows how the ontology concepts are formalized using terms from the clinical talk. Figure 23 also shows three different types of differential diagnoses (physical pain driven, delirium and total pain driven) and provides vocabulary details about a specific type of physical pain differential diagnosis (neuropathic pain).



**Figure 23.** Terms from clinical talk providing diagnostic vocabulary to the SPM ontology

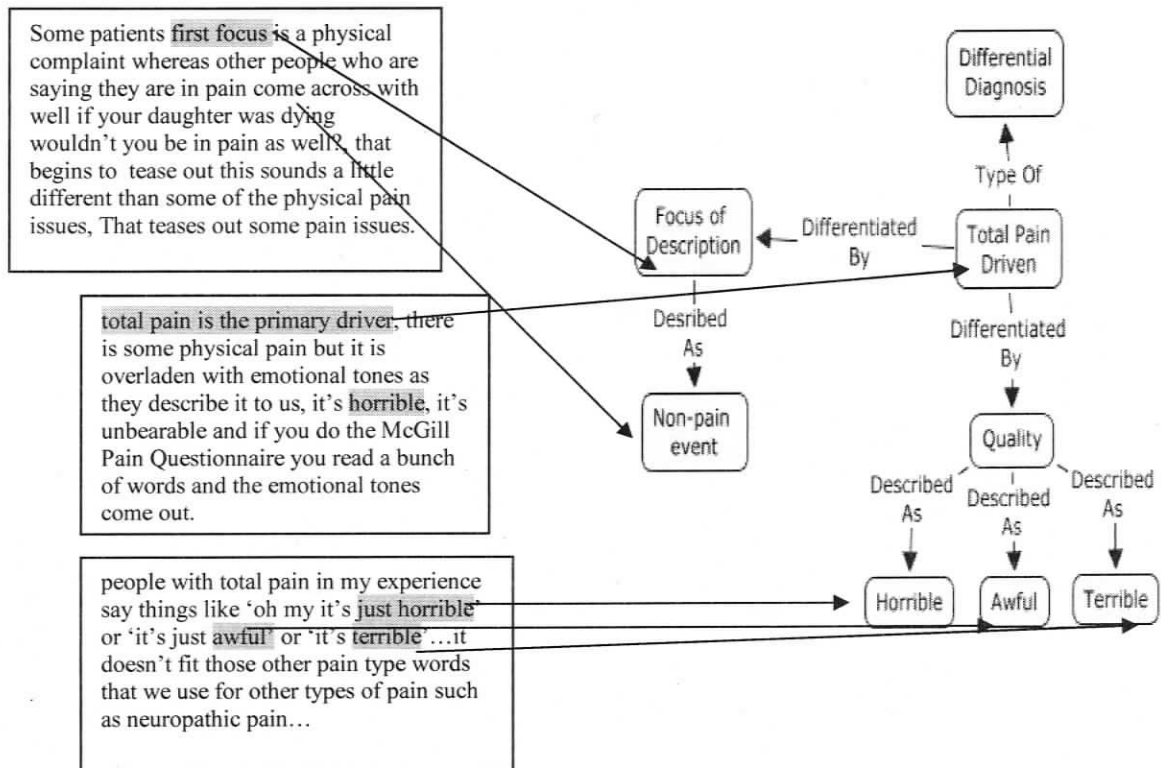
Figure 24, the second example, shows details for a specific differential diagnosis (delirium) and how the clinical talk provides terms for a delirium based differential diagnosis. It details how severe pain reports by a patient with delirium can be either

neurotoxic or non-neurotoxic and that delirium caused by neurotoxicity can be differentiated by signs such as myoclonus.



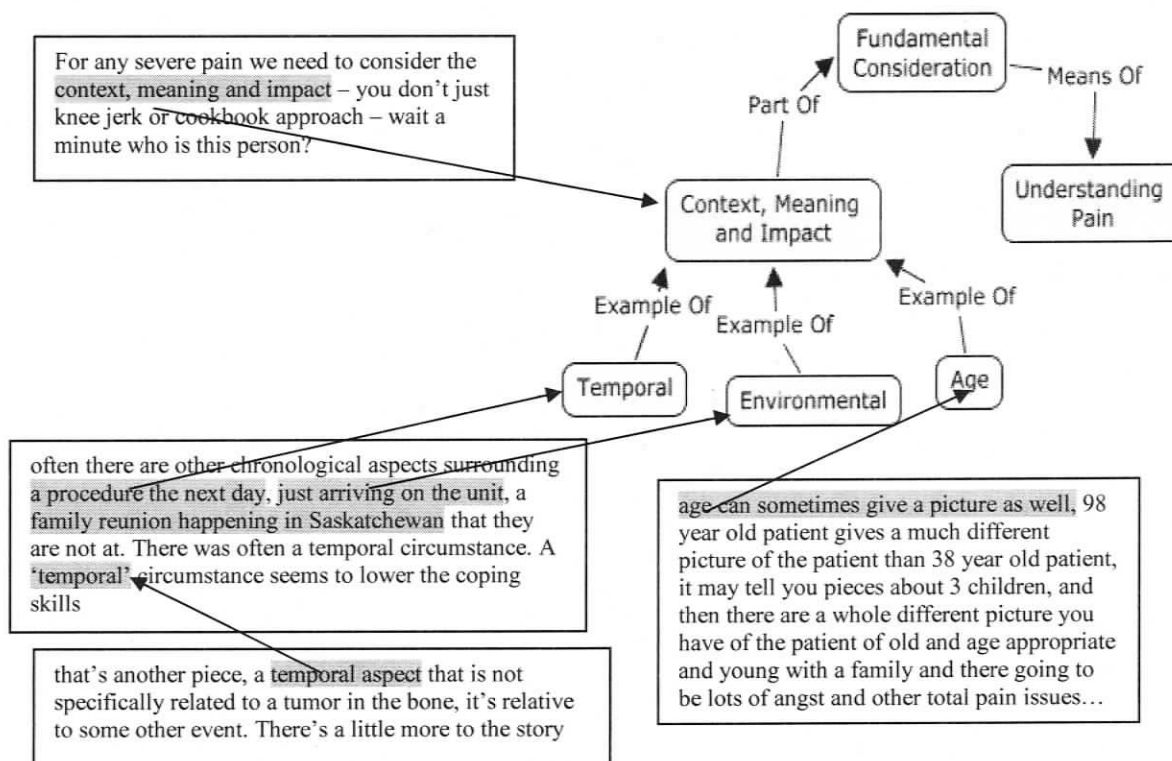
**Figure 24.** Details about differential diagnosis for delirium

Whereas figures 23 and 24 provided details on the physical pain and delirium differential diagnosis, figure 25 provides details for total pain driven differential diagnosis. The total pain differential diagnosis shows how the focus of description and quality of pain are different than in other types of diagnoses and provides examples of how focus and quality are described clinically.



**Figure 25.** Vocabulary of the 'total pain driven' branch of differential diagnosis

A final example of how the vocabulary brings out the meaning of the ontology concepts is shown in figure 26, which expands upon figure 22 from section 6.4.1 that described the understanding pain concept. One means of understanding pain is through the fundamental considerations and figure 26 shows that context, meaning and impact is one specific fundamental consideration. The empirical vocabulary uses clinical examples to give meaning to the context, meaning and impact consideration. For example it shows that a temporal event (missing a family reunion, upcoming medical procedure), environmental event (a new care setting) and age (young vs. old patient) are specific examples of contexts that can influence a severe pain episode.



**Figure 26.** Empirical vocabulary of context, meaning and impact branch of fundamental considerations as part of understanding pain

## 6.6 Summary of Conceptualization Phase Part II Chapter

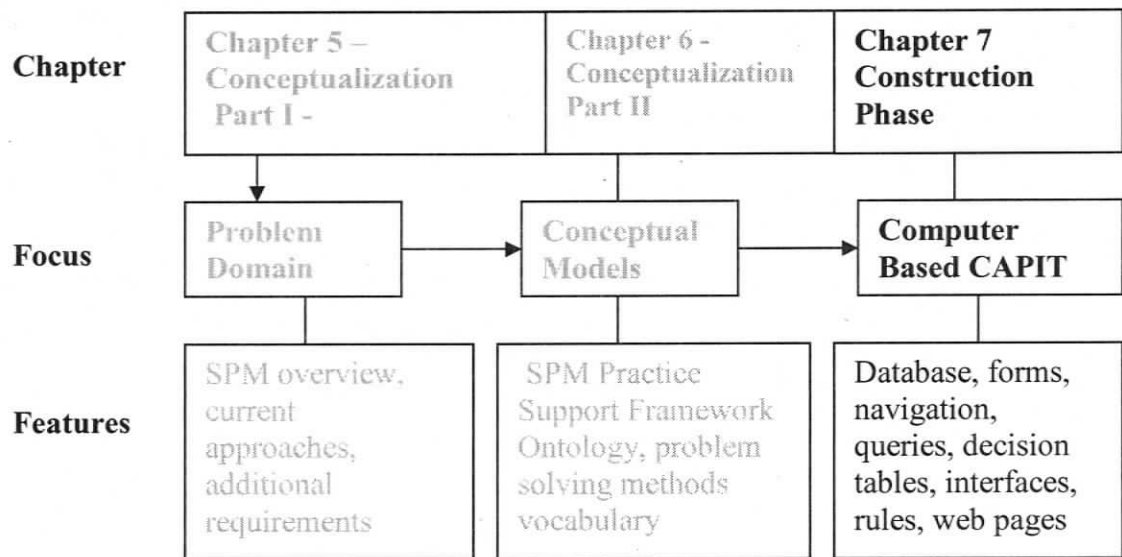
The conceptualization phase part II chapter began with an SPM practice support framework that defined the processes and information types of palliative SPM and was developed using the additional requirements to the paper based CAPIT that came from chapter 5. The GT framework illustrates how using principles of the GT method in combination with rigorous data collection through PD can capture knowledge around a domain area, in this case practice support needs for palliative SPM. The chapter then illustrated how to organize that knowledge by formalizing the SPM practice support framework into a set of informatics based solutions consisting of an ontology, set of problem solving methods and empirical vocabulary of SPM. The development of the informatics based solutions extend existing work on ontology and problem solving method development as it illustrates how to capture and organize empirical knowledge to develop ontologies and problem solving methods that function as a set of tasks and subtasks to provide practice support for a domain area.

### Chapter 7 – Results – Construction Phase

This chapter describes the features of the computer based practice support tool for palliative SPM. The chapter emphasizes how the features of the computer tool are implementations of the informatics based solutions (ontology, problem solving methods and empirical vocabulary) presented in chapter 6.

#### 7.1 Overall Framework of Construction Phase

The construction of the computer based CAPIT brings the aspects from the conceptualization phases into a tangible form. Figure 27 shows the results model that illustrates the progression from the problem domain to GT framework to the informatics based solutions, which are then implemented as the computer based CAPIT.



**Figure 27.** Progression from problem domain description and additional requirements (chapter 5) to conceptual models (chapter 6) to computer tool development (chapter 7)

The construction phase represents the internal workings and implementation of the computer based CAPIT. As described in the research approach chapter (section 4.3) the construction of the computer based CAPIT is presented in two ways. First is the technical description of how the ontology, problem solving methods and vocabulary are translated

into a prototype computer based system. The second description is from the user perspective and presents a view of the system in terms of forms, queries and reports.

## **7.2 Technical Description of the Computer Based CAPIT**

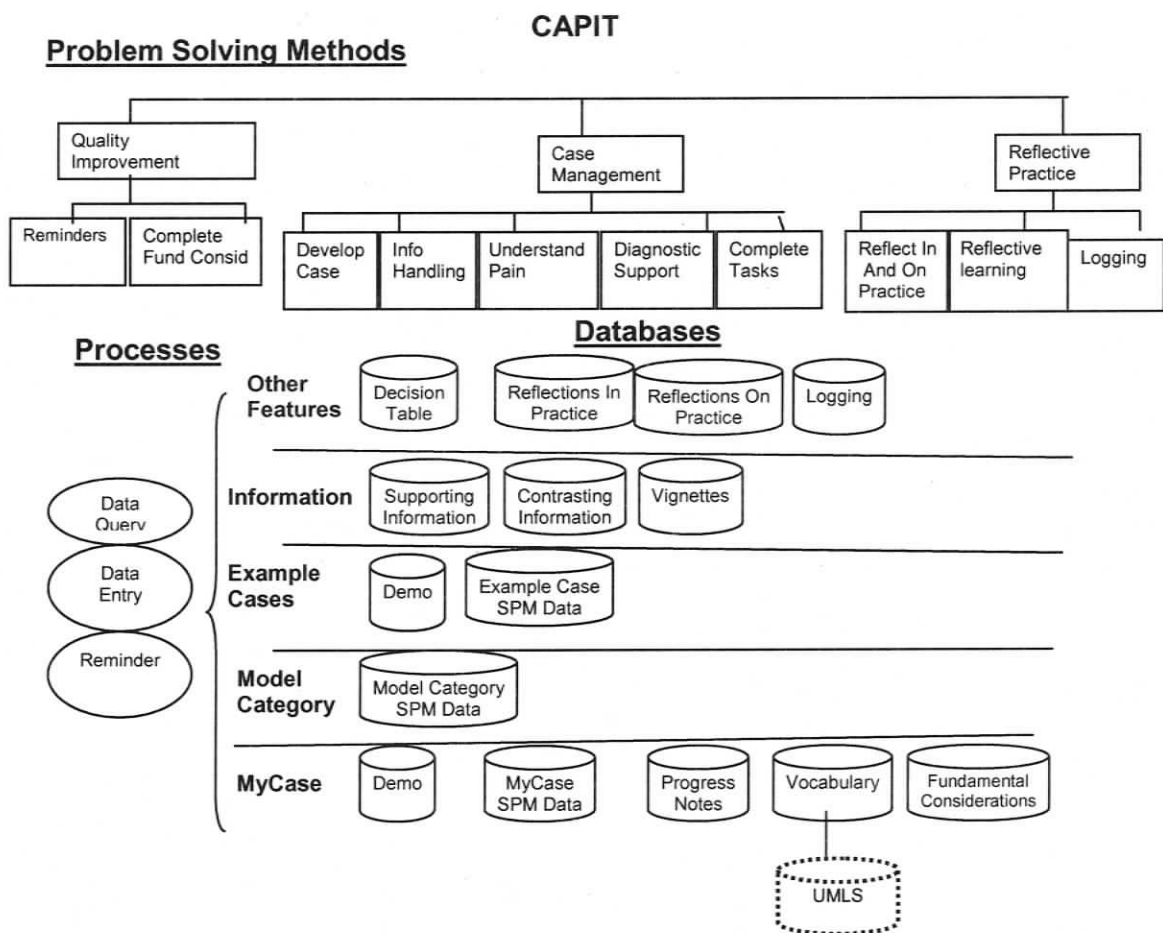
This part of the construction chapter is a technical description of how the informatics based solutions are translated into the computer based CAPIT. It presents the computer based CAPIT from the view of 'under the hood', which is a view that is hidden from the users. From an information management perspective it shows what information is managed. The prototype computer based CAPIT was developed as a Microsoft Access® database application. The programming that adds functionality to the database was done in Visual Basic for Applications.

Figure 28 shows the overall technical architecture of computer based CAPIT. The architecture diagram is based on the Integrated Advanced Information Management System (IAIMS) architecture described by Hripcsak (1997). Figure 28 shows that there are three main components to computer based CAPIT: problem solving methods, processes and databases. The relationship between the three components is the problem solving methods are implemented through processes that interact with the databases.

The problem solving methods are shown as a functional hierarchy diagram to illustrate all the functions of the problem solving method. The specific features of the computer based CAPIT are described according to the problem solving methods.

The databases tables are organized according to subject areas, which are listed in bold before the database tables. For example 'MyCase' represents the tables used to develop and maintain a patient severe pain case whereas 'information' is tables of different types of information. Figure 28 does not show all the databases within CAPIT but rather the key ones that are referenced in this chapter. Note that the MyCase, Model Category and Example Cases subject areas have a database table called SPM data, for example 'Model Category SPM data'. The SPM data refers to signs, symptoms, interpretations and strategies.

Processes represent the means of manipulating the data as part of the problem solving methods. A data entry process would be used to enter patient data to develop MyCase or to enter a reflection on practice whereas a data query process is used to retrieve data such as when doing a diagnosis or accessing supporting or contrasting information. Reminders provide a dialogue box to raise the user's attention to certain factors.



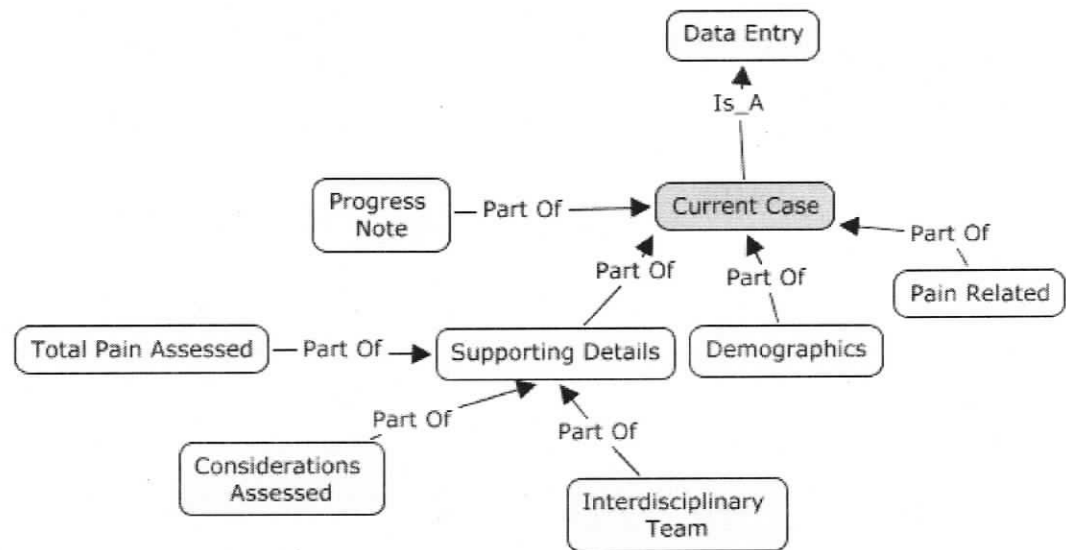
**Figure 28.** Technical architecture of computer based CAPIT.

The technical implementation of each of the three informatics based solutions (ontology, problem solving methods and vocabulary) are now explained.

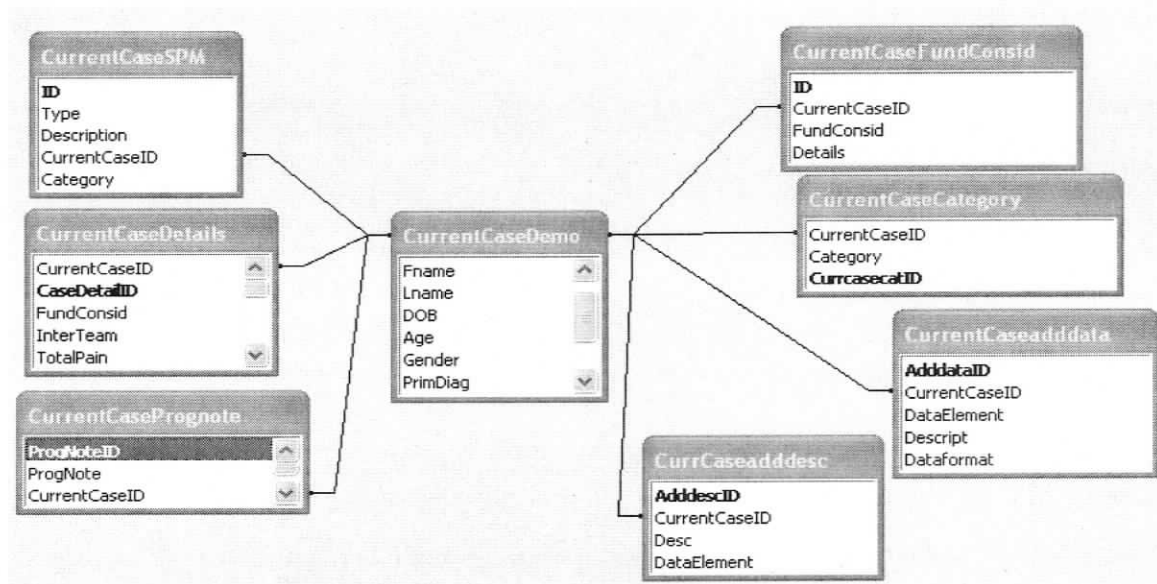
### 7.2.1 Ontology

In the literature review (section 2.2.3) it was described how ontologies represent a schema for knowledge bases that are free of technical specifications. However to become a computer based tool the ontology, problem solving methods and vocabulary need to be implemented as a technical architecture including a database and set of data definitions.

As described in the ontology section of chapter 6, part of the formalization of the SPM practice support framework into the ontology involved developing the concepts, relationships and degree of cardinality between the concepts. The relationships shows how the ontology concepts come together in order to form knowledge. The relationships between the ontology concepts are the basis for the relationships for the database of the computer based tool. Figure 29(a) shows the current case concept from the ontology and how it consists of pain related data, supporting details and demographic data. Also a patient may have multiple instances of pain related data and supporting details (such as having multiple signs or symptoms or instances of fundamental considerations). Figure 29(b) shows the database schema of the current case data elements and how it is an implementation of the ontology. It builds a patient case starting with data entry of mandatory demographics and then uses a number of one to many relationships to add pain details (signs, symptoms, interpretations and strategies) and fundamental considerations to the current case. All of the concepts from the ontology are represented in the database tables.



(a)

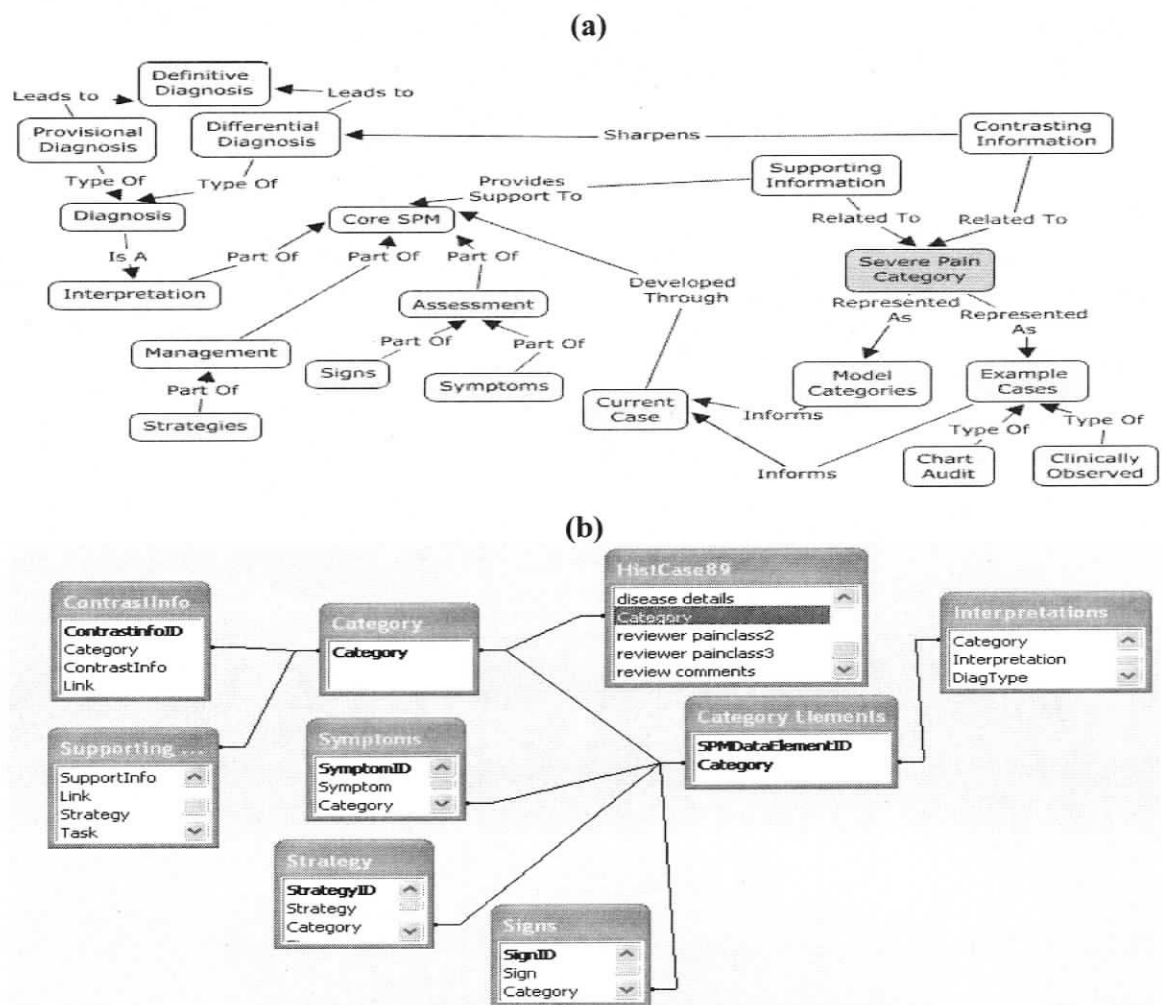


(b)

**Figure 29** (a) Top – Ontology representation of current case and (b) Bottom – Database schema of tables related to development of current case

Each of the remaining information types from figure 14 of chapter 6 (fundamental considerations, electronic, contrasting information, supporting information, vignettes, example cases and model categories) are also implemented through database tables.

An ontological representation of the information handling task of the case management problem solving method and how it is implemented through database tables is shown in figures 30(a) and (b). The ontological diagram in figure 30 (a) shows how information types are linked according to the category of pain and core SPM process, which enables supporting or contrasting information to be retrieved according to both the severe pain category and the core SPM process the information is needed for. Figure 30 (b) shows the ontology implemented as a set of database tables.



**Figure 30** (a) Top- Ontology representation of information handling aspect of case management problem solving method and (b) Bottom – database schema of tables for information handling

## **7.2.2 Problem Solving Methods**

This section describes the technical view of the three problem solving methods: case management, quality improvement and reflective practice.

### **7.2.2.1 Case Management**

As described in section 6.4.1 of chapter 6 the case management problem solving method provides data entry to develop a severe pain case, promote common vocabulary and provide a continuum of care to the case; provides information handling, navigation and overall flow through the SPM processes; provides the means of achieving particular tasks such checklists for assessment of the fundamental considerations, total pain and interdisciplinary teams, and provides the means of understanding pain. The technical implementation of each of those case management tasks will be described.

Although the technical implementation of the case management problem solving method uses the data and relationships shown in the ontology and database figures 29(a) and (b) the focus in this section is on process such as how and when the data is used as opposed to what data is used.

#### **7.2.2.1.1 Development of Severe Pain Case**

One of the tasks of the case management problem solving method is to develop the patient case, which supplies the data for the database tables in figure 29(b). Referring back to figure 28, developing a patient case is an example of a data entry process to add data to the MyCase databases. Upon starting CAPIT a severe pain case is built with demographic data including patient name, date of birth and primary disease. When the patient case is built it is assigned a caseID, which is the central identifier that links the patient case to pain data and other data entry. There are two parts to developing the severe pain case, the adding of pain related data and the adding of progress notes.

Severe pain data can be added to a patient case in two ways. First, when a model severe pain category (a pain category from the paper based CAPIT) is being viewed there is a button beside all of the SPM data from the model category (signs, symptoms, interpretations and strategies) that allows for addition of any of the SPM data to the patient case. Allowing entry of model severe pain data into the patient case helps promote charting about the patient case, which enhances communication about a patient case. Further because the model category represents a common set of data it promotes use of a common SPM vocabulary.

Second there is the option of adding additional pain related data to the patient case via a data entry form. The data entry form contains pain related data that came from the clinicians in this research but are not part of the paper based CAPIT. In particular some of the additional data terms were derived from the example (chart audit) cases. So for example if a user is viewing one of the example cases and notices that the case contains a data element that is not currently in the patient case they are developing, that data element can then be added to the patient case. Again that will enhance charting and promote a common vocabulary around SPM.

When data are added to a patient case there is program code that first checks if the patient case already contains that data element. If the data element has already been entered then a message box informs the clinician that data element has already been entered.

Finally progress notes can be added at anytime to a patient case. There is no limit to the number of progress notes that can be added to a case. Progress notes contribute to case management by providing the means of the continuum of care feature. Once a case has been developed progress notes can be added over hours, days or even weeks as part of ongoing care.

#### **7.2.2.1.2 Diagnostic Support**

Case management also provides support for the task of doing a diagnosis to help guide a clinician towards a definitive diagnosis. Multiple categories of pain that have similar signs

or symptoms are linked through the contrasting information table. That enables a user to retrieve multiple categories of severe pain to assist with a differential diagnosis.

To provide support for a differential diagnosis across multiple categories of pain a decision making algorithm was implemented as a parameter driven algorithm drawing on a decision table. The decision table is based on signs and symptoms from the empirical vocabulary. The decision making algorithm is an example of a process from the technical architecture diagram (figure 28) as it builds a data query to retrieve pain categories. Figure 31 shows the decision table consisting of the pain category and various iterations of signs and symptoms used to build the query in order to retrieve the category(ies) of pain that match the signs and symptoms that were chosen. For example querying on 'onset' with the value 'intermittent' will return incident pain and neuropathic pain as matches. Those two matching categories of pain can then be viewed to provide diagnostic support.

SSID	Category	DescribePain	LocatePain	Onset	Quality	OtherSymptoms	OtherSigns
12	Dementia or Delirium	No	No				
5	Incident Pain	Yes	Yes	Intermittent			N
1	Lack of Understanding of Scale	Yes	Yes				N
14	Neuropathic Pain	Yes	Yes	Constant	Burning		Hyperpathia
13	Neuropathic Pain	Yes	Yes	Intermittent			Allodynia
7	Neuropathic Pain	Yes	Yes	Sudden	Electric or shoo		
6	Opioid Induced Neurotoxicity	No	No			Recent rapid do	Mycologus Present
10	Plea for Relief of Physical Pain	Yes	Yes				
3	Sudden Medical Crisis	No		Sudden			Y
2	Sudden Medical Crisis	Yes	Yes	Sudden			
9	Titration Related Pain	Yes	Yes			Yes	
11	Total Pain	Yes					
4	Visceral colic or spasm	Yes	No	Periodic Waves	Cramping		N

\*(AutoNumber)

**Figure 31.** Decision table for enhancing a differential diagnosis across multiple categories of pain

**7.2.2.1.3 Information Handling**

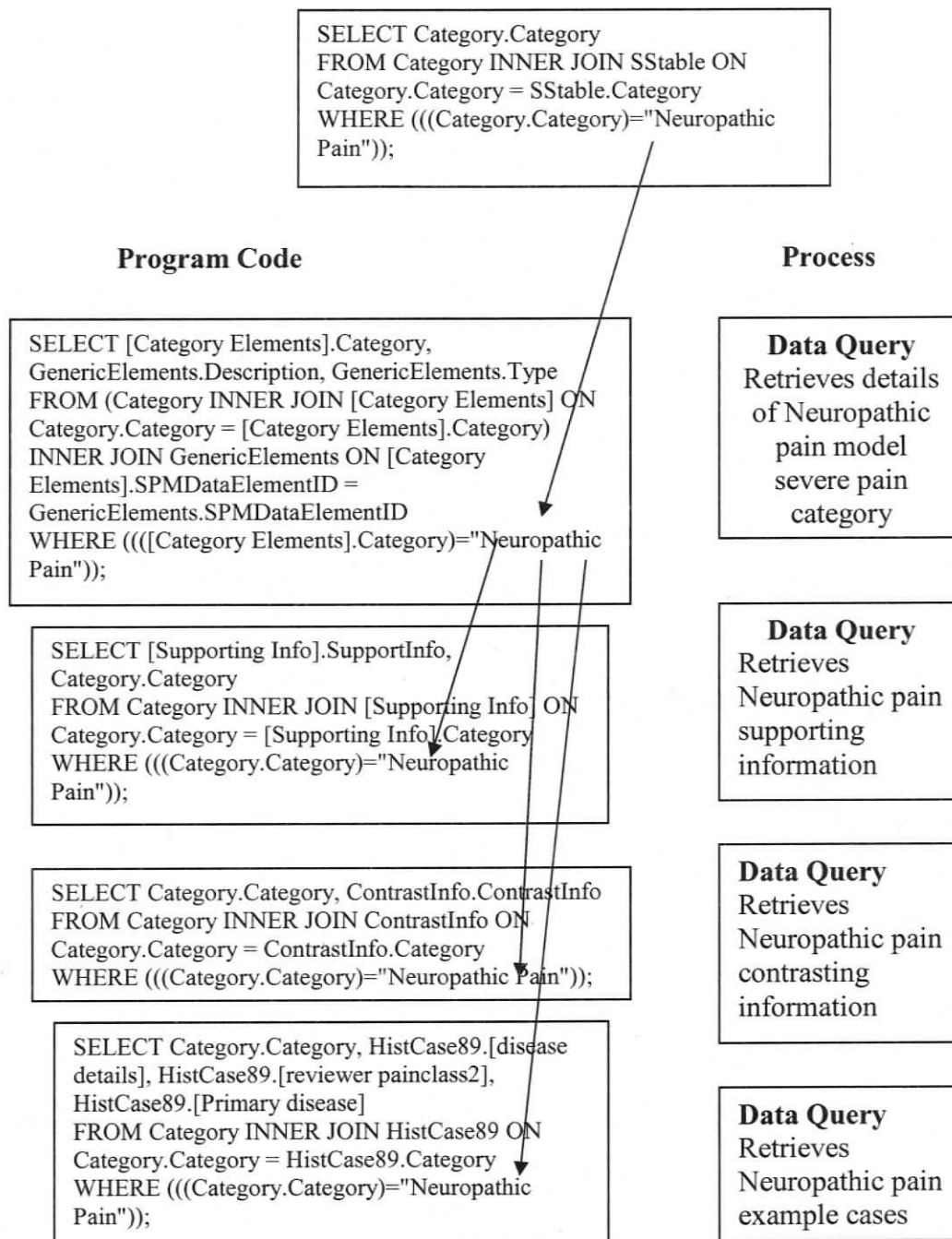
Information handling uses the relationships in the database tables illustrated in figure 30(b) to provide retrieval of information to support the task being done. Section 6.4.1 described how case management needs to enable drilling down on a pain category for deeper information but also going across categories to help with a differential diagnosis.

It also helps to deliver the requisite information for a task such as providing access to assessment tools.

Information handling also helps with navigation and management of the complexity of SPM, particularly when viewing multiple categories of pain. When a user retrieves a model severe pain category such as through a differential diagnosis as illustrated in the above section the pain category becomes a reference point to retrieve supporting and contrasting information. Figure 32 shows an example of how information handling supports navigation and management of complexity. Once a clinician selects a severe pain category through diagnostic support (neuropathic pain in figure 32) a data query process retrieves the model severe pain category and all its SPM data (signs, symptoms, interpretations and strategies), which enables viewing of the model severe pain category data elements.

Once the model severe pain category has been viewed the clinician has the option of running further data queries to retrieve supporting information to provide 'show me how to do this' support (such as details on what drugs to use or how to do opioid rotation), contrasting information to provide 'show me what else' support (such as how to differentiate neuropathic pain from incident pain), or example cases to illustrate how neuropathic pain appears in different clinical cases. The retrieval of information and example cases is facilitated by different data queries as shown in figure 32. All of the information that is retrieved is specific to the category of pain being viewed, which helps to manage the complexity of information.

### Diagnosis to establish pain category



**Figure 32.** Information handling to support navigation and management of complexity for neuropathic pain information

#### **7.2.2.1.4 Completion of Tasks**

Case management provides the means of assessing the fundamental considerations, total pain and consultation of the interdisciplinary team. Within each patient case there is a data element corresponding to total pain assessed, fundamental considerations assessed and interprofessional team consulted. When a clinician is developing a patient case those data elements can be assessed and recorded specific to each patient case to ensure all the necessary elements of SPM get assessed and recorded in the patient case.

As further information handling the case management problem solving method also provides information to help with those processes, such as providing access to supporting information about interdisciplinary teams or total pain if the clinician requires additional practice support for those areas.

#### **7.2.2.1.5 Understanding Pain**

The understanding pain process also involves information handling that is facilitated through relationships between database tables. There is a database table of vignettes, which are narratives from clinical practice, and are linked to the fundamental considerations table to allow the retrieval of vignettes corresponding to the fundamental considerations they refer to. For example querying on the fundamental consideration 'context meaning and impact' will retrieve vignettes about that consideration. Supporting information that is used to enhance the fundamental considerations is also linked through database tables. For example the description of ethical decision making from the fundamental considerations is concise and only provides the names and a brief overview of ethical models. If a user wishes more details about specific ethical models (such as the Latimer Model of Ethical Decision Making) they can retrieve such information from the supporting information database table.

#### **7.2.2.2 Quality Improvement (QI)**

As described in section 6.4.2 of the conceptualization chapter the QI problem solving method complements case management by ensuring that tasks such as assessment of fundamental considerations are actually completed. QI also provides rules and reminders

to raise attention to important aspects of the SPM process. In the previous section it was described that a patient case contains a data element corresponding to total pain assessed, fundamental considerations assessed and interprofessional team consulted. Part of the implementation of the QI problem solving method involves ensuring that those data elements are actually recorded as each of those data elements must be set to true before a severe pain case can be considered complete. Further, because the fundamental considerations are comprised of ten different considerations each of the considerations is stored in the patient's case to record their completion and also stored as a global variable. A global variable is a data element and that retains its value the whole time the user is using computer based CAPIT to develop a case. A global variable allows a user to go to different categories of pain and not have to assess the same fundamental considerations over and over. However in order for the fundamental consideration data element for the patient's case to be set to true all the data elements for the individual considerations needs to be checked off as completed.

The second part of the technical implementation of QI is reminders, which are data driven and are implemented based on data elements and the category of pain the user is viewing. Reminders help raise a user's attention to certain aspects of SPM such as that a sign from one category is also found in another category.

An example of the technical view of the reminders is shown in figure 33 with two reminders from the interpretation part of the core SPM process. In both examples the program code raises a reminder alerting the user to another category of pain that presents with similar findings (to enhance a differential diagnosis) and also to supporting information to enhance decision making.

(a)

If Me.Category = "Neuropathic Pain" Then  
MsgBox "Distinguish from Incident Pain – See Contrasting Information for  
details. Also – 'total pain' often is present in neuropathic pain – see fundamental  
consideration support for total pain overview"

```
Interpretation = True
```

```
End If
```

```
(b)
```

```
If Me.Category = "Opioid Induced Neurotoxicity" Then
```

```
MsgBox "See supporting information on category information page for an  
overview of the etiology of opioid induced neurotoxicity. Also see the contrasting  
information for non-opioid induced causes of delirium"
```

```
Interpretation = True
```

```
End If
```

**Figure 33.** (a) Top – Program code for interpretation reminder for neuropathic pain category and (b) bottom interpretation reminder for opioid induced neurotoxicity

### 7.2.2.3 Reflective Practice

The reflective practice problem solving method is also implemented through data elements from the tables. As described in section 6.4.3 of the conceptualization chapter the reflective practice problem solving method has three main aspects: logging what a user does while using computer based CAPIT, a mode to allow a user to engage in reflective learning to allow them to link research and practice, and the means of doing both reflections both in and on practice.

The implementation of the logging of computer based CAPIT activities involves uses a database table and program code that tracks and records when an action is done. Figure 34(a) shows the program code for the data entry process that logs when a clinician does a provisional diagnosis including logging of the category of pain for the diagnosis. That code will produce the first entry of the database log (LOGID 1388) in figure 34(b). The other log entries in figure 34(b) are produced by similar code as that shown in figure 34(a). For example if a user selects a provisional diagnosis of 'incident pain' spends time viewing the incident pain model category and then adds one sign and one strategy to their current case, and then views supporting information for incident pain it will produce the log in the database shown in figure 34(b).

(a)

```

Dim db As Database
Set db = CurrentDb
Dim rec As DAO.Recordset
Set rec = db.OpenRecordset("Log", dbOpenDynaset)
With rec
.AddNew
!Page = "Retrieve Model Categories"
!Event = "Provisional Diagnosis " & Me![cmbprovdia] & ""
!RPID = UserID
.Update
End With

```

(b)

LOGID	RPID	Page	Event	Date&Time
1388	13	Retrieve Model Categories	Provisional Diagnosis Incident pain	3/3/2006 3:40:44 PM
1389	13	Incident pain	Viewed Model Case	3/3/2006 3:40:45 PM
1390	13	Incident pain	Assessment-Signs	3/3/2006 3:40:46 PM
1391	13	Incident pain	Added Signs to MyCase	3/3/2006 3:40:51 PM
1392	13	Incident pain	Assessment-Symptoms	3/3/2006 3:40:59 PM
1393	13	Incident pain	Viewed Interpretations	3/3/2006 3:41:01 PM
1394	13	Incident pain	Viewed Management Strategies	3/3/2006 3:41:04 PM
1395	13	Incident pain	Added Strategy to MyCase	3/3/2006 3:41:07 PM
1396	13	Incident pain	Fundamental Considerations Not Assessed - reminder ignored	3/3/2006 3:41:14 PM
1397	13	Category specific information	Viewed category specific information for Incident pain	3/3/2006 3:41:14 PM
(AutoNumber)	0			3/3/2006 3:41:22 PM

**Figure 34.** (a) Top - Program code for data entry to record that a user performed a provisional diagnosis of incident pain and (b) Bottom - Sample database log of events

The implementation of the reflection in and on practice features is similar to the logging database except that the user determines when a reflective log entry is made. As the user navigates through computer based CAPIT they may wish to make a reflective note about something they may have learned about SPM, something they have observed about a case, or a question that they would like to take away from computer based CAPIT to seek further assistance on. Reflection on practice is done the same way as reflections in practice except they are done after completing management of a severe pain case. All reflective logs can later be viewed by the user as reports.

All reflective logs are stored in a database table that has a field called 'reflection type'. That field differentiates the reflections and enables the user to retrieve specific

reflections, such as 'LearnSPM' reflections, interdisciplinary team reflections or self reflective practice reflections. That differentiating field is what allows the creation of reflection specific reports. Figure 35 shows example records in the reflective log table and how they are differentiated by type of reflection.

ReflectLog	RP	reflect	Page	DateTime	ReflectType
61	15	enmeshment occurs with young families	Model case Neuropathic Pain	3/9/2006 10:39:32 AM	Reflection in Practice
62	15	counselling helped tease out total pain on patient	Fundamental consideration support	3/11/2006 7:00:50 AM	Interdisciplinary team reflection
63	15	stacking opioid not always used for incident type pain	Learn SPM Base Page	3/11/2006 7:01:22 AM	Learn SPM
64	15	here is a self reflective note	Self reflective practice	3/11/2006 9:54:12 AM	Self Reflective Practice

**Figure 35.** Example records of reflections in and on practice differentiated by type of reflection

The learn SPM feature of the reflective practice problem solving method is an information management feature that allows a user direct access to the educational material in computer based CAPIT without having to develop a case or deal with alerts and reminders. A user can access educational material on SPM and make reflections as they go along to enhance their learning. The learn SPM feature also provides a different means of accessing information. In the case management problem solving method information is retrieved relative to a category, so assessment related information for neuropathic pain is retrieved when you are in the neuropathic pain category or information for short acting opioids is retrieved in the incident pain category. The learn SPM feature is different as a user can view all assessment or management related information in one place as opposed to retrieving information according to a severe pain category as is done in the case management problem solving method. The learn SPM mode presents a different perspective of the information and allows learning by both breadth and depth of information.

The learn SPM mode also supplies supplementary information to support SPM. Although computer based CAPIT was developed to support SPM it was described that sometimes SPM involves more than just the bedside examination and draws upon more general principles of pain assessment and management. Because information about such

supporting processes cannot be incorporated within the description of a severe pain category without making the amount of information overwhelming it has been packaged separately and can be accessed through the LearnSPM page.

### **7.2.3 Vocabulary**

The conceptualization phase presented the vocabulary with respect to how it is used for communication by palliative clinicians and how it gives empirical language to the ontology concepts. The construction phase takes the vocabulary and formalizes it in two ways. First, the vocabulary terms are standardized into a set of tables representing an empirical vocabulary for palliative SPM. The vocabulary terms are empirically based as they came from the data sources used in this research. Second the standardized terms are mapped to four controlled vocabularies in healthcare to see how well the terms are represented in the controlled vocabularies. That helps identify the extent to which the language used clinically for palliative severe pain management is represented in existing controlled vocabularies and where extensions to such controlled vocabularies are needed.

The next four sections present the formalized vocabulary concepts for the three core SPM processes, assessment, interpretation and management, as well as for understanding pain. Understanding pain was included because its vocabulary includes terms such as context, proportionality and enmeshment, which are important terms for the patient centered and individual uniqueness qualities of SPM. The vocabulary terms were derived from the data sources used in this research and includes terms from the paper based CAPIT as well as from consensus meetings or clinical observations. Each vocabulary is presented in a table as a set of terms showing how the terms map to the Unified Medical Language Source (UMLS), Systematic Nomenclature of Medicine Clinical Terms (SNOMED-CT), International Classification of Disease Version 10 (ICD-10) and Diagnostic and Statistical Manual of Mental Disorders - Fourth Edition (DSM-IV). Those four vocabularies were chosen because ICD-10 is the most commonly used diagnostic coding language, SNOMED has recently been chosen by Canada Health Infoway as the Vocabulary for the Canada wide electronic health record, UMLS enables cross linking of multiple languages and is a common reference language and DSM-IV is a source of

psychology based terms which are relevant for many palliative conditions. A checkmark indicates the term is found in the vocabulary. Following the table is a synopsis of the vocabulary mapping.

The take away message to be noted from all the vocabulary that is presented is although the more general SPM terms are represented in some of the controlled vocabularies, the terms that are more specific to palliative care are represented quite poorly. For example many of the 'Understanding Pain' terms such as context or enmeshment are not represented in vocabularies nor are palliative relevant management terms such as opioid titration or opioid stacking.

The mapping of the vocabulary shown in this section has not yet been implemented in the computer based CAPIT. In the technical architecture diagram (figure 28) there is a database table called UMLS linked to the vocabulary table shown with a dotted border to show that it has not yet been implemented.

### 7.2.3.1 Assessment Vocabulary

Table 3 shows the terms in the assessment vocabulary. Some terms are shown as a general concept followed by specific examples for the term.

**Table 3. Assessment Vocabulary**

<b>Assessment Term</b>	<b>UMLS</b>	<b>SNOMED-CT</b>	<b>ICD-10</b>	<b>DSM-IV</b>
Acute Abdomen	✓	✓	✓	
Acute medical crisis				
Behavioral	✓	✓	✓	
Behavioral – Restless	✓			
Behavioral - Agitation	✓	✓	✓	
Cognition – Delirium	✓	✓	✓	✓
Cognition – Dementia	✓	✓	✓	✓
Cognition – Confusion	✓	✓	✓	
Depression	✓			

Assessment Term	UMLS	SNOMED-CT	ICD-10	DSM-IV
Dermatome	✓	✓		
Dysesthesia	✓	✓	✓	
Extreme pain				
Hyperalgesia	✓	✓	✓	
Incident related pain				
Internal pain				
Intermittent pain	✓	✓		
Myoclonus	✓	✓	✓	
Noiceptive pain	✓ as nociceptive stimulus			
Oral intake				
Pain crisis acute	✓			
Quality - unbearable				
Quality - sharp	✓	✓		
Quality - Shooting pain	✓	✓		
Quality - Cramping	✓ cramping pain	✓		
Visceral pain	✓	✓		
Visual analog scale	✓	✓		
Verbal rating scale	✓	✓		

With respect to the assessment vocabulary, the more generic terms such as behavioral and cognition are represented fairly well in UMLS, SNOMED and ICD-10 and less well in DSM-IV. The more palliative specific terms tended to only be found in UMLS or SNOMED if they were found at all. Some of the terms specific to SPM such as ‘incident pain’ were not found in any vocabulary Total pain assessment terms for quality such ‘unbearable’ or ‘horrible’ are not found in any vocabularies.

### 7.2.3.2 Interpretation Vocabulary

The interpretation vocabulary revolves around the two different types of diagnostic reasoning, differential and provisional diagnosis.

Table 4 shows the SPM interpretation terms and whether they are represented in the four controlled vocabularies.

**Table 4.** Interpretation Vocabulary

<b>Interpretation Term</b>	<b>UMLS</b>	<b>SNOMED-CT</b>	<b>ICD-10</b>	<b>DSM-IV</b>
Neurotoxicity	✓	✓		
Suffering	✓ as mental suffering			
Proportion	Variances are found			
Tolerance	✓	✓		
Pseudo addiction				
Total pain	✓	✓		
Psychosocial	✓			

In the controlled vocabularies differential diagnosis is found in both UMLS and SNOMED-CT but not found in ICD-10 or DSM-IV. The term provisional diagnosis is not found in any of the controlled vocabularies. As with the assessment terms, UMLS and SNOMED-CT contain most of the interpretation terms but the definitions of the terms are often generic and do not fit the context of palliative care. Variances of proportion are found in UMLS but the descriptions are from an anatomical perspective such as a proportion of foot or hand and not proportions of a pain episode. Total pain is only found in two of the vocabularies (UMLS and SNOMED-CT) as total pain body syndrome and the many pieces to total pain such as the 7 P'S of total pain as described by Downing (2006) are not found in any vocabularies. Thus the breadth of detail of total pain is missing from existing vocabularies.

### **7.2.3.3 Management Vocabulary**

The management vocabulary (table 5) is used to describe the different types of management strategies, and in some cases the sub-types of strategy, that can be used for severe pain management.

**Table 5. Management Vocabulary**

<b>Management Term</b>	<b>UMLS</b>	<b>SNOMED-CT</b>	<b>ICD-10</b>	<b>DSM-IV</b>
Analgesic – opioid	✓			
Analgesic – non opioid	✓	✓		
Adjuvant – drug	✓ (as pharmaceutical adjuvant)			
Adjuvant – non drug				
Algorithm – stack opioid				
Algorithm – rotate opioid	✓ (also listed as substitution or switching)			
Algorithm – opioid titration				
Algorithms – titration	Listed as laboratory procedure only			
Communication	✓	✓		
Interdisciplinary	✓			

As with the other vocabulary terms although some of the management terms are found they often have a different definition to how the term is used inSPM. Titration is listed only as a laboratory procedure (such as titrating acid-base balances in chemistry) and not in relation to titration of an opioid dose. Other terms related to strategies involving opioids such as ‘stacking opioid’ are also not found in any of the vocabularies nor are strategies such as non-drug adjuvants. UMLS has the best representation of the strategies with 6/10 terms being found in UMLS.

#### **7.2.3.4 Understanding Pain Vocabulary**

Table 6 provides terms used in understanding pain and their representation in the four controlled vocabularies.

**Table 6.** Understanding pain vocabulary

<b>Understanding Pain Term</b>	<b>UMLS</b>	<b>SNOMED-CT</b>	<b>ICD-10</b>	<b>DSM-IV</b>
Autonomy (independence)	✓			
Context – general	✓	✓		
Context – specific such as temporal or environmental				
Disease trajectory				
Functional Status	✓			
Enmeshment				
Impact of pain				
Beneficence	✓			
Holistic	✓			

UMLS is the only controlled vocabulary that contained moderate representation of understanding pain terms (5/9 terms). However even when the understanding pain terms appear they are often in a general context and not related to any specific concept such as pain. For example the term context is in both UMLS and SNOMED-CT but it is defined from a general sense and not related to any specific concept. The use of the term context from an SPM perspective such as environmental or temporal contexts of pain is not found in any vocabularies.

### **7.3 Implementation from the user perspective**

This section of the construction phase describes the system from the perspective of the user. As opposed to the ‘under the hood’ view that was described in the previous section this section presents the view from the front as seen by a user of the system. The user perspective involves much of the content that was described in the technical implementation such as the patient case, reflective logs, reminders or supporting and contrasting information but they are organized into forms and reports so data can be entered and viewed. The user perspective represents a dynamic information view of computer based CAPIT and shows how the ontology and problem solving methods are implemented to provide practice support and fit within workflow. It shows *how*

information is handled as opposed to the database tables that show *what* information is handled.

### **7.3.1 User Perspective of Problem Solving Methods**

#### **7.3.1.1 Case Management**

From the user perspective the tasks of the case management problem solving method are done through forms and reports. The tasks of the case management problem solving method: provide data entry to develop a severe pain case and provide a continuum of care to the case, promote common vocabulary, information management, provide navigation and overall flow through the SPM processes, provides the means of achieving particular tasks such checklists for assessment of the fundamental considerations, total pain and interdisciplinary teams, and provides the means of understanding pain.

##### **7.3.1.1.1 Development of 'MyCase'**

In order to fit within the workflow of clinical practice it was described in the conceptualization phase how the computer tool needs to be able to build and develop a patient case. The case management problem solving method uses forms to develop the case and forms and reports to allow viewing and printing of the case so it can be included in the paper chart. The term 'MyCase' was established to refer to the severe pain case that is being developed. Upon starting CAPIT in the Manage MyCase mode the user is asked to enter demographic information to develop MyCase. Figure 36 shows the form where MyCase is developed. That form corresponds to the 'current case demo' table from the database diagram in figure 29(b).

CreateCurrentCase : Form  
 Please create 'MyCase', which is a case that you will use to navigate through CAPIT. After you have entered the details click 'save record' to move to the next screen  
 Patient First Name:   
 Patient Last Name:   
 Date of Birth:  Enter as 1-Jan-00 OR Age:  0  
 Gender:    
 Primary Diagnosis:   
 Save Case

**Figure 36.** Form for development of MyCase

#### 7.3.1.1.2 Diagnostic Support for MyCase

Once MyCase has been developed the user is taken to a page to select a model severe pain category, which will provide the means of data entry into MyCase. That flow is consistent with SPM work practices as once a case has been developed the next process is to work towards a definitive diagnosis for the case. That select model category page provides diagnostic support for two types of diagnosis in that a user can do a provisional diagnosis and directly select a category of pain or get practice support for a differential diagnosis. Both of those types of diagnoses can lead to a definitive diagnosis. The differential diagnosis support uses a form to implement the decision table described in the previous section. Figure 37 (a) shows an example of the differential diagnosis feature where a query is done to retrieve pain categories where the patient can describe the pain, locate the pain, has intermittent onset and delirium is not present. After the user clicks retrieve categories they get a box that informs them how many categories of pain match their query and if they wish to see the matching categories. If they click yes they get the form shown in figure 37 (b) that shows the matching categories and gives them the option of selecting a category to view.

(a)

**Differential Diagnosis**

To run a differential diagnosis do the following:

1. Put a check in the check box for the sign or symptom you wish to query on. You can query on as many combinations of signs or symptoms as you wish.
2. Use the drop down box to select the specific value of the sign or symptom to query on - i.e. Describe Pain - Yes

3. Click retrieve categories. A box will pop up (see below) showing the categories of pain and you can click Yes to view the results or No to stop the category view. The pop up form either click 'close form' to go to the detailed category view of the categories of pain) Click Yes to view the results or No to stop the category view. The pop up form either click 'close form' to go to the detailed category view of the categories of pain)

(b)

**Figure 37.** (a) Top – Differential diagnosis feature (b) Bottom – Form displaying matching categories

### 7.3.1.1.3 Viewing and Printing of MyCase

Once MyCase has been managed the user may want to view all data added to the case or print the case. Figure 38 shows the View MyCase form, which is user view of all the data contained in the database tables shown in figure 29(b). The View MyCase feature brings together all the data about MyCase including pain related, demographic, progress

notes and supporting case details (fundamental considerations assessed, total pain assessed and interdisciplinary team consulted). Each of the case details should be checked off before the case is closed and beside each checkbox is an info button that will access supporting information about the particular case detail if needed.

**View MyCase**

**Demographics**

First Name:  Last Name:  Date of Birth:

Gender:  Primary Diagnosis:  Age:

**Button Bar**

**Severe Pain Data Elements**

Signs Symptoms Interpretations Strategies Fundamental Considerations Additional Data Progress Notes

<p>Return to Manage MyCase</p> <p>Run Reports</p> <p>Create Reflective Note</p>	<p><b>Description</b></p> <p>Delirium not present (unless compounding factor) although pt may be very agitated and restless during pain episode</p> <p>Delete Sign</p>
	<p><b>Description</b></p> <p>Severe pain directly related to one or more specific actions</p> <p>Delete Sign</p>

**Case Details**

Fundamental Considerations Assessed?  Click to View Checked and Missing Fundamental Considerations

Total Pain Assessed?

Interdisciplinary Team Consulted?

**MyCase Categories of Pain**

Category
▶ Incident pain
*

**Case**

Closed

In Progress

**Figure 38.** View MyCase form

A user is also able to preview or print reports of MyCase so it can be included as part of the medical record. Figure 39 shows a report of MyCase that can be printed and included in a medical chart.

## CAPIT Patient Case Report

**First Name:** Mr                      **Last Name:** Jones                      **Gender:** Male  
**Date of Birth:**                      **Primary Diagnosis:** Prostate cancer

**The patient has the following categories of severe pain:**

Incident pain

### Sign

Delirium not present (unless compounding factor) although pt may be very agitated and restless during pain episode

Severe pain directly related to one or more specific actions

### Symptom

Intermittent severe pain related to one or more activities or procedures

### Interpretation

Type and quality of pain is specific to the actual etiology eg. bone pain with movement or position change; bowel care; dressing change

### Strategy

Use short-acting sedation with analgesic if necessary

Additional adjunct supports such as distraction, hypnosis, imagery, music

Preemptive use of short or ultra-short acting opioid ie. once incident pain is identified, then focus on use in prevention

### Additional Data Elements and Descriptions

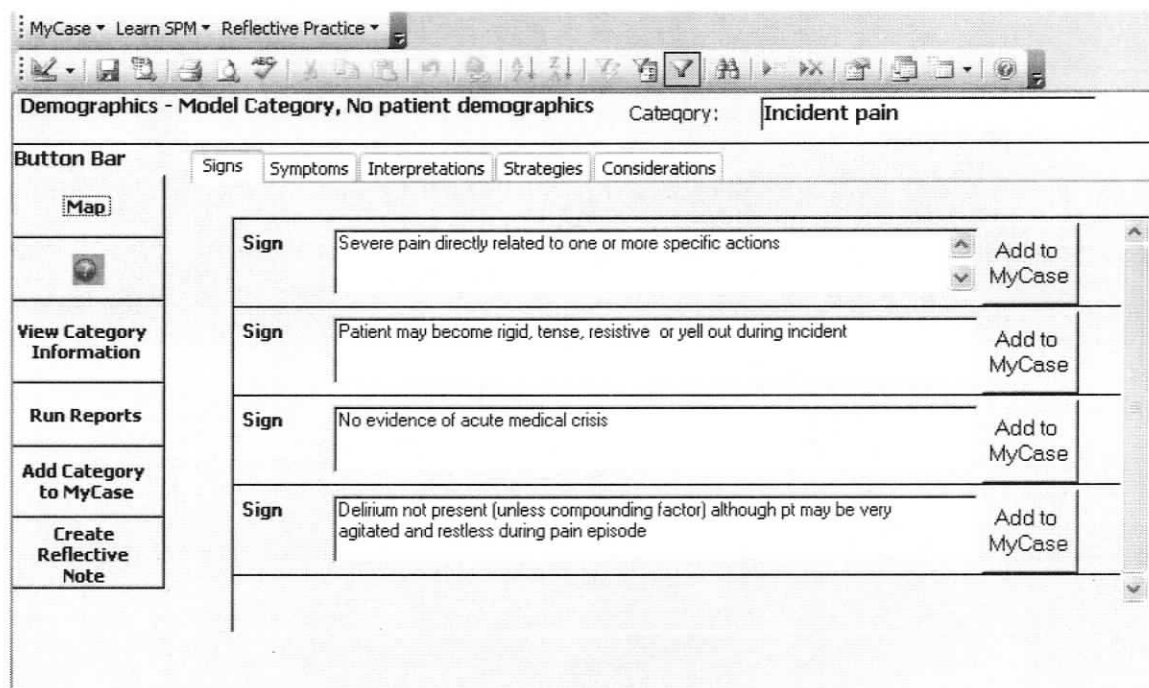
<u>DataElement</u>	<u>Description</u>
Quality	Burning
Event causing pain	Bowel
<u>Fundamental Consideration</u>	<u>Details</u>
Disease Trajectory	pps transition from 40-30%

**Figure 39.** Printed report of patient case

### 7.3.1.1.4 Information Handling

As described in the conceptualization chapter and illustrated through the database tables in section 7.2.2.1 of the construction chapter a large part of the case management problem solving method is information handling. Figure 40 shows the form that displays the model severe pain categories and all the accompanying details for the category (sign,

symptom, interpretation and strategy). The model categories page presents five tabs, one for each of the details about the category and one for the fundamental considerations. Figure 40 also shows the means of doing other tasks of the case management problem solving method such as buttons to add data from the model categories to MyCase, run a report to print model categories, add a progress note to MyCase or make a reflective note. Each of those buttons is provided as part of a common button bar that is consistent across all data entry forms.

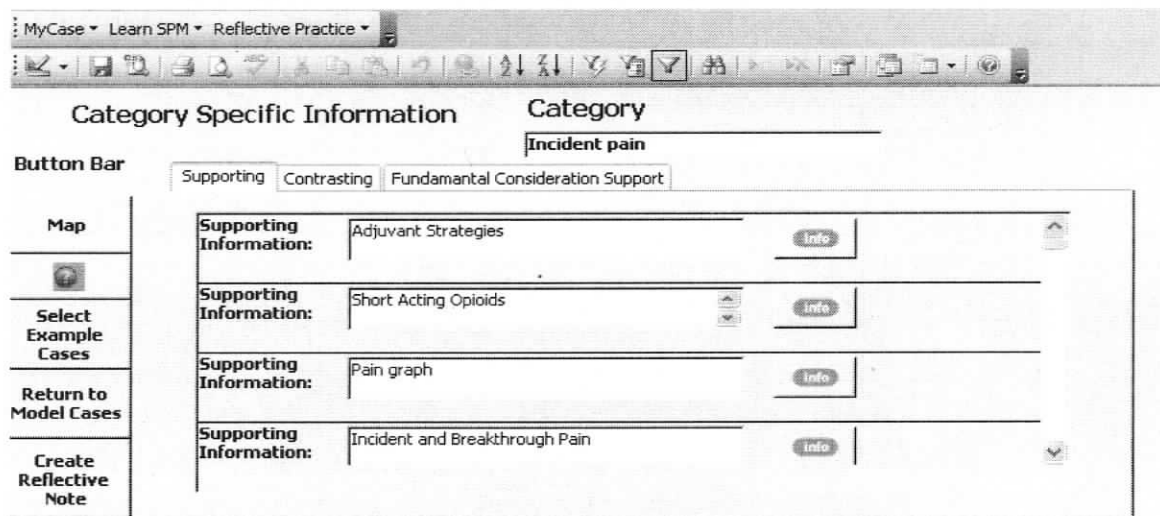


**Figure 40.** User view of model severe pain category

Providing the means of adding data to the MyCase addresses the need for enhanced charting and communication about a severe pain episode and also encourages use of a common vocabulary around SPM as the data that is added comes from the empirically derived SPM vocabulary.

Further information handling of the case management problem solving method are provided through buttons from the various pages and represent the user view of the data from the database tables in figure 30(b). That flow of the screens for the user views was designed to fit the problem solving behavior exhibited in GT-PD sessions as a clinician

would first look at the model severe pain category and then access supporting or contrasting information if needed. For example in figure 40 there is a button titled 'view category information' and clicking that button takes you to a form that retrieves information specific to a severe pain category. Figure 41 shows the 'category specific information page' for the incident pain category and shows the supporting information tab for incident pain which includes links to four types of supporting information including adjuvant therapies and short acting opioids. Clicking the 'info' button will retrieve a form with the supporting information. The contrasting information and fundamental consideration support tabs also provide links to information. The contrasting information tab would display information to help differentiate incident pain from other pain categories. The fundamental considerations support tab provides support for the fundamental considerations such as details about ethical models of care, total pain or interdisciplinary teams. The interdisciplinary team resources contain information about how to use a team perspective to SPM if you have no team as well as a link to the Canadian Virtual Hospice website to provide real time access to resources, both of which were needs identified as needs.



**Figure 41.** Category specific information screen

Further information handling is provided through the 'select example cases' button in figure 41 as that will retrieve the example (chart audit) cases for the category you are

viewing. When the 'select example cases' button is clicked the user is first provided with a form that contains a 'snapshot' of the example cases that match the pain category. The snapshot provides details about each example case such as location, quality, onset and description of pain. That allows the user to select example cases that resemble MyCase, which is a further example of information handling.

### 7.3.1.1.5 Information Handling– Presentation of Knowledge

Section 5.4.1 of the conceptualization chapter described how one of the challenges in designing the computer tool is to capture and organize the SPM knowledge of experienced clinicians into a form that other people will use. An example of how such knowledge is implemented from the user perspective is shown in the next two examples. In the conceptualization chapter there were examples of the ontology concept differential diagnosis and how the 'clinical talk' was used to give the differential diagnosis concept empirical vocabulary. Figures 23 and 25 in chapter 6 showed examples of differential diagnoses for neuropathic pain and a total pain driven differential diagnosis. To present the ontology concepts and associated vocabulary terms in a manner so they are understandable by the user they are presented as either decision tables or analytical models. Figure 42 shows a form that displays a decision table for differentiating neuropathic pain and incident pain and figure 43 shows a form of an analytical model for the total pain type of differential diagnosis.

Close Page    Print Page

**Differentiation of Nociceptive and Neuropathic Pain**

**1. Etiology of Nociceptive and Neuropathic Pain**

**Nociceptive Pain**  
Pain of nociceptive origin is the usual type of pain seen in both acute and chronic settings. It is due to stimulation of nociceptive nerve fibers from many sources (chemical, thermal, pressure, stretch) and is transmitted in a normal way from nerve endings to dorsal root ganglion to spinal cord and brain pain centers. Two general types are nociceptive somatic and nociceptive visceral pain.

**Neuropathic Pain**  
Neuropathic pain is a result of sustained aberrant somatosensory processing. There are three subtypes, deafferentation pain related to central mechanisms, mono- and poly-neuropathies in peripheral nerves and sympathetically-maintained pain due to sustained efferent activity in the sympathetic nervous system(1).

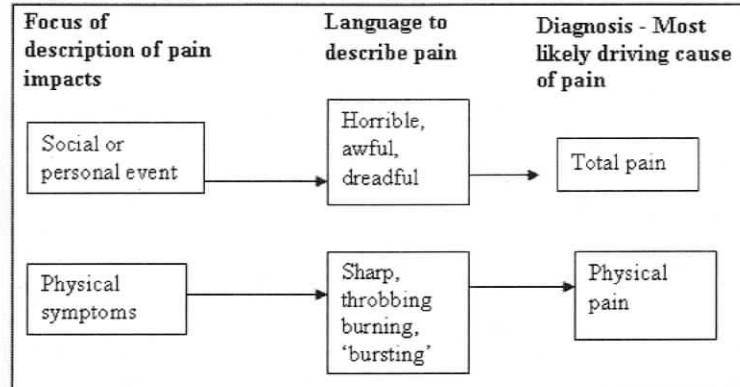
**2. Decision Table for Differentiation of Neuropathic Pain and Incident Pain**

	<b>Neuropathic Pain</b>	<b>Incident Pain</b>
<b>Sudden onset related to a specific action</b>	Possible	Yes - always
<b>Quality</b>	Often described as burning, electrical, shooting or spreading	Quality will depend on specific etiology
<b>Length of time of pain episode</b>	Constant or short duration	Very short term- subsides shortly after onset
<b>Presentation of pain</b>	Often in a dermatomal pattern	Varies depending upon specific etiology of pain
<b>Evidence of allodynia, hyperpathia or hyperalgesia</b>	Often present	Never present

**Figure 42.** Form showing a decision Table for Differentiation of Neuropathic Pain and Incident Pain

The patient cases from the chart audit also showed a difference in descriptive language between different pain etiologies. Two patients from the chart audit who were categorized as having "total" pain as the driving cause of pain described their pain as "all over" and "more of a discomfort than a pain" respectively. Those descriptions of pain are vague and do not pinpoint the pain to any particular area. Whereas patients from the audit who were determined to have pain driven by more physical etiologies described their pain differently using specific terms such as "hot, burning..." in the case of a patient with neuropathic pain. Two patient cases with "Sudden Medical Crisis" as the identified cause of pain are particularly revealing in terms of language as one case patient described their pain as "stabbing" and in a second case a patient described their pain as groin pain-"feels like it is going to burst open".

Fig. 1 shows an analytical model that summarizes the 'total' pain differential diagnosis described above. The model shows how the focus of the pain effects such as physical vs. social or personal and how differences in the language used to describe pain can help with a diagnosis of whether a patient's pain is driven by more physical or total pain components.



**Figure 1.** Analytical model of differential diagnosis for 'total pain' by focus of description and language used to describe the pain.

**Figure 43.** Form showing an analytical model of differential diagnosis for 'total pain' by focus of description and language used to describe the pain.

**7.3.1.1.6 Completion of Tasks**

Part of the case management problem solving method is providing the means of doing tasks such as assessing and recording fundamental considerations, total pain and consideration of interdisciplinary teams. Figure 44 shows the means of assessing and recording the fundamental considerations. A checklist is provided in which all the ten considerations need to be checked off as assessed and recorded. The fundamental consideration form also allows a user to add fundamentals considerations that are specific for MyCase. Figure 44 shows an example about a disease trajectory fundamental consideration being created for MyCase. There is a button titled 'details' beside each of the fundamental considerations that provides supporting information about the fundamental consideration in case a user requires that support.

MyCase ▾ Learn SPM ▾ Reflective Practice ▾

Demographics - Model Category, No patient demographics Category: Incident pain

Button Bar

Map

View Category Information

Run Reports

Add Category to MyCase

Create Reflective Note

Signs Symptoms Interpretations Strategies Considerations

Click the box next to each fundamental consideration as they are assessed. Click details to bring up information about the fundamental consideration. Additional information on fundamental considerations is available on the category specific information page.

<input type="checkbox"/>	Disease Trajectory	Details	<input type="checkbox"/>	Individual Uniqueness	Details
<input checked="" type="checkbox"/>	Ethical Decision Making	Details	<input type="checkbox"/>	Physical Pain embedded in the context	Details
<input type="checkbox"/>	Context, meaning and Impact	Details	<input type="checkbox"/>	Limits of any scale	Details
<input checked="" type="checkbox"/>	Cultural - Ethical/Social/spiritual	Details	<input type="checkbox"/>	Overlap/combinations of pain categories	Details
<input checked="" type="checkbox"/>	Communication related to pain management	Details	<input type="checkbox"/>	Not all severe pain can be completely relieved	Details

Add Fundamental Considerations to MyCase

Fundamental Consideration Details about MyCase

Disease Trajectory

Patient is in a PPS 40-30 transition

Add

Figure 44. Checklists for completion of fundamental considerations

### 7.3.1.1.7 Understanding Pain - Contextualization of Conceptual Models

The literature review described a need to make pain more ‘visible’ and also to develop a common language for pain. Conceptual models are helpful for providing a visualization and language for pain, but the challenge is how to represent the conceptual models through empirical elements of clinical practice. The user view of the understanding pain process helps to make pain more visible through a feature called model contextualization. Model contextualization was derived from the need to establish connections between research literature and clinical practice and does that by showing how a conceptual model presents in the context of an empirical case.

The model conceptualization feature can be illustrated through two cases that were observed on the clinical ward. It will show how Pincus and Morley’s Schema Enmeshment Model of Pain (SEMP) (described in section 2.1.5) can be used to contextualize the details of the cases to make them more explicit and visible. The cases will be illustrated as forms from computer based CAPIT.

#### Case 1 – Mother with Young Son

One patient case was a female with cancer who was suffering from pain in her back and hip that was bad enough that she went into emergency and was admitted to VHS. The patient was in obvious physical pain as she expressed discomfort when her back was examined and when physical touch was applied to her back. Yet when she was asked what the pain meant to her she replied that it meant she could not be with her son, she felt

by fighting the pain she was using up energy that took away from her abilities to be a mother. She talked about how her husband had to leave work early to pick their son up from school, which emphasized the impact her pain and illness was having on her family life. Her first focus on discussing her pain was related to how the pain was interfering with her life and less about the physical or illness related effects of the pain. It was later revealed that she also had nausea and had been vomiting but those details came out later in the assessment, after the discussion of how pain was impacting her family. She did not see herself as a sick patient because of the pain, she saw herself as a mother unable to do things like pick her son up from school or play with him in the backyard.

### **Case 2 – Patient with Multiple Symptoms - The ‘Domino Effect’**

The second patient case to illustrate understanding of pain comes a patient who described the interaction of multiple symptoms as being like ‘dominos’ where one symptom begins and brings with it another and another:

*The symptoms come and they are like dominos, you get nauseated and don't feel like eating, which can lead to weakness and pain and other symptoms occurring...Patient#1*

The ‘domino effect’ on pain is looked at in two ways. First, it may actually make a patient’s pain physical pain worse due to the effects of the other symptoms. Second, it may reduce a patient’s coping skills or threshold for pain. A patient’s physical pain may not have gotten any worse but the patient’s coping or tolerance skills for dealing with the pain may have decreased, which will make the pain feel worse. With respect to pain management, the patient in the above quote refers to the fact his nausea and lack of eating were the initial triggers that led to weakness and pain so part of managing his pain should ensure that his nausea is also treated to prevent the onset of the ‘domino effect’.

### **Contextualizing the Enmeshment Model with the above two empirical cases**

In the ‘domino effect’ case, although the patient is affected by his pain and other symptoms the patient is coping with the pain. As described in the total pain differential

diagnosis in section 5.4.4 the patient is using pain and other symptoms as the focus of his description. Therefore the pain and illness schemas are enmeshed, as the patient's illness is causing disruption with aspects of his life (weakness, not eating) but there would be minimal enmeshment of the self schema as the patient is coping well with the pain.

Figure 45 shows a form describing the 'domino effect' and illustrating its representation through the Pincus and Morley SEMP.

MyCase - Learn SPM - Reflective Practice

### Case - Patient With Multiple Symptoms - The 'Domino Effect'

Button Bar

Close Page | Print Page | Create Reflective Note

A patient case to illustrate understanding of pain comes from a patient who described the interaction of multiple symptoms as being like 'dominos' where one symptom begins and brings with it another and another

*'The symptoms come and they are like dominos, you get nauseated and don't feel like eating, which can lead to weakness and pain and other symptoms occurring'..Patient*

The 'domino effect' on pain is looked at in two ways. First, it may actually make a patient's pain physical pain worse due to the effects of the other symptoms. Second, it may reduce a patient's coping skills or threshold for pain. A patient's physical pain may not have gotten any worse but the patient's coping or tolerance skills for dealing with the pain may have decreased, which will make the pain feel worse. With respect to pain management, the patient in the above quote refers to the fact his nausea and lack of eating were the initial triggers that led to weakness and pain so part of managing his pain should ensure that his nausea is also treated to prevent the onset of the 'domino effect'

**Expressing the above case through SEMP**

In the case of the 'domino effect' although the patient is affected by his pain and other symptoms the patient is coping with the pain. Therefore the pain and illness schemas are enmeshed, as the patient's illness is causing disruption with aspects of his life (weakness, not eating) but there would be minimal enmeshment of the self schema as the patient is coping well with the pain.

'Domino Effect' - Pain and illness are enmeshed but patient is coping so the self schema is not enmeshed.

Figure 45. Form showing the domino effect

The case of the mother with the young son presents with a different pain enmeshment as she is not coping with her pain very well and her self schema has become enmeshed with the pain and illness schemas. Again referring back to the total pain differential diagnosis in section 5.4.4 the patient's focus of attention is on her son and how her pain is impacting her ability to be a mother. Her self-identity of a mother to her son has been impacted by her pain. Figure 46 shows the form from CAPIT describing the case of 'mother with young son' and showing how it is represented in the context of the Pincus and Morley SEMP.

**SEMP Case - Mother with Young Son**

**Button Bar**

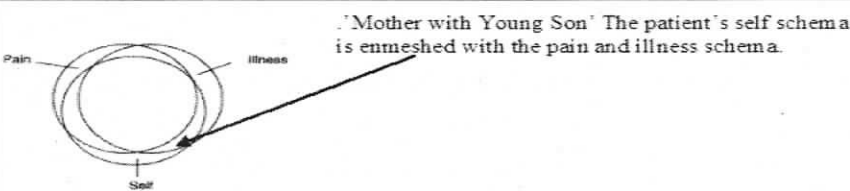
Close Page	Print Page	Create Reflective Note
---------------	---------------	------------------------------

**Case - Mother with Young Son**

One patient case was a female with cancer who was suffering from pain in her back and hip that was bad enough that she went into emergency at and was admitted to VHS. The patient was in obvious physical pain as she expressed discomfort when her back was examined and when physical touch was applied to her back. Yet when she was asked what the pain meant to her she replied that it meant she could not be with her son, she felt by fighting the pain she was using up energy that took away from her abilities to be a mother. She talked about how her husband had to leave work early to pick their son up from school, which emphasized the impact her pain and illness was having on her family life. Her first focus on discussing her pain was related to how the pain was interfering with her life and less about the physical or illness related effects of the pain. It was later revealed that she also had nausea and had been vomiting but those details came out later in the assessment, after the discussion of how pain was impacting her family. She did not see herself as a sick patient because of the pain, she saw herself as a mother unable to do things like pick her son up from school or play with him in the backyard.

**Enmeshment Model of Case**

The case of the mother with the young son presents with enmeshment of all three schemas as she is not coping with her pain very well and her self schema has become enmeshed with the pain and illness schemas. The patient's focus of attention is on her son and how her pain is impacting her ability to be a mother. Her self-identity of a mother to her son has been impacted by her pain.



**'Mother with Young Son' The patient's self schema is enmeshed with the pain and illness schema.**

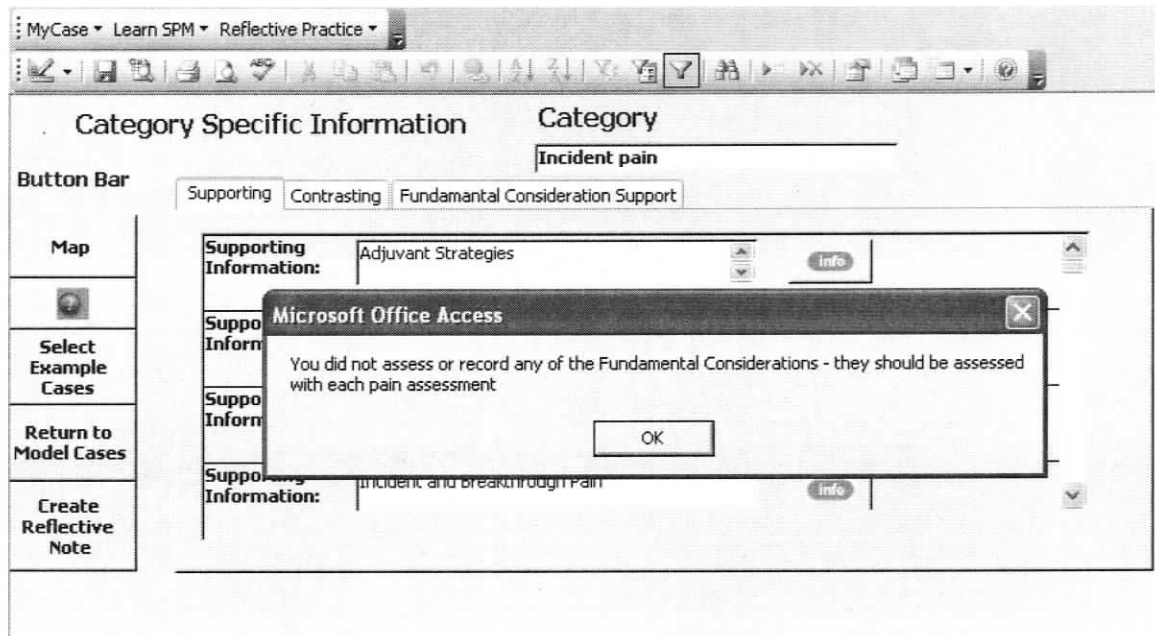
**Figure 46.** A mother's total pain and enmeshment

### 7.3.1.2 Quality Improvement

As opposed to the case management problem solving method where the user determines what forms and reports to view the QI problem solving method is more hidden to the user. The user view of the QI problem solving method involves alerts and reminders that are raised based on user actions within computer based CAPIT.

The first function of the QI problem solving method is to ensure that tasks from the case management problem solving methods are actually completed. In describing the user view of the case management problem solving method it was shown how a form is provided for assessing and recording the fundamental considerations. If a user navigates away from the view model category page without assessing or recording all of the fundamental considerations they get a message box informing them they have not assessed or recorded all of the fundamental considerations. The message box is shown in figure 47. The user then gets a second message box asking if they would like to finish

assessing or recording the fundamental considerations prior to going to the page they selected. If a user chooses to ignore the reminder to finish assessing or recording the fundamental considerations then it is recorded in the log.



**Figure 47.** Reminder that the fundamental considerations were not all assessed or recorded

Reminders about the need to assess and record the fundamental considerations, total pain and consideration of interdisciplinary teams are also provided on the View MyCase form. If a user attempts to change the case status from in progress to closed without having assessed and recorded fundamental considerations, total pain and consideration of interdisciplinary teams a message box tells them which of the checks they are missing. Figure 48 shows the View MyCase form after a user attempts to close MyCase without having completed and recorded all the checks. Figure 48 also shows a button called 'view considerations' that shows which fundamental considerations have been assessed and recorded and which have not. The user can then use that form to complete the assessment and recording of fundamental considerations.

### View MyCase

**Demographics**

First Name:  Last Name:  Date of Birth:

Gender:  Primary Diagnosis:  Age:

**Button Bar**

**Severe Pain Data Elements**

Description:

**Close Case**

Do you really want to close MyCase, You are missing the following details:  
 Fundamental Considerations Not all entered or recorded- see list to identify missing ones  
 Total Pain not assessed or recorded  
 Interdisciplinary Team not considered or recorded;

**Case Details**

Fundamental Considerations Assessed? 
 Total Pain Assessed? 
 Interdisciplinary Team Consulted?

Click to View Checked and Missing Fundamental Considerations

**MyCase Categories of Pain**

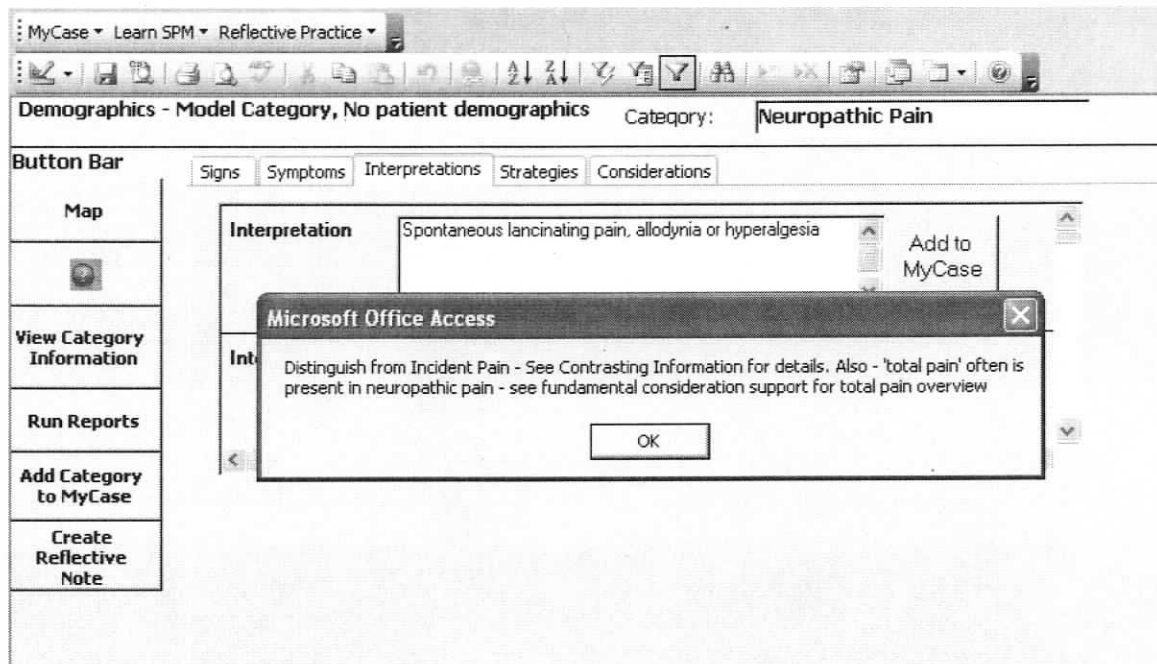
	Category
▶	Incident pain
*	

**Case**

Closed  
 In Progress

**Figure 48.** Quality improvement features of the view MyCase form

The second aspect of the QI problem solving method is reminders. An example is shown in figure 49 where a reminder is triggered as part of the interpretation tab in the neuropathic pain category page that reminds the user to distinguish neuropathic pain from incident pain and also that total pain is often present with neuropathic pain. The reminder is the implementation of the program code shown in figure 30(a).



**Figure 49.** Reminder for differential diagnosis for neuropathic pain and also that 'total pain' is often present in neuropathic pain cases

### 7.3.1.3 Reflective Practice

The user view of the reflective practice problem solving method also involves forms and reports to enable development and viewing of reflections. On any page within computer based CAPIT a user is given the option of making a reflective note by clicking on the 'create reflective note' button seen in the previous screenshots. That will enable them to create a general reflection in practice.

Forms are also used to encourage the creation of specific types of reflective notes such as about the use of interdisciplinary teams or ethical considerations around severe pain management. One of the requirements from the conceptualization chapter was to encourage ethical deliberations about a case as it was described how sometimes the urgency of a severe pain report pushes clinicians through ethics quicker than they should be. A form presents a framework for ethical deliberations that contains seven questions for ethical deliberation as well as the means of creating reflections about any of those seven questions.

Figure 50(a) shows the form presenting the ethical framework and figure 50(b) shows the form where the user can enter ethical deliberations.

### Seven Questions to Ask Oneself Before Proceeding

McDonald et al(1) use an ethical decisionmaking model for clinical and teaching purposes. One aspect of this model which may be helpful is an 'internal' testing-out process of various possible options before proceeding with decisions, using the following seven areas of focus:

1. What are the best consequences overall? Propose a resolution or select the best alternative(s), all things considered
2. Which factors would have to change to get you to alter your decision? Perform a sensitivity analysis. Consider your choice critically as these personally identified factors are ethically pivotal
3. What would the impacts be on the ethical performance of others? Think about the effect of each choice upon the choices of other responsible parties. Are you making it easier or harder for them to do the right thing? Are you setting a good example
4. Would a good person do this? Ask yourself what would a virtuous person – one with integrity and experience – do in these circumstances
5. What if everyone in these circumstances did this? Formulate your choice as a general maxim for all similar cases
6. Will this maintain trust relationships with others? If others are in my care or otherwise dependent on me, it is important that I continue to deserve their trust
7. Does it still seem right? Are you and the other decision-makers still comfortable with your choice(s)? If you do not have consensus, revisit the process. Remember that you are not aiming at 'the' perfect choice, but a reasonably good choice under the circumstances

**Enter Ethical Reflections**

Ethical Reflections

 Enter ethical reflections about one of the seven areas of focus from above. To view ethical reflections after you make them go to the reflective practice base and select 'reflections in practice'.

**References**

1. McDonald M, Rodney P, Starzorski R. A framework for ethical decision-making. version 6.0: www.ethics.ubc.ca; 2001.

Record: 1 of 1

---

### Ethical Deliberations In Practice

From the drop down list select one of the seven areas of focus for discussion and then enter the discussion comments in the text box. Click submit after entering your comments.

Close Page

5. What if everyone in these circumstances did this? Formulate your choice as a general maxim for all similar cases ▼

reflections entered here

Submit

**Figure 50.** (a) Top – Seven questions for ethical deliberation and (b) Bottom – Form to enable the user to enter ethical deliberations

The same approach (providing questions and the means to deliberate about the questions) is used to encourage reflections about interdisciplinary teams and reflections on practice.

The logging feature of the reflective practice problem solving method provides a form that summarizes all the activity a user has done in their current session using computer based CAPIT. It provides a count of the instances of activities done (such as assessments or data entry). Figure 51 shows the activity log form. The user is then able to click to see a report that provides details about the activities, such as what were all the data entries that have been done. The logging feature indirectly acts as a QI feature as one of the actions that gets logged is how many times the user got the warning message about not assessing or recording the fundamental considerations and whether they ignored the option to finish the assessment and recording. If a user views the log and sees that they are constantly not completing the assessment and recording of the fundamental considerations it might make them pay more attention to completing that task.

Activity	Count	
Assessment of signs	38	View Report
Assessment of Symptoms	2	View Report
Provisional diagnosis	16	View Report
Differential Diagnosis	0	View Report
Viewed Interpretations	2	View Report
Viewed Strategies	2	View Report
Viewed Supporting Information	2	View Report
Viewed Contrasting Information	0	View Report
Added Data	2	View Report
Fundamental considerations not assessed and reminder ignored	12	View Report

**Figure 51.** Form displaying computer based CAPIT activity log. Clicking ‘view report’ will produce a report of all instances of the activity

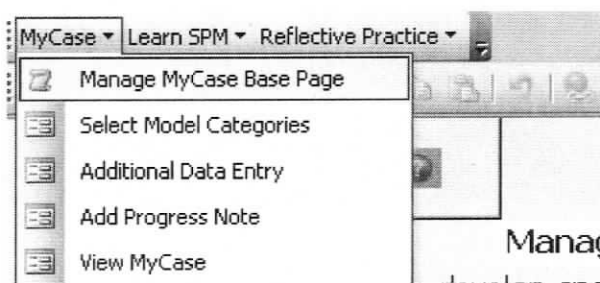
#### 7.4 User Perspective of Content Management

The last user perspective is how the content within computer based CAPIT is organized so it is manageable and easy to use. The user perspective in the previous sections

illustrated some of the forms and reports in computer based CAPIT but there are many forms and reports not shown. Because of the large amount of material in computer based CAPIT content management becomes very important to enable the computer tool to be helpful in providing practice support for SPM but not overwhelming to use.

#### 7.4.1 Modes

Part of the content management of computer based CAPIT is the creation of three modes from which a user can access the content. Upon starting computer based CAPIT a user is asked to select the mode they wish to use. Mode one is Manage MyCase where the user builds a severe pain case using forms such as the ones illustrated in the previous section. Mode two is reflective practice. That mode is where the user accesses reports on reflection in practice that were made while using computer based CAPIT and also where reflections on practice are made. Mode three is LearnSPM. The three modes were created to balance the content based on the distinct features within computer based CAPIT. Developing and managing a case, engaging in reflective practice and learning SPM are unique tasks so it made sense to structure the content into three modes based on those tasks. Each mode begins with a 'base page' that is the starting point for all the features within that mode. A custom designed menu is used to guide the user through the features in a mode as well as to move to another mode. Figure 52 shows the menu used to navigate within and between the three modes.

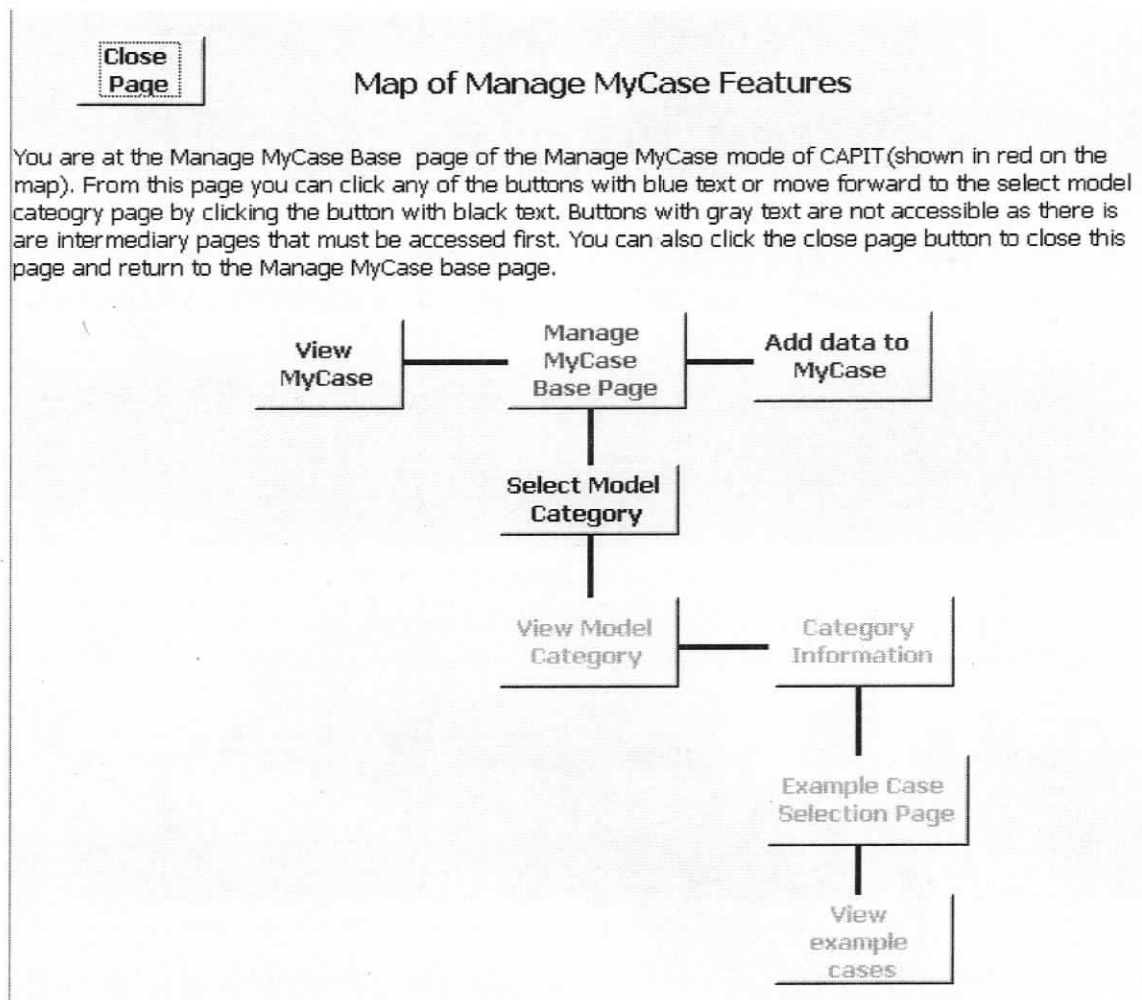


**Figure 52.** Menu from CAPIT illustrating the three modes and drop down menu of the MyCase mode

#### 7.4.2 Maps

As part of the prototyping process computer based CAPIT was demonstrated to two physicians and a comment that they made was they got lost in trying to keep track of

where they were and how to move between the many screens. They found the Manage MyCase mode particularly confusing at times as it has the most forms and sometimes a form can have five or six levels below it. Based on that feedback further content management was developed through the use of maps to show a user where they currently are in computer based CAPIT and also to show how to navigate to other pages. Figure 53 shows the map from the Manage MyCase Base Page screen that lays out all the main pages that are accessible through the Manage MyCase mode.



**Figure 53.** Map of Manage MyCase features

The map shows where the user is currently located and also shows what pages are immediately accessible and what pages have intermediary pages that must be accessed prior to accessing a page. For example the view model category page is an intermediary

page for the category information page and therefore you must go through the view model category page to get to the category information page.

### **7.5 Summary**

The construction chapter has completed the transition from user requirements for practice support to a set of informatics based solutions and finally to a computer based practice support tool for palliative SPM. This chapter illustrated how computer based CAPIT is implemented as a set of database tables and how forms, reports and program code were developed to represent the ontology and problem solving methods. In particular the chapter showed how the specific SPM practice support needs can be implemented as a computer based tool. The implementation was illustrated from a technical perspective that showed how the ontology, problem solving method and vocabulary became database tables, forms and program code, as well as from the perspective of the user that showed how implementation looks to the person using the computer based CAPIT. The results of the construction chapter answer the third research question about how and to what extent the informatics based solutions (ontology, problem solving methods and vocabulary) can be turned into a computer based tool. The extent to which the computer based CAPIT provides practice support will be answered in the testing phase in the next chapter.

The chapter also presented the empirical vocabulary around SPM and showed the degree by which it is represented in four controlled vocabularies. Of significance is that although general terms for assessment or management of pain were found in some of the controlled vocabularies many of the terms specific to palliative care were not found in the vocabularies. That points to the need for better incorporation of palliative care terms into medical vocabularies.

## Chapter 8 – Testing Phase

This chapter describes the usability testing of computer based CAPIT. Usability testing answers the fourth research question about to what extent does the computer based CAPIT provide practice support for SPM.

### 8.1 Overview of Testing Phase

The testing phase was done in a laboratory setting as a tablet computer with CAPIT loaded onto it was brought to the office of the testing subject. Testing consisted of each subject being given three cases of a patient presenting with severe pain. The category of pain the patient has differs in the three cases. Each case has a series of tasks that are completed as part of management of the case. Examples of tasks include viewing and searching for information, doing a diagnosis, entering data, running reports and interacting with reminder boxes. The test cases, tasks for each case and post testing interview questions are in appendix B.

The testing phase was done in six steps that are described as follows.

1. The testing subjects were greeted and given an overview of the purpose of the testing and how CAPIT (both paper and computer versions) were developed.
2. A demonstration was provided that introduced the users to the functionality in computer based CAPIT. However it should be emphasized that the explanation of functionality did not in any way provide guidance as to how the tool is used to provide support for the testing cases. The explanation was simply an overview of the features of the tool.
3. The subject was given the first case and set of tasks and was instructed to read the case and complete the tasks. Each subject was video recorded as they used the tool and also recorded using the 'think aloud' protocol.
4. After completing the case a set of follow up questions were asked that related to specific tasks that were done within the case. Those questions were asked after

each case as if they were left to the end of the testing of all three cases the subject would have to rely on memory and may not be able to give as rich of detail for the answers.

5. Repeat steps 3 and 4 with cases two and three
6. After completing the three cases a follow up interview was conducted that asked questions about features in the tool. The follow up questions are done in two sets, a set of specific questions that asked about specific features and a set of general questions to obtain overall impressions.

### 8.1.1 Testing Subjects

Five subjects took part in usability testing, three physicians and two nurses. None of the testing subjects were involved in either the conceptualization or construction phases of the study. One of the subjects worked full time at the hospice where the research took place, two worked part time and two work at centres outside of the research hospice. The subject profiles including experience level with computers and palliative SPM are presented in table 7.

**Table 7. Usability Testing Subjects**

	S1	S2	S3	S4	S5
Age range	21-30	51-60	51-60	51-60	51-60
Discipline	Physician	Physician	Physician	Nurse	Nurse
Years in palliative practice	1	7 (part time)	15	25	10
How often do you use a computer	Several times a day	Several times a day	Several times a day	Several times a day	Several times a day
Level of computer experience (poor, average, excellent)	Average	Average	Average	Average	Average
Comfort level using computers (uncomfortable, comfortable, extremely comfortable)	Comfortable	Extremely Comfortable	Comfortable	Comfortable	Extremely Comfortable

	S1	S2	S3	S4	S5
Level of knowledge about palliative SPM (poor, average, excellent)	Average	Average	Excellent	Excellent	Average to excellent

The usability testing results are presented in two sections. The first section (section 8.2) presents the results of the usability testing interviews. The second section (section 8.3) presents the coding of the usability issues that were encountered while completing the tasks.

### 8.2 Usability Testing Interview

The usability testing interview provided insight on usability issues the subject may have encountered during the testing as well providing information about other features in Computer based CAPIT. The interview was done in two parts. Following each case four or five questions were asked about specific features of CAPIT that were tested in the case. The questions were asked at the end of each case to prevent the subject from having to rely on memory at the end of the test.

At the completion of all three cases the subjects were given a post testing interview. Two types of post testing questions were asked, general and specific. Specific questions queried on specific features such as 'How helpful is the ability to build and develop MyCase?' whereas general questions included 'Does the tool fit with your practice workflow? Why or why not?'

Subjects were also asked about how helpful computer based CAPIT is at providing practice support for palliative SPM with 1 being not at all helpful and 5 being extremely helpful. Four of the subjects gave a score of 4 and one gave 3.5 for an average score of 3.9/5. The score does indicate that Computer based CAPIT is useful for providing practice support for palliative SPM although the small number of testing subjects does not permit any statistical validation to be done on the scores.

A summary of the results from the interviews is presented in this section. The interview results are presented according to the three problem solving methods.

### **8.3.1 Case Management**

#### **8.3.1.1 Supporting Information**

All five of the subjects said that having access to supporting information is useful. However there were some specific comments made about how to make the supporting information more useful, particularly in clinical settings. All of the subjects had at least one usability issue because of too much information. Supporting information such as how to rotate a patient's opioid or what are examples of short acting opioids are meant to be used to support clinical practice. Three of the five subjects said that the supporting would be more useful in clinical settings if the information was presented in a more concise manner. Currently CAPIT only has one way to view the supporting information, all or nothing. Three quotes below, one from a physician and two from nurses commented that a two or three point overview or 'quick facts' would be better in pressed for time clinical situations with the option to get more detailed information if needed.

*I think the information could be presented more simply because if you are going to opioid rotation you want some advice don't you?....and so I think ultimately the bottom line is how do I do it and what should I switch to?....be more concise and more directive...Testing Subject #3, Physician*

*Quick facts would be good, it could be you have quick facts and the need more info button to take you over to the bigger thing....some people may just want a reminder...then people have the option and it's not as cumbersome for people that have a lot of knowledge... Testing Subject #5, Nurse*

*I'm looking for quite short punchy stuff when I'm doing clinical work...you can make references to other material but I wouldn't go through all this...it starts to swim in front of my eyes... Testing Subject #4, Nurse*

Non clinical supporting material such as the Pincus and Morley Schema Enmeshment Model of Pain (SEMP) tested positively with all of the subjects. However because the SEMP was new material to many of the subjects they felt it would have more value over time as they become familiar with the model and how to apply it to specific cases.

*Yes, but it takes time to go through those models and time to learn how to incorporate them into your case, but having them is helpful...I think those types of materials will have value over time, as you learn about them and they become part of your thinking..but yes, they're helpful...they give different looks at pain...*

Testing Subject #1, Physician

One comment on the Pincus and Morley material was that the patient cases presented in the context of the SEMP were very helpful, and in fact one physician felt the cases were more helpful than the actual Pincus and Morley reference material.

*I wouldn't give the venn diagram (Pincus and Morley Model) but give a reference where they could look it up but explain as you did what was happening with the mother and son and how she was sacrificing herself in terms of what she had to do as that applies in so many instance... Testing Subject #3, Physician*

One suggestion to improve the supporting information was to make it easier to read such as highlighting key points such as medication doses so a clinician could focus in on it.

*You might find that if you put in doses, highlighting that might make it quicker to go through the page, to focus in on things... Testing Subject #2, Physician*

Another suggestion was to filter the information as one physician commented that supporting information about delirium is a mixture of research and clinical information and that makes the supporting information too exhaustive. The physician's suggestion was to just pick out the top causes of delirium that are relevant clinically and present that as the supporting information.

*I take issue with the statement routine use of screening instruments...we don't actually do the delirium rating scale on the ward, we do in research... just pick out the top ones (causes of delirium) as that list is too exhaustive...it should be really if we have delirium think about this....renal failure and a few common things....there's probably about 4 causes that would cover most things... Testing Subject #3, Physician*

Although supporting information was perceived as valuable for providing depth about SPM the information needs to be layered to enable quick facts to be used easily in clinical settings with the option of getting more information if necessary.

The use of conceptual models as supporting information for providing different perspectives of pain was also found to be helpful. In particular the model contextualization feature that linked research and practice scored quite favorably.

#### **8.3.1.2 Diagnostic Support**

The diagnostic support scored favorably with all five testing subjects. In particular the differential diagnosis feature that enables queries to be built using combinations of signs and symptoms to retrieve categories of pain was described as very helpful. One of the testing cases had the patient exhibiting delirium and a task was to use the differential diagnosis feature to help determine that the delirium was due to opioid neurotoxicity as

opposed to other causes of delirium. Two comments below describe the usefulness of the differential diagnosis feature for helping with decision making about severe pain, particularly when a sign may present across more than one pain category.

*yes it is useful because I think a lot of people may have recognized the delirium but they wouldn't necessarily recognize that it's opioid neuro and that's what is causing the delirium...* Testing Subject #3, Physician

*Yes, it's helpful for someone, it shows that a sign may present across more than one category so for delirium it reminded me to also check the calcium level to make sure it's not a reason why the patient is delirious...* Testing Subject #1, Physician

The only downside about the differential diagnosis feature was that it is complex to use and all five of the subjects needed some level of guidance about the feature. However that should dissipate as people become more familiar with the tool.

### **8.3.1.3 Navigation**

All five of the testing subjects needed some guidance for navigation through the screens, particularly while completing the tasks for first case. Four of the five testing subjects said that although the tool is complex it becomes easier to use once you become familiar with the menus and buttons of it.

One physician struggled a lot with the navigation and was the only one of the five testing subjects who said they would not use the tool in its current form because it is too complex to use.

*I think it needs a bit of work on the design as I was kind of struggling a bit looking around...so it's probably you need some kind of navigator tool... Testing Subject #3, Physician*

The suggestion from the above quote of a 'navigator tool' is in fact what the Manage MyCase Maps are intended to do. However, despite a reminder box about the maps every time a user goes to the Manage MyCase base page, not one of the testing subjects used the maps. Therefore a design issue is the maps need to be made more prominent to get users to actually look at them.

Another helpful comment about usability linked navigation difficulties to the amount of material on a page. A physician comments that there were times when after being told what to do he was still confused about what he was supposed to do and he attributes that to the amount of material on a page.

*there needs to be one or two alternatives rather than so much on one page and at times I was looking around like where the hell am I now, even when you told me what I need to do, so like this box I'm supposed to click...where is it?... Testing Subject #3, Physician*

Two helpful suggestions were made to improve the navigation. The first suggestion was to make the buttons more consistent. Currently some features are accessed by buttons and some are accessed by down menus and it was described how having all similar features in one place would enhance usability. For example to make a progress note the function is accessed via drop down menu while to make a reflection in practice note you click a button. Subjects found that confusing as they are both data entry tasks. The second suggestion was to color code the buttons that are of a similar purpose, so for example all data entry buttons could be colored red.

#### **8.3.1.4 Charting**

All five testing subjects described the ability to build a patient case and to add ongoing progress notes to the case as helpful. A physician makes a comment below that a useful feature is the ability to not only view severe pain data but to build a case and make it specific for a patient, which a lot of tools do not let you do.

*I like that you could enter data, a lot of tools you just try and find the case that best matches your case but in this tool you're actually building a case and choosing their treatment options...so I thought that was good....* Testing Subject #1...Physician

A comment about the progress notes feature is that it would be helpful when a clinician is doing home care.

*Progress notes are essential you have to have that...so that is very helpful....and it's very helpful if you're in a situation like a home to be able to add a progress note...* Testing Subject #3, Physician

The ability to print documents from the tool was cited as a useful feature as that enhances communication.

*What will happen often on the ward is nurses will photocopy things and put them in the chart for clinicians to look at..being able to print from this tool acts as a communication tool....* Testing Subject #4, Nurse

As expected the charting tested very favorably. The main suggestions for improvement where more drop down lists of predefined terms as currently diagnosis needs to be typed in.

#### **8.3.1.5 Support for Workflow**

All five subjects said that the tool does fit with their workflow of how they do SPM although there were varying levels of fit. One nurse describes in the quote below that the tools fits quite well.

*I think it fits...I think you've captured the things that go on in people with severe pain and there is good decision making guides in there....so I think it fits...*

Testing Subject #5, Nurse

Likewise a physician commented that the flow of the tool is consistent with what she already goes through in her practice.

*I suppose you chose what kind of pain they have and then go onto to the manage the case part and go through signs and symptoms and then go onto the 10 things (fundamental considerations) of pain...I think it flows fine...it goes with what you go through anyways... Testing Subject #1, Physician*

However one nurse commented that although the flow of the tool fits with her workflow it does slow her workflow down, which takes away from the overall usefulness of the tool. In particular she commented that the large passages of reading such as in some of the supporting information add too much extra time to her workflow.

*Well if my workflow is I'm in the moment with my patient those large areas of reading slows it down....and it's visually dense too... Testing Subject #5, Nurse*

A physician echoed the above comment and said that although the tool does support his workflow it needs to be simpler and take less time to complete a patient case. He said the tool needs to target 10 minutes per patient for all aspects of the SPM process.

One suggestion to improve the fit of the tool into workflow was to have a more concise charting mode that allows that allows a clinician to build a patient case without the additional buttons on pages such as for supporting information.

Another comment was made that it takes time to use the features in the tool, particularly the features that involve typing and that impacts workflow. A suggestion was made to

allow clinicians to customize the progress notes feature so that key phrases that are used repetitively could be saved and inserted into progress notes to reduce typing.

*If you really wanted to get sophisticated in progress notes you might want to have some set phrases so if someone types in delirium it might bring up phrases about Opioids or other things... a lot of us are fairly slow at typing...or let us type in a note we might constantly use... Testing Subject #2, Physician*

Another suggestion made by three of the testing subjects was that the tool needs to be linked to other computer based tool used in practice. For example if a history has already been done through an electronic patient record system then CAPIT should be able to retrieve those details. Four of the five subjects stated that CAPIT would not be well used if it involved duplication of work done in other systems.

### **8.3.2 Quality Improvement**

#### **8.3.2.1 Reminders about Completing the Fundamental Considerations**

Usability issues due to reminders are classified as System understandability – Operation issues and comprised the largest percentage of usability issues. Despite the subjects being told in the tutorial that reminder boxes were part of the system functionality many of the subjects were surprised when a reminder appeared and they simply clicked okay rather than actually reading the reminder and trying to understand what it was telling them.

Only one testing subject found the reminders to complete the fundamental considerations helpful. That subject was a palliative care fellow and only had one year of palliative care experience. She describes how the reminders help to draw attention to things.

*I think it's good that there is actually a checklist there as otherwise I know in my head I might do yeah,yeah I know that but because you actually have to check off*

*what you are considering it's more helpful for considering that...* Testing Subject #1, Physician

The other four testing subjects are considerably more experienced in palliative care and the consensus was that although the checklists for completing the fundamental considerations are helpful the reminders telling a user when their checklists have not been completed should be optional.

### **8.3.2.2 Quality Improvement - Reminders for Interpretations and Strategies**

Other reminders such as ones to draw attention to certain signs, symptoms, interpretations or strategies were also only found useful by the palliative care fellow. She also pointed out that more experienced clinicians might not find the reminders helpful although non palliative clinicians might find reminders useful.

*Yes it's helpful to know that sufenta or fentanyl are your options.... for advanced palliative care physicians it might not be that new or helpful for them.. but for a family doctor doing a case it might be helpful for them...* Testing Subject #1, Physician

One interesting comment about the reminders came during testing with a nurse. She thought the reminders were actually instructions that needed to be followed. She felt that the way the reminders were written and the way they appeared on the page, popping up in the middle of the page with a noise, signified a directive note.

*It looked more instructive than a reminder... I had the impression it was telling me what was required ...the other thing I noticed is these things pop up right in the middle of the page with a noise and any other dialogue box that does that usually means you've made a mistake...* Testing Subject #4, Nurse

Suggestions to improve the reminders were to make them optional, so a clinician would click a button and get a reminder if they wished but also to make the reminders more user friendly.

*It might be how you position your dialogue box....maybe a light bulb goes on and the idea is to give you a reminder but it's not directive... Testing Subject #4,  
Nurse*

Based on the testing results a new design approach for reminders is needed. Although a common suggestion from the testing subjects was to make them optional they are meant to remind clinicians of things they may have overlooked so making them optional could be counter productive.

### **8.3.3 Reflective Practice**

#### **8.3.3.1 Reflection in Practice**

The reflection in practice feature tested poorly and in fact two of the five testing subjects said they did not understand the difference between reflection in practice and reflection on practice. One physician said he did not make a distinction between a reflective in practice and a progress note and in practice he simply combined the two when he charted.

Although the reflection in practice feature tested poorly there suggestions made to enhance the feature to make it more usable. Two of the subjects made a suggestion to link the reflection in practice to e-mail so when a reflection is made the user automatically gets an e-mail message with the reflective note. That would enable development of an ongoing file of reflective material. Another suggestion was to have a reminder come up when starting CAPIT to point that the things the clinician wishes to look up.

*I don't know if it's all that useful to me unless it would come up with a list to somehow remind you wanted to look up these things... or if you click on reflective*

*notes and it says 'here are the things you wanted to look up' – that would be useful, otherwise I don't think I'd really use the reflective notes ....*Testing

Subject #1, Physician

A nurse commented that the reflection in practice feature could be helpful for orientation to SPM for student nurses or medical residents to identify where their learning needs are.

### **8.3.3.2 Reflection on Practice**

Similarly the reflection on practice feature tested poorly with all five testing subjects saying they would use the feature minimally if at all. However all five of the testing subjects said they recognize the importance of self reflective practice. Two testing subjects, one physician and one nurse offered suggestions on how to improve the reflection on practice feature to make it more useful.

The physician commented that because the reflection on practice feature is currently several screens away from where patient cases are built that it is easy to forget about the reflection on practice. She suggested a reminder, possibly when closing a case, which might ask if you want to make a self reflection.

*I think if there was a pop up button that asked if I wanted to make a self reflection, having it off to the side I probably wouldn't use it as much, especially if you're reflecting on how it affects you as that's not something you automatically think of doing so you need something to remind you... Testing*

Subject #1, Physician

A nurse commented that the questions that are used to promote self reflections are too general. For instance one of the self reflection questions is 'when have you suffered' and the nurse felt that is too general to engage meaningful reflection as everyone has suffered at some point in their life. She felt a better way to frame the questions would be to encourage self reflection based on the case you have just worked on.

*I think it should be linked to the case...the overall is what did you learn from yourself in this situation... what can you not write in the chart from this case and what does this particular case bring up for you?....* Testing Subject #4, Nurse

Therefore although there was consensus about the importance of self reflective practice the way it is currently implemented in CAPIT needs design revisions.

#### **8.4 Coding of Usability Issues**

During each usability testing session the computer screen and think aloud commentary by the subject was recorded using the Hypercam© software. Each session was transcribed verbatim. Usability issues were then coded based upon a coding scheme described by Kushniruk and Patel (2004). The coding scheme contains five categories of usability issues: information content, comprehension of graphics and text, issues in navigation, system understandability and user actions. Some of the coding categories contain multiple parts, for example comprehension issues are coded as comprehension of text or graphics. Table 8 shows the usability issues by testing subject and total counts for each issue.

**Table 8.** Usability issues by subject

<b>Issue</b>	<b>S1</b>	<b>S2</b>	<b>S3</b>	<b>S4</b>	<b>S5</b>	<b>Total</b>
User action - goal	2	2	2	3	2	11
User action - scrolling	0	1	2	2	2	7
User action – time for task completion	0	1	0	0	0	1
System understandability - Operations	9	7	10	7	7	40
Navigation - Ability to select/find wanted information or screen	5	4	9	6	8	32
Informational Content – Too much information	2	4	3	2	1	12
Comprehension - text	4	1	6	7	2	20
Comprehension - graphics	0	2	1	3	1	7
<b>Total Usability Issues by Subject</b>	<b>22</b>	<b>22</b>	<b>33</b>	<b>30</b>	<b>23</b>	<b>130</b>

As table 8 shows the five subjects had a total of 130 usability issues for an average of 26 issues per subject. To put the number of issues in context here are the number of tasks and subtasks completed by each subject. Each subject completed a total of 50 tasks (19 for case one, 14 for case two and 17 for case three). Many tasks had subtasks within them, for example data entry may have 5 fields of data to be entered. The total number of subtasks was 154 (61 for case one, 40 for case two and 53 for case three). Therefore each subject did 50 tasks and 154 subtasks.

The most common usability issue was system understandability, which comprised 40/130 or 30.8% of the total issues. System understandability issues include when the subject did not understand how to do something such as run a report or when they did not understand a system function such as a pop up box. Navigation issues, which are when the subject could not find the required information or page, were the second most common error comprising 32/130 or 24.6% of the total issues. When those two types of issues are combined (72/130) they are over half (55.4%) of the total issues that occurred. Comprehension of text, which is when the subject could not understand written documentation within CAPIT, was the third most common error at 15.4% of the total issues. The remaining issues occurred less frequently with all subjects having at least two issues due to ability to accomplish a goal and at least one error because of too much information. All but one subject had at least one error due to scrolling and comprehensions of graphics.

In all five subjects the number of issues decreased considerably from case one to case three as the subject became more familiar with the tool.

### **8.5 Summary of Usability Testing**

The usability testing did provide meaningful insight about the design of computer based CAPIT. For the most part the features within computer based CAPIT tested favorably. Helpful feedback from the interviews included the need to structure the supporting information so that it is presented in a concise and direct way for clinical practice with

the option of getting more detail if necessary. The model contextualization feature that presents clinical cases in the context of a conceptual model tested favorably and more than one subject commented that such material will have ongoing value over time as the users become familiar with such material and incorporate it into their practice.

Quality improvement features such as checklists to facilitate completion of tasks were deemed as helpful however reminder dialogue boxes tested poorly. Reminder dialogue boxes either caught the subject by surprise and were not understood and simply ignored, or in the case of one nurse, the dialogue box actually confused her because of the way the box presented and the wording within the box.

The reflective practice features also tested less favorably and although all the subjects acknowledged the importance of reflective practice they still said they would use the reflective practice features minimally if at all. A suggestion to improve the reflective in practice feature was to have it automatically e-mail a user with a list of topics they would like follow up on. Suggestions to improve the reflection on practice feature was to have it more prominent to encourage its use and also to make the reflective questions specific to the severe pain case the user is has just worked on.

The coding of the transcripts helped identify the types and frequency of usability issues and the interviews were very helpful for getting details about why some of issues occurred and how they could be reduced in future versions of computer based CAPIT. In particular the testing showed that the reminders, reflective practice and organization of supporting information need new designs. Features for better navigation are also needed as navigation issues were the second highest occurring class of issues.

## **Chapter 9 Discussion**

This chapter provides a summary and discussion of the results, limitations of the study and future work.

### **9.1 Summary of Results**

The literature review pointed to the complexity of palliative SPM and how it would be a challenge to develop a tool that contained the required depth and breadth to support palliative SPM. This dissertation did show that it is possible to apply informatics based approaches for understanding palliative SPM, to model informatics based solutions and to implement those informatics based solutions as a computer based severe pain tool.

The summary of results from this dissertation is presented in two ways. First is a listing and description of five key points from each of the three results chapters: conceptualization (chapters 5 and 6), construction (chapter 7) and testing (chapter 8). Second is a review of the research questions and the extent to which they were answered by the results.

### **9.2. Summary by Results Chapters**

#### **9.2.1 Conceptualization**

1. A grounded theory-participatory design (GT-PD) method was used for conceptualization. Participatory design was used to engage with the participants and grounded theory was used to make sense of the data.
2. A SPM practice support framework was developed that contains the core steps done in SPM as well as two types of practice support enhancements in process and information support.
3. An empirically derived ontology was developed around the process and information supports needed for practice support in palliative SPM. The ontology is a formal representation of the SPM practice support framework and included establishing formal names and relationships for the concepts in the SPM practice support framework.

4. A set of three problem solving methods was developed for palliative SPM: case management, quality improvement and reflective practice. The problem solving methods are different representations of the ontology concepts.
5. An empirical vocabulary for palliative SPM was derived from the data in this study. The vocabulary provides value in that it not only provides a common terminology for discussing palliative SPM but it also provides a means of linking research and practice.

### **9.2.2 Construction**

1. A technical architecture diagram was presented that represents the problem solving methods, database tables and processes contained with the computer based CAPIT.
2. The computer based CAPIT was presented in two ways. A technical view described the technical architecture of CAPIT and the user view illustrated the front end view from the perspective of a user.
3. The ontological models were implemented as a set of database tables using the relationships between the ontology concepts as a basis for relationships between the database tables
4. The three problem solving methods were implemented using programming code to facilitate the entry and retrieval of data from the database tables
5. The empirically derived SPM vocabulary was mapped to four controlled medical terminologies: Unified Medical Language Source (UMLS), Systematic Nomenclature of Medicine Clinical Terms (SNOMED-CT), International Classification of Disease Version 10 (ICD-10) and Diagnostic and Statistical Manual of Mental Disorders - Fourth Edition (DSM-IV). The mapping was only moderately successful as although the more generic SPM terms mapped successfully the terms specific to palliative care mapped poorly.

### **9.2.3 Testing**

1. Five testing subjects, three physicians and two nurses, did usability testing of three simulated patient severe pain cases containing a total of 50 tasks and 154

subtasks. The subjects encountered 130 usability issues completing the tasks for an average of 26 issues per subject.

2. The most common usability issues were navigation and understanding system messages accounting for 55.4% of all usability issues.
3. Computer based CAPIT scored an average of 3.9/5 to the question how helpful computer based CAPIT is at providing practice support for palliative SPM with 1 being not at all helpful and 5 being extremely helpful.
4. Access to supporting information, diagnostic support and the ability to develop a patient case were features that tested favorably
5. Reflective practice and the quality improvement reminders were features that tested poorly.

### **9.3 Summary by Research Questions**

The research questions presented in this dissertation are as follows:

1. How can we capture and organize knowledge within the context of SPM to extend existing work on development of ontologies?
2. How to represent problem solving methods as a series of tasks that provide a continuum of practice support for SPM?
3. How and to what extent can a set of informatics based solutions (ontology, problem solving methods and vocabulary) be implemented as a computer based practice support too for SPM?
4. To what extent does the computer based tool provide practice support for SPM?

The results will be discussed in relation to each research question.

#### **Question 1 - How can we capture and organize knowledge to extend existing work on development of ontologies within the context of SPM?**

One of the contributions from this study was the development and use of a hybrid grounded-theory participatory design (GT-PD) method to capture and make sense of

SPM domain knowledge. The use of the GT-PD method illustrated that capturing and organizing knowledge about a complex domain area requires much methodological rigor.

The PD aspect of the method was used to capture knowledge around SPM. A critical part of the PD was that knowledge was captured from different types of clinicians and from different sources. The paper based CAPIT was the starting point for SPM knowledge in this study. However, there were very specific requirements needed by other clinicians in order to make the paper based CAPIT more usable. It was nurses who insisted that it needed to support charting and case development to enhance communication because that is part of day-to-day nursing practice. Likewise it was counselors who insisted that a consideration of total pain needed to be brought to attention during each pain assessment, as it can be overlooked when a patient has obvious physical pain. But it was not only palliative clinicians who provide knowledge but also other data sources like research literature. Incorporating conceptual models as a source of knowledge becomes a means of making pain more 'visible', which was identified as a need in the literature review. The model contextualization feature of the computer based CAPIT, which presented an empirical severe pain case in the context of the Pincus and Morley SEMP tested quite well during usability testing. Thus capturing knowledge around a domain area requires multiple perspectives to provide both breadth and depth of knowledge.

In order to organize knowledge we first need to make sense of the knowledge. GT was used to code the data in order to develop concepts and relationships from the data. The GT coding identified a set of additional requirements for SPM, which were then used to develop a SPM practice support framework. The SPM practice support framework was a key aspect of understanding the domain knowledge as it contains the core steps done within SPM plus process and information practice support enhancements. The practice support enhancements were differentiated into process and information support to enable relationships to be made between the processes (uses of information) and information types (sources of information) to ensure that one or the other is not left orphaned as information without a process to support is not helpful and vice versa.

The SPM practice support framework was then used to develop a SPM ontology as a means of modeling domain knowledge. That approach to ontology development extends existing ontology research in that it illustrates how to develop an ontology that begins with empirical data followed by articulation of the practice support needs of a domain area and finally proceeds to development of a formal ontology. Much of the ontology research to date has focused on implementation of the ontology such as for IS design, as opposed to providing details of how the ontology is actually developed. Weber (2003) states that ontologies represent an ideal base for building theories about IS representational phenomena, yet existing research on building conceptual models such as ontologies is largely devoid of theory (Weber, 2003).

This dissertation provides an approach to applying theory to ontology design by designing a SPM ontology based on concepts derived from empirical data allows the ontology concepts to reflect the language used in day to day clinical practice. For example the term 'interpretation' came directly from the paper based CAPIT but upon further discussion it was revealed that an interpretation actually contains two types of diagnosis, a differential and a provisional diagnosis. That became an important part of the ontology as those two types of diagnosis involve different approaches to problem solving. That is an example of how the SPM ontology developed in this study is grounded in SPM data that is used in day-to-day practice.

Although the ontology itself was not evaluated the design of the computer based CAPIT was based on the ontology model and the problem solving methods were ways of bundling the ontology concepts. Usability testing of computer based CAPIT with respect to workflow was favorable and for the most part the problem solving methods also tested favorably. That indicates that the approach used in this study is an appropriate means of capturing and organizing knowledge for ontology development. The approach extends existing ontology research by illustrating an empirical basis for developing an ontology and also contributes to the broader field of ontology design in that the approach can be applied in other research settings.

**Question 2 - How to represent problem solving methods as a series of tasks that provide a continuum of practice support for SPM?**

As described in the literature review much of the existing research on problem solving methods has involved developing methods that achieve a specific task (such as heuristic classification) to enable them to be reused across different domain areas. This dissertation took a different approach and introduced the concept of practice support to refer to problem solving methods that provide a continuum of support. Three problem solving methods for SPM were identified in this dissertation: case management, quality improvement and reflective practice. Each of the three problem solving methods was defined as a series of tasks and subtasks that provide ongoing practice support.

Representing problem solving methods as a series of tasks requires a detailed understanding of how a problem needs to be solved at the moment of the problem but also what processes and information leads up to and follow the problem. For example part of the case management problem solving method is diagnostic support. However querying pain categories by signs and symptoms as part of a differential diagnosis requires appropriate data entry of the signs and symptoms, which involve a process (data entry) for collection of appropriate data (signs and symptoms) leading up to the diagnosis. Further once a pain category is retrieved through a diagnosis a clinician may require practice support for selection of an appropriate management strategy. The support provided for the management strategy needs to be specific for the pain category being viewed, which requires further information handling to deliver the right information at the right time. Therefore although the problem being solved is a diagnosis it is only part of an ongoing set of tasks in order to provide continuous case management practice support. All aspects of that continuous case management process need to be understood and modeled in order for the problem solving method to provide ongoing practice support.

Parts of the problem solving methods developed in this dissertation are able to be used in other settings although much of the implementation details of the problem solving methods depend on context specific circumstances. For example the concept of the case management problem solving method can be used in other settings but the details of case management such as the data used to develop a severe pain case, the types of supporting and contrasting information used; and the means of understanding pain will vary between care centres. Likewise parts of the quality improvement problem solving method can be used in other settings such as the use of reminders to draw attention to particular management strategies or check boxes to ensure completion of fundamental considerations. The specifics of what management strategies or fundamental considerations are used however will likely be different in other care centres and thus the problem solving methods will need to be adapted to reflect local practice.

The practice support concept that was introduced in this dissertation presents a perspective on clinical tool design that can inform other tool design both in and outside of palliative care. The practice support framework presented in this study provides a checklist of the comprehensive details that need to be considered when designing clinical tools.

**Question 3 - How and to what extent can a set of informatics based solutions (ontology, problem solving methods and vocabulary) be implemented as a computer based practice support tool for SPM?**

Implementing the informatics based solutions into computer based CAPIT involved turning the informatics solutions into system design components. The ontology concepts define the data used in SPM and relationship among the data and those concepts were made into data elements and database tables. All of the ontology concepts were able to be transformed into data elements. In some instances it was necessary to create multiple data elements such as one data element for each of the ten fundamental considerations.

As with the ontology; all of the tasks and subtasks of the three problem solving methods were implemented as features in the computer based CAPIT. Program code to enter and

retrieve data and forms and reports were used to implement the problem solving methods as different means of entering and retrieving data from the database tables. For example as part of information handling of the case management problem solving method when a user selects a model category of pain a data query is created to retrieve supporting and contrasting information that corresponds to the model category being viewed.

The extent to which the informatics based solutions can be implemented is answered through the usability testing results. For the most part the implementation of the case management problem solving method tested quite well with the data entry processes for building a patient case and diagnostic support testing particularly well. The biggest issue with case management was navigation as the number of features and screens required while building a case was found to be confusing at times.

Quality improvement did not implement as well because the reminders and dialogue boxes did not test favorably. Having the quality improvement checklists to encourage completion of tasks such as the fundamental considerations tested favorably but just not the system generated reminders about doing the tasks. However that finding about system reminders is consistent with literature on decision support systems that has shown that users typically turn off reminders and other alerts if given that option. Therefore a better mechanism is needed as part of system design to enable reminders to be used but to allow them to be modifiable according to clinical expertise level or other contexts where the computer tool is being used. Suggestions were made by the testing subjects for improving the reminders and they include having them come up on the side of the page rather than in the middle of it and allowing a user to choose when the reminder appears.

**Question 4 - To what extent does the computer based tool provide practice support for palliative SPM?**

Usability testing was done on five subjects that involved reading three cases of a patient with severe pain and performing a series of tasks based on the cases. Computer based CAPIT received an average score of 3.9/5 from the five testing subjects to the question how helpful is computer based CAPIT at providing practice support for palliative SPM.

The score is based on 1 being not at all helpful and 5 being extremely helpful for providing practice support. From that perspective computer based CAPIT appears to be very good at providing practice support for palliative SPM. The five testing subjects were not part of any of the research in developing the paper or computer based CAPIT and four of the subjects practice palliative care either full time or part time in settings other than the hospice where the research took place. Those four subjects bring an outside perspective to the testing and help demonstrate the usefulness of computer based CAPIT in settings other than the research hospice. The sample size precludes statistical interpretation from being done on the data but rather the purpose of the data is to inform the iterative design of the computer tool.

Interviews with the testing subjects were done following completion of the tasks to obtain insight about the extent of practice support provided by computer based CAPIT and to suggest ways to better provide practice support. Usability comments were made that the flow of screens in CAPIT does follow the steps done while doing SPM and so it does not introduce unnecessary steps. The ability to develop and manage a patient case and the ability to view signs and symptoms across multiple categories of pain through a differential diagnosis scored favorably. Suggestions for further practice support included linking CAPIT to existing electronic patient record systems to prevent duplication of data entry and to enable data from other systems such pharmacy or radiology to be incorporated into CAPIT.

The ability to access supporting information was deemed as helpful although the structure of the information met with some critique as to its clinical usefulness. Currently the information is presented all or nothing and in some cases is a mixture of clinical and research related information. To support clinical practice where clinicians are pressed for time the testing subjects felt supporting information should be more concise and present only three or four key points. Another suggestion for how CAPIT could better provide practice support would be to allow it to be customizable as it currently contains a lot of features and a clinician still has buttons or links to those features whether they use the features or not. If a clinician could customize the interface to only have the features they

want it would make the interface less busy and easier to use as there would be less options to consider when moving from screen to screen.

The usability testing reiterates the challenge of developing a pragmatic tool that has intellectual integrity but is still clinically usable. The rich knowledge representing the practice support needs of SPM that was obtained through the GT-PD method and modeled into an ontology and set of problem solving methods becomes somewhat filtered by the usability testing results such as removal of quality improvement prompts or the ability to customize the tool to suit individual needs. It presents somewhat of a paradox to strike the ideal balance between theory and clinical pragmatism such as balancing the comprehensive practice support needs of SPM with the time pressures of clinical practice.

#### **9.4 Limitations of the Study and Future Research**

Despite the methodological rigor and use of multiple palliative data sources that accompanied the GT-PD method the biggest limitation of this study is that it was only done at one site. Thus the practice support requirements and data and information collected to meet those requirements will have a site specific bias. An attempt to overcome that limitation was to use as many different participants as possible to obtain as broad a perspective as possible about palliative SPM. Further, the testing phase was done with subjects who were removed from the other two phases of the study and in fact four of the testing subjects practice either full or part time at centres other than the hospice where the research took place. However the clinicians involved in this study acknowledged there will be local practice variations with respect to how case management occurs, how understanding pain is done and what quality improvement needs might be. Thus important future research will be to see the extent to which the ontology, problem solving method and empirical vocabulary are representative of SPM at other palliative care centres. As indicated in the results section the ontology was developed with concepts to be as general as possible so in theory it should be easy for other centres to refine the ontology concepts and the way those concepts are bundled as problem solving methods to suit their local practice. Further the computer based CAPIT

was developed to enable the information presented within it, such as the supporting and contrasting information, and the forms used to collect and display data to be adapted to support SPM practices in other settings.

A further limitation is that although a number of different participants (physicians, nurses and counselors) were used to obtain data for the conceptualization phase, the GT coding was done solely by the researcher and not directly validated by the participants. The validation of the GT coding was done through the usability testing of the prototype computer based tool, which was developed based on the practice support requirements that were derived from the GT coding. However the usability testing cases were developed by a physician and the testing subjects only involved physicians and nurses. Therefore a limitation is that some of the aspects of the computer tool such as the total pain material, psychological models (i.e. Pincus and Morley SEMP), and interdisciplinary team resources were only evaluated from the perspective of physicians and nurses. Some of those practice support requirements, such as the need to always assess for the presence of total pain and the need to consider an interdisciplinary team perspective were suggested by counsellors and thus further usability testing involving counsellors and interdisciplinary teams are needed to provide a comprehensive evaluation of computer based CAPIT.

Although this dissertation provides a detailed perspective of SPM and pain is the most common occurring symptom in palliative patients there are other symptoms including dyspnea, nausea and delirium that also occur frequently. Similar to pain there are diagnostic support and supporting information available for those symptoms and one limitation of computer based CAPIT is that it only provides practice support for severe pain. As described in the previous paragraph the computer tool was designed to enable the information within it to be adapted for different settings and therefore future research may involve expanding the robustness of computer based CAPIT to make it a more comprehensive tool that includes other symptoms.

The construction phase involved a lot of programming and design work but there were still features left out because of time constraints. In particular although the empirical SPM vocabulary has been mapped to four controlled medical vocabularies they have not been implemented into computer based CAPIT. Further the testing phase identified numerous enhancements to computer based CAPIT that would make the tool more useable. Such enhancements include better navigation support, restructuring of the supporting information and the ability to make computer based CAPIT customizable such as expert and novice modes of use. Therefore there is much future research that could be done to further develop the features of computer based CAPIT.

The GT-PD method used in this research provides a comprehensive means of interacting with the participants to obtain data through PD and coding the data through GT, which presents an advance in research for using specific case studies to obtain results that are usable in the broader context. However the research still falls within the qualitative realm and thus carries a certain degree of subjective interpretation. Although usability testing was favorable there are no statistical interpretations that can be made from the results.

A final limitation is that the testing of computer based CAPIT was done in a laboratory setting and although CAPIT scored favorably for providing practice support for palliative SPM a better indication would be to test it out on the clinical ward. Once the enhancements identified above are made to computer based CAPIT it will be helpful to do further testing in different environments such as an in patient palliative care ward as well as during home care delivery to see how well the computer tool supports palliative care delivery in different contexts. It is anticipated that ward testing will be done once some refinements are made to clean up some of the usability issues that were identified during testing.

## Chapter 10 – Conclusion

This chapter concludes the dissertation with a summary of the contributions to knowledge and a concluding summary.

### 10.1 Contributions to Knowledge

This research has made contributions to the fields of health informatics and palliative care.

First, the dissertation has made a methodological contribution to enhance the field of health informatics in that the GT-PD methodology provides an empirical approach for obtaining robust user requirements of a complex healthcare domain area. The dissertation showed how the GT-PD method was able to articulate the information, problem solving and vocabulary needs of palliative SPM.

Second, another contribution to health informatics is that it extended existing research on ontologies and problem solving methods by illustrating how to capture and organize knowledge in a clinical domain area to develop an ontology and set of problem solving methods that provide ongoing practice support. The dissertation introduced the term ‘practice support’ and a key aspect of organizing the knowledge was the development of a practice support framework to represent the process and information practice support enhancements of a domain area. That ensures that the processes and information needed to support those processes are both defined.

Third, a contribution was made to palliative SPM a part of which is the development of a palliative care specific computer based tool. To date there has been little development of tools specific for palliative care. The research also made a contribution to palliative SPM in that it developed ways of bridging research and practice, helped establish a common vocabulary for SPM and provided a comprehensive framework of the practice support needs of SPM.

## **10.2 Concluding Summary**

In conclusion, although many of the contributions from this dissertation will make immediate contributions to the fields of health informatics and palliative SPM it will also make an ongoing contribution over time. A comment from the usability testing was that although much of the material presented in the computer based CAPIT is helpful, such as the Pincus and Morley SEMP material and the contextualized patient cases, it takes a while to understand the material and subsequently to incorporate it into clinical practice. Therefore part of the methodological and theoretical contributions from this dissertation will be ongoing and will be realized over the passage of time as those contributions make an ongoing contribution to palliative SPM and to the fields of health informatics and palliative care.

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## **Appendix A – Chart Audit Information**

**Phase One Retrospective Chart Audits** - Audits of medical records that had at least one episode of 10/10 pain. After querying all patient records at VHS, 44 individual patients were identified as having at least one 10/10 episode. Those medical charts were pulled and the following data was extracted from them. A palliative care physician from VHS performed the audits. The data extracted from the audit was centered on four themes: the pain episode (date of pain episode, location of pain, whether it is a new or previous pain (did patient report similar pain in the past?), does pain occur related to activity or procedure, who reported the pain episode (patient, family, healthcare provider), number of previous or future occurrences of 10/10 pain); medications (i.e. current opioid regime of patient, signs of opioid neurotoxicity); intervention: (intervention given for pain and outcome of intervention) and additional details (such as evidence of emotional/spiritual pain, presence or absence of bone metastasis and concerns about drug-seeking behavior from the patient).

**Phase Two Retrospective Chart Audits**- Phase two of the chart audits involved widening the scope of the study to also include 8 or 9/10 pain episodes and focus the study on severe pain, rather than just 10/10 extreme pain. Therefore, phase two of the chart audits included 44 audits of individual patients with at least one episode of 8 or 9/10. The charts that were used for phase 2 were acquired by querying all VHS patients who had 8 or 9/10 and then removing the patients who were audited in phase one to prevent duplication of data. Removing the 10/10 patients left 187 individual patients. We audited 44 of the 187 patients in order to keep consistent with the number of audits from phase one. The 187 patients were put into a Microsoft Excel spreadsheet and using systemic sampling, every fourth patient was selected for audit. The phase two audits were done by two clinicians, a physician and a nurse. That strategy was done to get different interpretations and perspectives on the data.

## **Appendix B – Usability Testing Cases and tasks**

### **Cases and task listing for Usability Testing of Computer CAPIT**

#### **Case 1**

Christine Smith is a 58 year old woman with advanced breast cancer. Her PPS is 30%. She is known to have metastases to bone (including spine) and to her brain. She was originally diagnosed 5 years ago and has undergone multiple courses of chemotherapy and radiation. She most recently completed radiation to her head for her cerebral mets and also to her lumbar spine following a diagnosis of spinal cord compression made two weeks ago. She is limited primarily to bed but is able to move her legs and has 3/5 strength bilaterally. She has no numbness or tingling. She has a catheter in place.

She used to work as a nurse but now is on disability. Her husband has a home based business and their two children are both living in Toronto where they are originally from.

She is currently on Hydromorph Contin® 60 mg q12h and has been taking IR hydromorpone 10 mg as breakthrough approximately 7 times a day for severe back pain when ever she moves in bed. She is currently on dexamethasone 4 mg am and noon.

She was admitted to the palliative care unit last night and this morning when you tried to help her sit up, her body became tense and she screamed out “Stop, stop, stop!”.

You quickly put the head of her bed back down and her pain subsided quickly. “We are not going to try that again I hope!!!” she exclaimed. She described her pain as having been “10/10” in the usual place where she feels pain in her back when you lifted the head of her bed. Her pain is now “2/10”.

You suspect the patient has incident related pain but would like some additional information on incident related pain and some support on how to appropriately manage that type of pain.

### **Tasks Case 1 (Category - Incident Pain)**

1. Log into the system and enter the patient name, age and diagnosis.
2. From the Manage MyCase base page select the 'select model category' menu item
3. Select a provisional diagnosis of incident pain
4. From view model category page add the symptom "intermittent severe pain brought on by one or more activities or procedures" to MyCase
5. View the interpretations for incident pain
6. View the strategies for incident pain
7. Add the incident pain category to MyCase
8. Click the overview button to read the overview of fundamental considerations. Then check off the fundamental considerations disease trajectory, cultural – ethical/social/spiritual, individual uniqueness and limits of any scale
9. Preview the model category report for incident pain
10. Click the button to go to the category information page
11. View the supporting information on short acting opioids
12. Create a progress note that says sufentail is 10X as potent as fentanyl and then close the supporting information page on short acting opioids
13. Go to the select example cases page and select and view one example case of incident pain
14. Go to the additional data entry form and add to MyCase that a specific action that brings about the patient's pain is when going from lying to sitting
15. Go to view MyCase and preview the MyCase report
16. Go to reflective practice base page
17. Go to the reflection in practice page and select the view logs option
18. View the report that shows how many assessments of signs you have done

19. Return to MyCase and close the case – click ‘yes’ when you get the alert about not finishing all the assessments and asking if you still want to close the case

### **Case 1 Specific Questions (asked after completing the case)**

Was the reminder about short acting opioids helpful?

Was the content of the incident pain model category appropriate to help with your diagnosis?

Was the reminder about completing the fundamental considerations helpful?

Did you have trouble accessing the supporting information on short acting opioids?

Was the example incident pain case helpful?

Was the reflective practice log showing how many assessments you have done helpful?

## **Case 2**

Susan Jones is a 68 year old woman with wide spread pelvic malignancy. She has been cared for at home by her husband and daughter. She had been doing fairly well until recently. Her PPS was 50% four days ago. At that time she was on a MEsilon® 100 mg po bid as well as gabapentin 600 mg po tid.

Since that time she has had increasing pain requiring multiple breakthrough doses and subsequently was switched to sc morphine in an attempt to improve her pain control. Her dose is now 50 mg sc q4h and her gabapentin is up to 900 mg po tid. Her daughter states that while the pain initially seemed improved by switching her to morphine sc that this response was only transient and that the dose has had to be increased almost every day. In fact she had to give her breakthrough doses of 25 mg sc almost every hour in addition to her regular dose and “things seem to be getting worse not better”. Her PPS is now 30%.

When you examine Susan she appears sedated and unable to concentrate on what you are saying. She tells you that her pain is “8/10” but can not describe her pain to you. Although she is somewhat sedated she also appears agitated and is mumbling to herself.

She thinks that she is at school and that you are a teacher. You notice that she has some myoclonus. Touching her leg causes her to jump and she yells out “Don’t touch me!” The daughter tells you that she did not previously have pain in her leg but “The pain seems to be all over now”. She asks whether this means that the “Cancer is spreading everywhere”.

You suspect that the patient is experiencing opioid-induced neurotoxicity and consider opioid rotation in an attempt to help her symptoms. However you also want to ensure the patient’s cognitive impairment is not due to other causes.

### **Tasks Case 2 (Categories - Opioid Neurotoxicity and Delirium and Dementia)**

1. Select the develop and manage MyCase Mode and enter the patient name, age and diagnosis
2. From the Manage MyCase base page select the ‘chosed model pain category’ menu item
3. Use the differential diagnosis function on the diagnosis page to select cognitive impairment ‘delirium’ and then retrieve the categories of pain that match
4. Select the opioid induced neurotoxicity category
5. From the model category page add the ‘myoclonus usual’ sign to MyCase
6. Add the ‘Rapid recent dose escalation common over past few weeks & days, with transient or no pain relief obtained’ symptom to my case
7. Add the ‘Opioid rotation and/or hydration’ strategy to MyCase
8. Add the Opioid Induced Neurotoxicity Category to MyCase
9. Make a reflective note that says ‘need to learn more about opioid rotation’
10. View the supporting information on ‘opioid rotation’
11. View the contrasting information ‘Other causes of delirium’
12. Make a progress note for the patient’s case that says ‘Delirium is drug induced – opioid rotation indicated’
13. Return to the manage MyCase Base Page, and then proceed to the view MyCase page
14. Close the case – click ‘yes’ when you get the alert about not finishing all the assessments and asking if you still want to close the case

### **Case 2 Specific Questions (asked after completing the case)**

Was the differential diagnosis feature helpful?

Was the content of the opioid induced toxicity page helpful?

Was the reflective note feature helpful?

Was the supporting information on opioid rotation helpful?

Was the contrasting information on other causes of delirium helpful?

### Case 3

Larry Brown is a 38 year old man with metastatic melanoma. The original diagnosis was made 3 years ago and he was treated with surgical resection. He now is known to have recurrence of his disease with metastases to his lung made on a follow-up chest Xray that he had 2 months ago. At the time of recurrence he was asymptomatic and the fact that his cancer had returned was a complete shock to him as he was “feeling so well”.

At the time of finding out about his recurrence he had just returned to work as a teacher. His wife is also a teacher but has been off on maternity leave for the last 3 months. They have two other children who are 8 and 6 years old. His wife reported to the social worker on their last visit that she is worried about how Larry is doing and that she thinks he might be depressed. Larry tells the social worker that he feels “he is a burden on his wife” who is providing most of the care for him and their three children. Both of them say that they have been fighting more especially around issues involving the children.

Larry is visiting you today in an outpatient clinic where he has been followed for his ongoing pain that returned soon after finding out about his recurrence. He is currently on Hydromorph Contin® 60 mg po tid as well as gabapentin 1200 mg po tid. He has not taken any hydromorphone breakthrough in the last 2 days as it does not “help anyway”. He has appeared comfortable throughout the interview but rates his pain as “9/10” when asked and describes it as a “deep horrible ache”. He has previously taken codeine, oxycodone, morphine and the fentanyl patch for pain control but “they did not help

either". He is once again off on disability and he rarely leaves the house as "his pain is too bad and he really can not cope with seeing anyone that they know".

You consider switching him to methadone as you believe Larry's pain problems are partially due to titration problems his drugs but you also wonder if he has some total pain issues.

### **Tasks Case 3 (Categories - Titration Pain and Total Pain)**

1. Select the develop and manage MyCase Mode and enter the patient name, age and diagnosis
2. From the Manage MyCase base page select the 'select model categories' menu item
3. Select a provisional diagnosis of titration pain
4. Add the symptom 'Often indicates that several drug switches may have been tried' to Mycase
5. Add the interpretation 'Bring current pain under control - Consider opioid rotation if pain is due to intolerance, side effects or ineffectiveness [eg. Codeine ceiling' to MyCase
6. Check off the fundamental considerations context meaning and impact, disease trajectory and multiple categories
7. Add the fundamental consideration context, meaning and impact to MyCase and for details put 'patient has young family – feels like a burden to family'
8. Click the button 'view category information' click okay when the reminder appears about finishing the fundamental considerations'
9. View the supporting information on opioid rotation and make a progress note for MyCase that says 'patient not taking medication as prescribed'
10. Move to the fundamental considerations support tab and view the supporting information on total pain and suffering then close the page
11. View the Pincus and Morley material under the fundamental consideration support tab. Also view one of the patient cases described in the context of the SEMP then close the page
12. Go to reflective practice base page by selecting it from the menu
13. Select the reflections on practice option

14. Make a self reflective comment using one of the self reflective questions as a guide
15. Return to Manage MyCase Base Page and the proceed to the Select Model Category Page to select a provisional diagnosis of 'Total Pain'
16. From the total pain category page add the symptom 'May include feeling like a burden to family as well as a deep sense of overwhelming loss' to MyCase
17. Go to the view MyCase page and view the page that shows what fundamental considerations have not been assessed or recorded

### **Case 3 Specific Questions (asked after completing the case)**

Is the Pincus and Morley material helpful for making sense of the case?

Does the reflection on practice material encourage you to make self reflections? Do the reflections help you reflect about your own suffering?

How easy was it to navigate from the reflections on practice page to the Manage MyCase Base Page and then to the Model Category Selection Page to select the total pain category?

Are the reminders about assessing and recording the fundamental considerations and the checklists showing which ones have been recorded helpful?

### **Post Testing Questions**

The specific questions asked are open ended and are as follows:

- a. How helpful is the ability to build and develop MyCase?
- b. Were the Mange MyCase maps helpful for navigation through the MyCase features?
- c. How helpful are the navigation buttons?
- d. How appropriate is the terminology within CAPIT?
- e. How appropriate is the content within CAPIT?
- f. How helpful were the checklists for completing fundamental considerations?
- g. How helpful was the supporting information?
- h. How helpful is the ability to enter progress notes?
- i. How useful is the ability to enter reflective logs?

The general questions are open ended to capture overall impressions of the tool and are as follows:

- a. Does the tool fit with your practice workflow? Why or why not? What are some suggestions to make it better fit with your workflow?
- b. What problems (if any) did you encounter using the tool?
- c. What did you like about the tool?
- d. What were the limitations of the tool?
- e. Where do you think improvements could be made in the tool?
- f. Did you find the tool usable? Why or why not?
- g. If you had this tool would you use it? Why or why not?

A final question was asked about how helpful computer based CAPIT is at providing practice support for palliative SPM with 1 being not at all helpful and 5 being extremely helpful. The users were also invited to provide additional comments about the above question.

## Appendix C - Paper Based Severe Pain Tool

### Fundamental Considerations

#### \* Fundamental Considerations

In addition to various etiology & treatment possibilities above, management approaches for all categories need to include a decision-making process that takes into account:

- Disease trajectory factors such as functional status [PPSv2, ECOG, etc].
  - In this sense, what may be the most appropriate treatment for a patient with higher function such as PPS 70% would be very different than a patient at 20% with different prognosis
- Ethical decision-making
  - Principles & models such as Latimer Ethical Model or Kuhl Ethical Grid
  - Beneficence & nonmaleficence - what is best practice evidence in each category
  - Autonomy - what if patient refuses 'best practice' and requests a 'less best practice' option
  - Justice - resource availability & limitations - how far does one go, what is fair, how much burden on pt/family/health system
- Context/meaning/impact of pain for the patient and surrounding family/team
  - "Am I dying?"; fear that pain can't be controlled; sense of helplessness; panic re 911 or can it be controlled at home; "did I do something wrong?"; high stress on nursing & medical to find answers quickly; potential for divisiveness or differing views on what to do; "you wouldn't let a dog die like this"; 'rippling' impacts of severe pain during & subsequent; relation to previous pain; pain vs suffering; everyone on the 'ceiling' adds more stress to pt
- Need for team & holistic, broad approach in complex pain management
- Cultural - ethnic/social/spiritual - meaning of pain; varied expressions of pain [emotionally expressive versus stoical] - impact on assessment; religious context;
- Communication related to language difficulty & interpretation/medical jargon; who makes decisions; truth-telling; numbers of family & dynamics of information sharing, stress on staff; expectations of treatments, even if futile
- Individual uniqueness - although experience and knowledge contributes to understanding of the likely treatments and outcomes, it is however true that every person is different, every pain is different, every circumstance for assessment and treatment is different; dynamic nature of pain experience requiring ongoing reassessment; ?? say
  - Physical pain is embedded in context of psychological, social, emotional & spiritual elements of 'being'
- Limits of any scale - in regards to accurately represent the experience of pain, distress and suffering. There is no perfect pain scale – changing 'ceiling' of 10/10 & meaning; different pain level with different staff (relationship issues)
- Overlap/combinations of pain categories - a patient may present with 1 or more categories of pain, each necessitating its own strategy [which recognizes complexity], but then requires the use of multiple strategies simultaneously
- Not all severe pain may be completely relieved - our limits, pt limits, need for new knowledge, adverse event limits, etc

## 11 Severe Pain Categories

### 1. Lack of Understanding of Scale

Symptoms	Signs	Interpretation *[filters]	Strategy *[add filters]
<ul style="list-style-type: none"> <li>● Able to locate and describe pain</li> <li>● When asked, pt rates pain as high eg. 8, 9 or even "11/10"</li> <li>● Often readily admit difficulty with or frustrated by use of scale to measure pain</li> </ul>	<ul style="list-style-type: none"> <li>● Not in obvious severe pain eg. smiles or sits easily while says score is 10/10</li> <li>● Medical crisis not present</li> <li>● Delirium or dementia not present</li> </ul>	<ul style="list-style-type: none"> <li>● Pain is present but not at the level indicated by score</li> <li>● Inaccuracy of rating is due to difficulty with one or more factors such as               <ul style="list-style-type: none"> <li>☞ Fatigue or frailty</li> <li>☞ Limited education</li> <li>☞ Hard of hearing</li> <li>☞ Language or culture</li> <li>☞ Developmental stage or disability</li> </ul> </li> <li>● Inadequate understanding or explanation by staff</li> </ul>	<ul style="list-style-type: none"> <li>● Education for staff in use &amp; teaching of scales</li> <li>● Explanation &amp; reinforcement with patient and family</li> <li>● Improve conditions for accuracy               <ul style="list-style-type: none"> <li>☞ Increase alertness if fatigued by allow/assist to waken</li> <li>☞ Appropriate audible improvements</li> </ul> </li> <li>● Use another pain assessment tool or approach if cannot understand</li> <li>● Seek family or other input to clarify pain severity</li> <li>● Goal is to have pain score accurately reflect actual pain level experienced by patient and then treat pain accordingly</li> </ul>

### 2. Sudden Medical Crisis

Symptoms	Signs	Interpretation	Strategy *[add filters]
<ul style="list-style-type: none"> <li>● Sudden onset of frequent yelling, screaming related to pain</li> <li>● May rate pain as "11/10"</li> <li>● Able to locate pain</li> <li>● Can describe pain but may limit 'conversation' due to severity</li> <li>● Some pain may or may not have been present prior to this episode</li> <li>● May have other symptoms perhaps associated with this crisis</li> </ul>	<ul style="list-style-type: none"> <li>● Extreme pain clearly evident as indicated by:               <ul style="list-style-type: none"> <li>☞ Physical signs - acute, rigid abdomen; visible fracture; bleeding; etc</li> <li>☞ Behavioral - either very restless and agitated or lying rigidly; acute pain facies; apprehension</li> <li>☞ Autonomic signs - shock; diaphoresis; tachycardia; etc</li> </ul> </li> <li>● If imminently dying, may become confused and disoriented, followed by drowsiness and coma</li> </ul>	<ul style="list-style-type: none"> <li>● Full or 'complete' medical assessment usually not possible due to urgency or ability of pt to describe</li> <li>● Possible or probable terminal event</li> <li>● This is a sudden and serious change, either expected or unexpected</li> <li>● Demands immediate response and assessment:               <ul style="list-style-type: none"> <li>☞ To determine if urgent surgical or other active intervention is feasible &amp; approp.</li> <li>☞ If death is imminent</li> <li>☞ To provide immediate pain relief irregardless of above</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>● Rapidly increase or 'stack' opioid by SC/IV/SL route until pain 'breaks' then hold &amp; reassess</li> <li>● Investigate &amp; treat this crisis if feasible and appropriate</li> <li>● Other comfort measures eg. splint, position, 'hold' pt</li> <li>● Obtain other assistance as approp.</li> <li>● Involvement of family               <ul style="list-style-type: none"> <li>☞ As substitute decision-maker if necessary</li> <li>☞ Communication - Information re seriousness and implications if imminently dying</li> <li>☞ Emotional support and crisis intervention</li> </ul> </li> <li>● Add sedation if intractable &amp; dying</li> <li>● Goal is to have pain 'broken' or reduced to &lt;8/10 within one hour and good relief over several hours depending on cause &amp; further appropriate treatment</li> </ul>

### 3. Visceral Spasm or Colic

Symptoms	Signs	Interpretation	Strategy *[add filters]
<ul style="list-style-type: none"> <li>• Intense 'cramping' pain</li> <li>• Occurs in periodic 'waves'</li> <li>• Other periods of time with little or no pain</li> <li>• Able to describe quality</li> <li>• May have some difficulty in describing pain due to diffuse or referred pain pattern</li> </ul>	<ul style="list-style-type: none"> <li>• No evidence of an acute abdomen</li> <li>• Pain may be in a typical or vague, referral pattern eg. bladder spasm, renal colic, tenesmus, bowel obstruction</li> <li>• Very restless during colic</li> </ul>	<ul style="list-style-type: none"> <li>• Rarely a terminal event; if so, see section on 'sudden medical crisis'</li> <li>• May require some investigations to determine cause and appropriate treatment</li> </ul>	<ul style="list-style-type: none"> <li>• Reverse cause if possible</li> <li>• Antispasmodics</li> <li>• Opioids</li> <li>• Reassurance</li> <li>• Goal is to have current pain 'broken' or reduced to &lt;8/10 within one hour. Reduce severity and frequency of future painful episodes as pain is likely to recur, depending on etiology,s</li> </ul>

### 4. Opioid Induced Neurotoxicity

Symptoms	Signs	Interpretation	Strategy *[add filters]
<ul style="list-style-type: none"> <li>• May or may not say they are confused, have difficulty thinking, feeling drowsy, etc</li> <li>• When asked, pt rates pain as high at one moment, but deny having pain at another</li> <li>• Often difficulty locating or describing pain</li> <li>• Rapid recent dose escalation common over past few weeks &amp; days, with transient or no pain relief obtained</li> </ul>	<ul style="list-style-type: none"> <li>• Delirium present mild, moderate or severe and often progressive</li> <li>• Agitation, restlessness</li> <li>• Myoclonus usual</li> <li>• May not be in obvious extreme pain</li> <li>• Oral intake has commonly been reduced in recent days</li> </ul>	<ul style="list-style-type: none"> <li>• Neurotoxicity due to increased metabolites from dose escalation &amp;/or decreased renal clearance</li> <li>• Pain may be due to myoclonic spasms causing or exacerbating existing pain</li> <li>• "Yelling" may be delirious in nature and misinterpreted as pain</li> <li>• If delirium is due to other etiologies, then use section # 11 strategy</li> </ul>	<ul style="list-style-type: none"> <li>• Opioid rotation +/- hydration OR Opioid reduction +/- hydration</li> <li>• Monitor and improve renal function as possible</li> <li>• Add neuroleptic low dose &amp; titrate to control delirium and stop once toxicity cleared</li> <li>• Reduce or hold other drugs which may exacerbate delirium</li> <li>• Use sedatives only if agitation worsens, situation is unsafe or pt is imminently dying</li> <li>• Goal is to have pain 'broken' or reduced to &lt;8/10 within one day and full control over several days</li> </ul>

## 5. Titration Related Pain

Symptoms	Signs	Interpretation	Strategy *[add filters]
<ul style="list-style-type: none"> <li>● Able to locate and describe pain well</li> <li>● States that pain control not working with both regular meds and BTDs</li> <li>● Often indicates that several drug switches may have been tried</li> <li>● May have difficulty with adverse effects before adequate analgesia obtained</li> <li>● May be frustrated with ability of professionals to provide pain relief</li> <li>● May not have taken meds as directed</li> <li>● No recent reduction in oral intake</li> </ul>	<ul style="list-style-type: none"> <li>● No evidence of acute medical crisis</li> <li>● Either pain location &amp; quality unchanged from previous complaints or possibly a new site of pain</li> <li>● Delirium not present</li> <li>● No myoclonus</li> </ul>	<ul style="list-style-type: none"> <li>● Inadequate control [possibly never controlled] &amp; now escalating</li> <li>● May represent tolerance to current dose of analgesic or opioid</li> <li>● Inadequate equianalgesic dose on opioid rotation or route change; drug error</li> <li>● Adverse effects may be limiting compliance</li> <li>● May be 'pseudo-addiction'</li> <li>● Some 'total pain' may be present but proportionately driven more by physical cause</li> <li>● Assess 'new' pain if a factor</li> </ul>	<ul style="list-style-type: none"> <li>● Bring current pain under control               <ul style="list-style-type: none"> <li>▫ Titrate analgesic upwards on regular basis with BTDs</li> <li>▫ Use short-acting opioids only until pain is in control</li> <li>▫ Consider opioid rotation if pain is due to intolerance, side effects or ineffectiveness [eg. Codeine ceiling]</li> <li>▫ Use adjuvant treatments and drugs as appropriate</li> </ul> </li> <li>● Attention to reduction of adverse drug effects</li> <li>● If a 'new' pain is identified, then appropriate investigation &amp; treatment</li> <li>● Education and support of pt, family, professionals in titration techniques and pain control</li> <li>● Debunking 'myths' &amp; provide education on effective pain control</li> <li>● Goal is to gain effective pain relief via better titration over several days and prevent future titration pain by education</li> </ul>

## 6. Incident Pain

Symptoms	Signs	Interpretation	Strategy *[add filters]
<ul style="list-style-type: none"> <li>● Intermittent severe pain related to one or more activities or procedures</li> <li>● Pain subsides shortly after action</li> <li>● Probably comfortable except during precipitating physical factor</li> <li>● Often pain is recurrent and predictable</li> <li>● Patient is usually fearful of activity or precipitating event</li> <li>● Can locate and describe pain accurately</li> </ul>	<ul style="list-style-type: none"> <li>● Severe pain directly related to one or more specific actions               <ul style="list-style-type: none"> <li>▫ Patient may become rigid, tense, resistive or yell out during incident</li> </ul> </li> <li>● No evidence of acute medical crisis</li> <li>● Delirium not present (unless compounding factor) although pt may be very agitated and restless during pain episode</li> </ul>	<ul style="list-style-type: none"> <li>● Type and quality of pain is specific to the actual etiology eg. bone pain with movement or position change; bowel care; dressing change</li> <li>● True incident pain is predictable, both to onset and duration. It is a subset of breakthrough pain (BTP) but requiring a different approach</li> </ul>	<ul style="list-style-type: none"> <li>● Preemptive use of short or ultra-short acting opioid ie. once incident pain is identified, then focus on use in prevention</li> <li>● Modify action or procedure if possible to reduce pain intensity</li> <li>● Additional adjuvant supports such as distraction, hypnosis, imagery, music</li> <li>● Use short-acting sedation with analgesic if necessary</li> <li>● Goal is to ensure baseline opioids are sufficient to cover rest pain and to reduce severity level of incident pain to mild or no pain over next several 'incidents'</li> </ul>

## 7. Neuropathic Pain

<b>Symptoms</b>	<b>Signs</b>	<b>Interpretation</b>	<b>Strategy *[add filters]</b>
<ul style="list-style-type: none"> <li>● Can locate and describe pain accurately</li> <li>● Pt may have constant, burning pain and/or sudden, severe 'shooting' or electrical' pains</li> <li>● May also describe pain as "spreading"</li> <li>● May describe some things which trigger the pain and normally wouldn't [eg. clothes touching the skin]</li> </ul>	<ul style="list-style-type: none"> <li>● Evidence of sensory nerve [dysesthesia] &amp; possibly motor damage</li> <li>● Evidence of allodynia, hyperpathia or hyperalgesia</li> <li>● May be in a dermatomal pattern</li> <li>● Delirium not present</li> </ul>	<ul style="list-style-type: none"> <li>● Spontaneous lancinating pain, allodynia or hyperalgesia</li> <li>● When 'new' or in addition to nociceptive pain, patient may describe as extreme during paroxysmal activity</li> <li>● Distinguish from incident pain which is usually nociceptive in nature</li> <li>● Some 'total pain' is likely present but proportionately driven more by physical cause</li> </ul>	<ul style="list-style-type: none"> <li>● Drugs - eg. anticonvulsant, steroids, antidepressants, opioids</li> <li>● Modify disease or cause if possible eg. radiation for cauda equina syndrome, etc</li> <li>● Adjuvant measures to reduce 'trigger' events eg. bed sheet splints, avoid hot/cold, etc</li> <li>● Goal is to reduce severe peak pain episodes over several days, and full or acceptable pain relief over several weeks</li> </ul>

## 8. Total Pain

<b>Symptoms</b>	<b>Signs</b>	<b>Interpretation</b>	<b>Strategy *[add filters]</b>
<ul style="list-style-type: none"> <li>● Some physical pain is usually present but often over laden with emotional tones such as horrible, dreadful, unbearable</li> <li>● Progressive anxiety and/or depression along with feelings of helplessness, dependence, anger, fear, fatigue</li> <li>● Concurrent multiple negative life experiences</li> <li>● May include feeling like a burden to family as well as a deep sense of overwhelming loss</li> <li>● 'Can't you give me something to end this'?</li> </ul>	<ul style="list-style-type: none"> <li>● Not in obvious extreme pain; may display chronic pain facies instead</li> <li>● Evidence of psychological, social, emotional or spiritual distress</li> <li>● Behaviour may appear confused or irrational (not delirium)</li> <li>● Primary relationships may appear strained or conflicted</li> <li>● Coping skills often depleted</li> <li>● "Internal" vs "external" sources of pain</li> </ul>	<ul style="list-style-type: none"> <li>● Physical pain is often the trigger or focus for other sources of expressed pain</li> <li>● Some physical pain is present but proportionately driven more by psychosocial issues</li> <li>● "Suffering" predominates "pain"</li> <li>● Coping skills are exhausted</li> <li>● May involve or be complicated by psychiatric disorder eg. clinical depression, anxiety disorder, etc</li> <li>● Health care system deficiencies may be contributing factor</li> </ul>	<ul style="list-style-type: none"> <li>● Improve physical pain control and assess effect on reported pain &amp; temperament</li> <li>● Perform thorough psychosocial assessment in all domains</li> <li>● Utilize appropriate screening tools for depression, grief, coping, etc</li> <li>● Assess &amp; treat/refer if psychiatric or personality disorder</li> <li>● LISTEN for the meaning of the pain or suffering (utilise effective communication skills)</li> <li>● Provide emotional, intellectual, spiritual support as needed</li> <li>● Support coping skill development, problem solving, and access to resources</li> <li>● Utilize a multidisciplinary approach</li> <li>● Advocacy for improved health systems &amp; communication</li> <li>● Attention to self-awareness, motivation, actions in working with someone in pain</li> <li>● Goal is to gain effective physical pain relief over several days and to work with/through total pain             <ul style="list-style-type: none"> <li>⊕ Consider palliative sedation if dying</li> </ul> </li> </ul>

## 9. Plea for Relief From Physical Pain

Symptoms	Signs	Interpretation	Strategy *[add filters]
<ul style="list-style-type: none"> <li>• Very frustrated, angry or suspicious from perceived prior lack of attention to pain relief</li> <li>• May rate pain at 8, 9 or even "11/10"</li> <li>• Able to locate &amp; describe pain accurately</li> <li>• Frequent urgent requests for increased doses due to fear or lack of response by prior staff</li> <li>• Often say prior staff not pay attention to pain, etc, etc</li> </ul>	<ul style="list-style-type: none"> <li>• No evidence of acute medical crisis</li> <li>• Initially may appear as if in severe pain</li> <li>• Not delirious</li> <li>• Behaviors resolve when pain is effectively treated or trust is gained</li> </ul>	<ul style="list-style-type: none"> <li>• Understandable but misleading behavior, likely due to inadequate recognition of pain by previous professionals</li> <li>• Not drug addiction</li> <li>• Distinguish among 'plea for pain relief' vs pseudo-addiction vs 'total pain'</li> <li>• Some aspects of 'total pain' are likely present, triggered by unrelieved physical pain</li> <li>• Exaggeration, conscious or not, in order to obtain attention &amp; good pain relief eg. actual pain is 3/10 but pt tells you 10/10</li> </ul>	<ul style="list-style-type: none"> <li>• Rule out addiction</li> <li>• Demonstrate [not just reassure] close attention to pain assessment and steps to control</li> <li>• Determine the accurate pain level</li> <li>• Treat physical pain accordingly</li> <li>• Education of professionals may be required in relation to good symptom assessment &amp; control</li> <li>• Involve interdisciplinary team in 'support' issues and re-building confidence; ensure coordination and consistency</li> <li>• Goal is to gain effective physical pain relief over several days and increasing level of trust and relationship with health care providers such that total pain is reduced</li> </ul>

## 10. Drug-seeking addictive behavior

Symptoms	Signs	Interpretation	Strategy *[add filters]
<ul style="list-style-type: none"> <li>• Typical drug seeking patterns suggestive of addiction eg. 'lost' drug prescription, "pills fell down toilet," seek from multiple MDs, "only IM or IV meds work," etc</li> <li>• Describes pain in 'severe' terms and often with negative experiences with the medical system</li> </ul>	<ul style="list-style-type: none"> <li>• Not in obvious extreme pain</li> <li>• No evidence of acute medical crisis</li> <li>• Past &amp;/or current drug addiction usually evident</li> <li>• Not delirious [but may be agitated if in withdrawal]</li> <li>• Behaviors do not resolve when known physical signs of pain are not present or have disappeared with good pain assessment and treatment</li> </ul>	<ul style="list-style-type: none"> <li>• Pt may still have legitimate pain and analgesics should be provided but with clear 'contract' controls</li> <li>• Fully effective and appropriate pain relief may not be possible depending on degree of patient adherence to treatment contract and follow-up</li> <li>• Keep 'antennas' up for potential violent behavior</li> </ul>	<ul style="list-style-type: none"> <li>• Treat physical pain just as appropriately for other clientele but with recognized 'cautions' in abuse situations eg. limit amounts, require 'contract'</li> <li>• CAGE assessment</li> <li>• Right of addicted pts to receive appropriate analgesics to provide adequate pain relief despite active current addiction</li> <li>• Provide emotional and other practical supports to assist in comfort as possible and acceptable to patient</li> <li>• Addiction counselling recommended if appropriate</li> <li>• Interdisciplinary team necessary</li> <li>• Goal is to rule out other severe pain factors, and then to contract for pain reduction over several weeks</li> </ul>

## 11. Dementia or Delirium

### Symptoms

- Pain usually cannot be well described nor located due to attention span, etc
- May or may not answer when asked about pain
- May be change in usual behavior pattern
- Staff or family or pt indicated presence of some pain

### Signs

- May "yell out" when moved or touched
- No evidence of acute medical crisis
- Pt usually unable to quantify pain but may be able to indicate presence of pain

### Interpretation

- Pt may not in fact be in pain, but says 'yes' if asked - not *able* to understand [different than *lack* of understanding]
- Multiple causes for either dementia or delirium require appropriate assessment and treatment
- A recent change in behaviour in dementia may indicate new or increased pain

### Strategy \*[add filters]

- If either case
  - ☞ Assess and treat known physical pain
  - ☞ Need to look at non-verbal assessments
  - ☞ Assess reliability of reported pain level
  - ☞ Use other more appropriate scales such as non-verbal
- If dementia:
  - ☞ Do .....
- If delirium
  - ☞ Do .....
- Goal is to rule out other severe pain factors listed here, to reduce physical pain accordingly if present