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**Expressing the Immeasurable:  
A Methodology for Developing a Visualization Tool for  
Patients' Assessments of Pain**

**Abstract**

The interdisciplinary field of pain medicine increasingly acknowledges the subjective aspects of chronic pain, and the difficulty for patients to adequately describe it. Although the field has developed rudimentary tools for accounting for subjective aspects of chronic pain that have gained widespread acceptance, more tools are increasingly needed, especially as medicine tends toward more patient-centered approaches. The project described is in preliminary, conceptual development. It is a visualization tool that accounts for important, subjective aspects of pain: type, intensity, duration, and when it is possible to do so, location. The nature of communicating difficult, highly subjective experiences by patients and the ability of physicians to interpret them demand a new methodological approach, as outlined.

**Background**

Chronic pain -- defined as prolonged pain lasting from one month to years -- affects more than 57 million people in North America alone, and accounts for the majority of all reasons for disablement [5]. As centers for the relatively new, multidisciplinary field of pain medicine emerge in North America and Europe, the wider practice of traditional Western medicine is simultaneously emphasizing a new orientation toward so-called "patient-centered" medical care.

Pain, and especially chronic pain, is notably a difficult problem for physicians and patients alike. As Elaine Scarry [7] points out, pain often renders a sufferer "without language." That is, pain is an inner experience, and others cannot truly observe its progress or share in its suffering. Further, because chronic pain is a highly subjective experience that is deeply influenced by psychological and cultural factors [1], it resists strictly empirical medical approaches. Thus, patients have no means to establish its validity as an "objective" part of the world for physicians or others. Often, pervasive distrust leads to undertreatment [3] and undermining of family and work relationships [2]. For physicians, chronic pain challenges Western medicine's underlying systems of thought that assume clean distinctions between mind and body. This is only recently acknowledged by medical research and widely accepted by physicians. For example, recent advances in medical research have demonstrated that "purely" psychological pain is not without physical manifestations, from brain activity to blood chemistry. In addition, psychopharmaceuticals have surprisingly revolutionized the

treatment of pain in ways that are not fully understood, since they directly affect the nervous system – that is, a major pathway of pain.

It may be generally observed that physicians primarily rely on empirically-based medical tests, and only tangentially take into documented account a patient's subjective assessment. There are few established methods for systematically accounting for these subjective aspects. However, the growing specialty of pain medicine has led in the development of specific methods, some of which have spread to wider medical arenas. For example, two of the standard assessments [4] are a ranking of the severity of pain and a description of the character of pain. The first is an assessment of the severity of pain in the form of a ranking from 1 to 10, tied to simple facial icons specifically developed for children. The success of this measure and the growing importance of a patient's self-assessment in the wider practice of medicine has resulted in recent legislation that requires all U.S. hospitals to use this measure as a "fifth vital sign." The second tool is a lexicon that is consistently employed to describe the character or kind of pain sensation, such as burning, stabbing, throbbing, and so forth.

#### **Expressing the Immeasurable: A Visualization Tool for Patients' Assessments of Pain**

As useful as these two primary tools of subjective self-assessment of pain may be, they are still extremely limited. The visualization tool proposed here is intended to enable patients to express more aspects of their pain, such as type, intensity, duration, and location (when it is possible to do so) by means of visual annotation. The goal of this tool is twofold: to augment a patients' expression of pain (in direct relation to anatomy where possible), and to provide what is often lost in a patient's usually long pursuit of treatment for chronic pain -- a longitudinal record. While certain constants will be identified, such as adherence to the lexicon for the character of pain, the proposed methodology seeks to identify and encourage a patient's highly subjective expression of pain.

#### **Methodology**

In general terms, phenomenology is the study of the development of human consciousness and self-awareness. As a qualitative method, it strongly resonates with the methodological approaches of contextual computing, and is employed here for its ability to take into account subjective aspects of patients' experience, and its assumption that mind and body are not separable [6]. The differences between a phenomenological and ethnographic approach will be more fully explicated in the workshop.

#### **Methodology: Phase One: Type, Intensity, Duration, Location**

Patients currently have three standard methods to express their pain to physicians: enumerating their current experience of pain on a 1 to 10 scale; answering questions during physical examination; and filling in a textual questionnaire, usually completed upon intake (or first visit) only. The first phase of this research is comprised of open-ended interviews akin to the so-called "expressive ethnography" methods. Patients will be presented with a range of three visualization tools that will allow them to describe the type, intensity, duration, and where possible, the location(s) of their pain. While these three possible visualization tools adhere to the existing lexicon of pain medicine, they range from "objective" anatomical visualizations to highly expressive, artistic renderings. The approach here parallels that taken by other researchers who use the work of artists, such as psychologist Paul Ekman's use of Bill Viola's work to study facial expressions.[9]

The results of this phase will be shared with a focus group comprised of the interdisciplinary pain medicine teams in order to determine the viability of multiple aspects of each visualization tool. The anesthesiologists (usually the primary pain physicians) and psychologists in particular express an interest in artistic and open-ended expressions, because they see in them similar potentials that children's drawings have in abuse cases; that is, these expressions could offer useful insight into a patient's state of mind/body, and could be a potentially useful tool for helping patients to express states that are otherwise difficult to articulate by other means.

#### **Methodology: Phase Two: A Longitudinal Record**

Initial research, along with discussions with physicians at pain centers at Emory University and the University of Washington, have revealed a primary problem experienced by most patients who suffer from chronic pain: the search for a cure or alleviation necessitates visits to several or many physicians over time. Patient records are not often transferred, physicians in various specialties use differing assessment tools, and most importantly, these records are not assembled into a cohesive whole except in centers for pain medicine. In addition, chronic pain patients often suffer from years of pain, but no longitudinal assessment tools exist that enable them to keep track of the history of their pain, or to express its course to multiple physicians. This phase of the study focuses on developing a prototype for a visualization tool that depicts a patient's pain over time. In this phase of the study, focus groups comprised of both patients and physicians from Emory University Hospital will participate together, rather than as the separate groups as described in phase one.

#### **Conclusion**

The two phases of research will result in the development of two visualization tools that will augment a patients' expression of pain in terms of the type, intensity, duration, and where possible, the location(s) of their pain; and will provide a portable historical (or longitudinal) record. While the lexicon of pain medicine will be adhered to, the emphasis will be on subjective expression of pain in ways that both patients and physicians find useful. Pending human subjects approval, the tools will be used and evaluated by both patients and physicians at Emory Hospital's Center for Pain Medicine over the course of one year. Though these two tools will provide highly subjective expressions of a patient's experience of pain, the methodology suggested here is particularly well suited to account for experience that typifies pain — that is, inextricable physical and psychological aspects. Further, pain medicine leads in certain aspects of the field of medicine, from growing patient-centered approaches to acceptance of the important roles of how mind and body interact. Thus, pain medicine is more likely than other fields in medicine to value and accept the visualization tools that help patients express pain as outlined here. Finally, pain, and chronic pain in particular, affects millions, is difficult to treat, and is notoriously difficult to express and describe. It is hoped that tools such as these will offer patients a useful, long term way to express, articulate, and keep track of their pain for ongoing treatment.

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[3] Fishman, S., Teichera, D. *Challenges and choices in drug therapy for chronic pain*. Cleveland Journal of Medicine, vol. 70, no.2, Feb. 2003.

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[6] Roy, J. "Saving Intentional Phenomena: Intentionality, Representation, and Symbol" in Petitot, J., ed., *Naturalizing Phenomenology: Issues in Contemporary Phenomenology and Cognitive Science*, Palo Alto, Stanford University Press,

[7] Scarry, E. *The Body in Pain: The Making and Unmaking of the World*, Cambridge, Oxford University Press, 1987.

[9] In a recent article, Paul Ekman of the University of California San Francisco used Bill Viola's *The Passions* to illustrate his study of facial expressions. *Smithsonian magazine* January 2004.