

Unrelieved Pain: An Ethical and Epistemological Analysis of Distrust in Patients

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La douleur non soulagée est un problème clinique grave auquel la bioéthique a accordé peu d'attention. Les auteurs de cet article affirment qu'elle est due au scepticisme à l'égard des patients, qui met en évidence un manquement tant éthique qu'épistémologique de la part des infirmières et infirmiers de même que des médecins. Ils proposent une analyse bâtie sur des concepts issus de précédents travaux portant sur l'articulation de la confiance en matière de soins infirmiers et débattent, en particulier, du manque de confiance des cliniciens dans l'expérience subjective des patients, de leur méfiance à l'égard de ceux qui appartiennent à des groupes marginalisés et relativement peu puissants ainsi que de leur refus de croire à la douleur et à la souffrance des patients ou de se laisser atteindre par celles-ci. Des croyances et des valeurs profondément ancrées dans notre société influencent au quotidien les décisions prises pour soulager la douleur. Les auteurs de cet article abordent la nécessité d'en prendre conscience et d'en faire l'examen critique.

Unrelieved pain is a serious clinical problem that has received little attention in bioethics. This paper contends that unrelieved pain is the result of distrust in patients that reveals both an ethical and epistemological failure on behalf of nurses and physicians. The analysis is conceptually framed in previous work on the articulation of trust in nursing. Specifically, an argument is made that clinicians do not trust patients' subjective experiences, distrust patients from marginalized and relatively less powerful groups, and resist entrusting themselves or becoming vulnerable to patients' pain and suffering. The authors discuss the need for awareness and critical examination of deeply entrenched societal beliefs and values that influence everyday decision-making in pain management.

Many patients experience moderate to severe unrelieved pain despite advances in treatment options. Inadequate pain relief as a result of both the under-prescribing and under-administration of analgesics has been documented repeatedly for almost 30 years, from Marks and Sachar's (1973) seminal work to current research (Watt-Watson, Garfinkel, Gallop, Stevens, & Streiner, 2000). Analgesia often is not prescribed or administered in spite of patients' reports of pain (Close, 1990; Donovan,

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Dillon, & McGuire, 1987; Marks & Sachar; Watt-Watson & Graydon, 1995; Watt-Watson et al., 2000). Surprisingly little attention has been given in the bioethics literature to the phenomenon of unrelieved pain. Exceptions include work by Rich (1997, 2000) and Hunter (2000), who frame this issue as the failure of clinicians to fulfil their moral duty to relieve suffering, and Greipp (1992), who has developed an ethical model for the under-medication of pain based on the codes of ethics of the International Council of Nurses (1977) and the American Nurses Association (1985). In this paper, we further this work by arguing that unrelieved pain is at least partly a consequence of a lack of trust in patients that reflects both an ethical and an epistemological failure on the part of clinicians. In the words of Scarry (1985), "To have pain is to have certainty; to hear about pain is to have doubt" (p. 13).

Theoretically, this paper is located within Peter and Morgan's (2001) and Peter's (2002) articulation of trust as a normative and epistemological concept or phenomenon in nursing. This work draws extensively on Baier's (1985, 1986, 1994) use of the notion of trust in feminist ethics. First we delineate various meanings of trust, highlighting the significance of reciprocal trust. Then we illustrate that unrelieved pain is associated with several interrelated aspects of trust involving clinicians — namely, their failure to trust in patients' subjective experiences, their distrust in patients from marginalized and relatively less powerful groups, and their reluctance to entrust themselves, or become vulnerable, to patients' suffering. Finally we put forth some suggestions that reflect the need for awareness and critical examination of deeply entrenched societal beliefs and values that influence everyday decision-making in pain management. To simplify this very complex issue, we limit the scope of the paper to unrelieved pain in adult patients who are mentally competent and not drug addicted. In addition, because poor pain management is a problem common to medicine and nursing, we generally refer to physicians and nurses collectively as clinicians.

Trust and Reciprocal Trust: Distinguishing the Meanings

Trust has been examined extensively as a concept or phenomenon in nursing (Hupcey, Penrod, Morse, & Mitcham, 2001; Johns, 1996; Meize-Grochowski, 1984; Morse, 1991; Thorne & Robinson, 1988), medicine (Illingworth, 2002; Mechanic & Meyer, 2000; Pearson & Raeke, 2000; Thom & Campbell, 1997), and other health disciplines (Semmes, 1991; Thorstensen, 2000). Much of this scholarship has focused on the development of trust in the clinician. Other work has explored the notion of reciprocal or bilateral trust, in which the importance of clinician trust in

the patient is highlighted (Arnason, 1994; Katz, 1984; Lynn-McHale & Deatruck, 2000; Nelson, 1996; Thom & Campbell; Thorstensen; Thorne & Robinson; Wilson, Morse, & Penrod, 1998). Ultimately, trust in the patient is of ethical significance because it demonstrates a sharing of power and respect for the patient's knowledge and virtue. Such trust can also foster the development of clinician-patient relationships — an aspect of practice that has been described as ethically fundamental to both nursing and medicine (Bishop & Scudder, 1999; Pellegrino, 1995).

The notion of trust has been described as lacking in conceptual clarity (Hupcey et al., 2001). To clarify the meaning of trust, particularly reciprocal trust, or clinician trust in the patient, we delineate four inter-related types of trust.

The first type of trust emphasizes the act of trusting. The act of trusting entails relying on others to be dutiful, caring, and good, resulting in the dependency and vulnerability of the truster. The vulnerability of the truster is the result of the trustee's power to inflict harm on the truster (Baier, 1985, 1986, 1994). Baier (1986) states that "trust alters power positions" (p. 240), referring to the loss of power experienced by the truster and the gain in power experienced by the trustee when a relationship of trust is initiated. She also explains that trust is not necessarily good, as one can be exploited or harmed while trusting another. Acknowledging the truster's vulnerability to harm brings to light the need to morally evaluate relationships of trust (Peter & Morgan, 2001).

Entrusting oneself to patients could entail different actions. It could mean trusting patients not to harm us either physically or emotionally. It could, however, also involve making oneself vulnerable to them in some way — perhaps to rely on a patient to carry out a treatment as directed in one's absence. In this paper we will develop the idea of resistance, on the part of clinicians, to give themselves over — or to entrust themselves — to the pain and suffering of their patients. In this form of entrustment, the clinician's surrendering to the patient's experience entails a diminishing of personal control and susceptibility to the "infectiousness" of pain and its impact.

The second type of trust implies a judgement whereby persons are evaluated in terms of the goodness of their will or moral character. Character traits associated with trustworthiness include discretion, patience, honesty, reliability, tact, and resilience (Baier, 1994). The health literature on trust places much emphasis on honesty (Bok, 1978; Morse 1991; Teasdale & Kent, 1995; Thom & Campbell, 1997). In bioethics, honesty, or veracity, is often held to be a central obligation or virtue (Beauchamp & Childress, 2001; Yeo & Mitchell, 1996). Honesty is an

essential dimension in the “network of trust relationships.” Without honesty, we would not be able to rely on information provided by others or on the sincerity of personal interactions (Peter & Morgan, 2001). As Bok states: “Trust in some degree of veracity functions as a foundation of relations among human beings; when this trust shatters or wears away, institutions collapse” (p. 31). In this paper we will show that a belief in patients’ trustworthiness, particularly their honesty, is fundamental to the clinician’s evaluation of their reported pain.

The third type of trust is epistemic in nature. It can entail the evaluation of competence, whereby individuals are trusted or distrusted on the basis of the knowledge and specific competencies they do or do not possess (Baier, 1986). This type of trust is commonplace in terms of ascertaining a clinician’s competence. Empirical research indicates that clinician competence is necessary for the development of patient trust (Mechanic & Meyer, 2000; Semmes, 1991; Thom & Campbell, 1997). Competence is critical in professions like nursing and medicine where individuals are trusted to provide a service that requires a broad range of knowledge and skills. Nursing and medical knowledge itself is subject to much scrutiny as to its soundness or trustworthiness, particularly since the advent of evidence-based practice (Peter, 2002).

Epistemic trust is also central to clinicians’ trust in their patients. Arnason (1994) and Katz (1984) focus on mutual trust and cooperation between patient and clinician with respect to decision-making. They argue that cooperation is possible only when both parties engage in authentic dialogue. In order to preserve the patient’s autonomy, the clinician must honour the patient’s values. According to Bergum (1994), each person gives unique meaning to his or her health concerns, and thus the clinician must work with the patient to develop mutual understanding: “The kind of knowledge needed for ethical care must be constructed in the relationship between professional and patient, who strive together to understand what meaning the disease has within the experience of the individual patient” (p. 72). The salient words are *together*, *mutual*, and *constructed*. Neither perspective is privileged. The two parties — patient and clinician — work together to develop a shared knowledge and understanding. The participation of both parties is essential.

Similarly, Katz (1984), Nelson (1996), Peter (2002), and Thorstensen (2000) stress the importance of a clinician’s trust in the patient’s judgement, knowledge, and experience. This kind of trust encourages power-sharing and helps to diminish the epistemic privilege of health professionals. Katz discusses the often unacknowledged vulnerability of

clinicians: "Physicians first must learn to trust themselves to face up to and acknowledge the tragic limitations of their own professional knowledge" (p. 102). The empirical findings of Semmes (1991) and Thorne and Robinson (1988) also support the role of reciprocal trust in facilitating mutually beneficial clinician-patient relationships. Their findings indicate that many patients have developed an expertise in managing their health problems that merits respect.

The fourth type of trust is that described by Baier (1986), who refers to a "network of trust" and "climates of trust" (p. 258), thereby situating intimate and dyadic relationships of trust within a broader, community context. Peter and Morgan (2001) develop this idea further, exploring its relevance for nursing ethics. They argue that it is important to recognize that the care nurses offer is possible only because they practise within a broader system, or network of trust, that provides them with the means — technological, epistemological, and so on — to provide this care. Nurses and other clinicians work within elaborate health-care systems with multiple individuals, groups, and organizations. This network of relationships includes other professional groups, governments, unions, schools, granting agencies, businesses, professional regulatory bodies, hospitals, and community agencies. Nurses, in turn, participate in the network of trust by providing assistance, knowledge, respect, guidance, and psychological and physical security. Ultimately, the network can act as either a facilitator of or a barrier to care, depending on the trustworthiness of the system.

Situating dyadic relationships of trust within a network also fosters an appreciation for the political context in which clinicians work. Power imbalances, financial constraints, and organizational and government policies can greatly influence a clinician's ability to establish trusting relationships with patients. Cultural beliefs and biases also enter into determinations of who and what can be trusted. In fact, entire groups of individuals are trusted or distrusted on the basis of societal beliefs about their characteristics.

Distrust and Unrelieved Pain

We argue in this section that distrust in patients' reports of pain manifests in three distinct ways, reflecting the complexity of and interrelationships among various notions of trust. First, clinicians are likely to trust the objective aspects of clinical knowledge more than patients' subjective experiences and self-reports, revealing an epistemic stance that lacks trust in the vagueness of the subjective. Second, distrust of patients' complaints of pain is compounded when patients belong to

marginalized or relatively less powerful groups such as women or members of visible minorities. These groups may be distrusted because they are perceived to be epistemically unreliable and/or dishonest. Third, although both of these manifestations of distrust reveal an inability on the part of clinicians to act on reports of pain, the reluctance of clinicians to entrust themselves to patients is most profoundly demonstrated in their resistance to becoming vulnerable to patients' pain and suffering. They shield themselves behind cultural misconceptions about the danger of opioids and over-estimations of their own knowledge and abilities.

Distrust in the Subjective

Pain is private, subjective, and multidimensional. Melzack and Dennis (1978) point out that noxious stimuli enter a nervous system that has already been activated by past experience, culture, anticipation, and emotions. Cognitive processes act selectively on sensory input and motivation to influence the transmission of pain. Hence the degree and quality of one's pain are determined by cultural and personal factors such as previous pain experiences, the perceived cause and consequences of pain, and one's feelings about and responses to pain (Melzack & Wall, 1965, 1996). The plasticity of the nervous system, which contributes to the individuality of the pain response, is being increasingly recognized. Pain, therefore, is a highly variable and personal experience, not merely a noxious stimulus.

No objective tests exist to validate a person's pain. In this sense, pain differs from other symptoms such as fever and dyspnea. Furthermore, patient self-reports of pain and clinician ratings differ (Camp & O'Sullivan, 1987; Grossman, Sheidler, Swedeen, Mucenski, & Piantadosi, 1991; Iafrati, 1986; Teske, Daut, & Cleeland, 1983; Zalon, 1993). Rich (1997, 2000) contends that scientific objectivity is accorded greater value than patients' subjective experiences. In the absence of a definitive test, pain can be difficult to assess. While nurses have identified "asking the patient" as the most frequent means of determining pain intensity, fewer than 50% regard it as the most influential factor in pain assessment (Ferrell, McCaffery, & Grant, 1991). Patient behaviours such as movement and verbal expression are the most frequent means of assessing pain and determining analgesic intervention. This is unfortunate, because patients frequently do not express pain or their need for help. Also, their pain may be minimal if they do not move (Watt-Watson, Stevens, Streiner, Garfinkel, & Gallop, 2001).

In addition, clinicians tend to focus on diagnosing and treating disease, not on relieving symptoms. Thus the relief of pain is of minor importance. Scarry (1985) makes this case poignantly: "Physicians do not trust (hence, hear) the human voice...they in effect perceive the voice of the patient as an 'unreliable narrator' of bodily events, a voice which must be bypassed as quickly as possible so that they can get around and behind it to the physical events themselves. But if the only external sign of the felt-experience of pain (for which there is no alteration in blood count, no shadow on the X ray, no pattern on the CAT scan) is the patient's verbal report (however itself inadequate), then to bypass the voice is to bypass the bodily event, to bypass the patient, to bypass the person in pain. Thus the reality of a patient's X-rayable cancer may be believed-in but the accompanying pain disbelieved and the pain medication underprescribed" (p. 6-7). As Kirmayer (1988) argues, the disease revealed by the tests is more real and more important than the distress of the patient.

Trust in the observable, objective, and quantifiable as opposed to the personal, subjective, and qualitative in clinical care reflects ancient biases in Western culture. Lloyd (1984) explains that binary oppositions developed in the ancient world by the Pythagoreans linger on in our ideas about reason and knowledge. The clear and determinate continue to be associated with what is superior and male, the vague and indeterminate with what is inferior and female. This insight reveals an historically constructed bias that is evident today in our evaluation of what constitutes reliable clinical and scientific knowledge. From a positivistic perspective, objective diagnostic tests, such as blood counts, provide the clearest, most determinate results possible. Therefore, trusting them seems to be most rational.

Because medicine's primary goal is to cure disease, it would be easy to claim that distrust of patient subjectivity is a problem in medicine only. Nursing places an emphasis on attending to the subjectivity of patients, as expressed in its interest in quality of life, caring, and treating the patient as a person, and its valuing of the nurse-patient relationship. Yet the inadequate assessment and under-medication of pain is a serious problem in nursing (Close, 1990; Madjar, 1999; Watt-Watson & Graydon, 1995; Watt-Watson et al., 2000).

According to Kelly (1998), nursing students and new graduates must reconcile the ideals they learn in the academy with the ideals they learn in the hospital setting. In striving to meet the demands of their work and to become valued team members, recent graduates compromise their standards of care. The nurses who participated in Kelly's

research placed more value on speed and task accomplishment than on caring interactions with patients. Kelly's findings are consistent with Fagerhaugh and Strauss's (1977) classic political perspective on institutional pain management. These authors explain that pain work is peripheral to the staff's legal and organizational responsibilities, resulting in a lack of genuine accountability for the care of patients who are in pain. Staff are accountable for medical tasks, not psychosocial ones, thus reflecting the underlying acute-care model. We hypothesize that novice nurses become re-socialized in the workplace such that their epistemological stance shifts from a focus on subjectivity to a focus on the objectivity characteristic of the medical/acute-care model, leading to a diminished response to patients' subjective experience of pain.

Distrust in the Marginalized and the Relatively Less Powerful

Researchers have found that clinicians do not believe patients when they report pain. Women, the elderly, and members of ethnic minorities are the patients most likely to be disbelieved. The reasons for the disbelief are unclear; however, we surmise that the disbelief reflects the second and third types of trust we have outlined above: patients are viewed as lacking in virtue, particularly honesty, or are deemed to be unreliable knowers.

In a recent study, Watt-Watson et al. (2001) explored this lack of trust in patient reports. Their findings suggest that some nurses have their own benchmark for the level of pain that is acceptable and, possibly, when and how pain is to be expressed. In that study, nurses administered only 47% of the average analgesic dose prescribed for patients with moderate to severe pain. In the final hierarchical regression model of the relationship between pain knowledge and analgesics administered, nurses' belief that patients overstate their pain contributed to 4% of the variance. In other studies, people with chronic non-malignant pain have reported that when others do not believe they have pain, they are blamed for their pain and/or the authenticity of their pain is challenged (Seers & Friedli, 1996; Walker, Holloway, & Sofaer, 1999).

Patients from marginalized groups are the most vulnerable. Evidence since the 1980s indicates that the pain management of these people differs from the norm. For example, it has been found that female patients receive fewer post-operative analgesics than male patients (Calderone, 1990; Faherty & Grier, 1984; McDonald, 1994), that older adult patients receive fewer analgesics than younger adult patients (Duggleby & Lander, 1994; Melzack, Abbott, Zackon, Mulder, & Davis, 1987; Winefield, Katsikitis, Hart, & Rounsefell, 1990), and that

patients from racial minorities receive less opioid analgesia post-operatively than Caucasian patients (McDonald). Bernabei et al. (1998) report similar data in a study with 13,625 cancer patients aged 65 or older living in a nursing home. Older patients, members of racial minorities, the cognitively less able, and women are the groups most likely to experience unrelieved pain and minimal or no analgesic administration. Todd, Samaroo, and Hoffman (1993) found that Hispanics with long-bone fractures were twice as likely as non-Hispanic whites to receive no pain medication in emergency departments, although Choi, Yate, Coats, Kalinda, and Paul (2000) found no racial differences in the amount of analgesia given in emergency departments.

Feminist theorists contend that certain groups, such as women, the aged, and people of colour, may be viewed by society as less trustworthy than others, both epistemically and morally (Code, 1991; Sherwin, 1998; Young, 1990). Young's analysis is especially helpful in that it acknowledges that such negative judgements may be unintentional: "Judgments of beauty or ugliness, attraction or aversion, cleverness or stupidity, competence or ineptness, and so on are made unconsciously in interactive contexts and in generalized media culture, and these judgments often mark, stereotype, devalue, or degrade some groups" (p. 133). These types of pejorative and somewhat automatic judgements may underlie clinicians' distrust in the reports of some patients.

Avoidance of Vulnerability

The avoidance of vulnerability relates directly to the first type of trust we have described — the entrusting of oneself to another. Specifically, we argue that clinicians avoid entering into patients' experiences of pain in order to protect themselves from vulnerability. Although pain may be a private experience, it is possible for one person to experience vicariously, through close intersubjectivity, the pain of another. Madjar's (1999) phenomenological study of nurses working in burn care illustrates exquisitely how nurses avoid becoming vulnerable by distancing themselves from their patients. She describes defences that nurses use to protect themselves from becoming overwhelmed by their patients' pain, such as qualifying, defining, explaining, or denying pain such that it becomes invisible or not real; nurses learn to construct pain as inevitable, temporary, sometimes beneficial, and of no great concern. Like Scarry (1985), Madjar concludes that patients in pain are ultimately distanced to the extent of being objectified. Nurses become detached

and self-focused, concentrating on their technical performance as opposed to the relief of suffering.

Similarly, Maeve (1998) explored the experiences of nurses caring for patients who were suffering and dying. They tempered their involvement with their patients by avoiding intense relationships, by separating themselves physically from their patients, and by using humour. In this way they were able to distinguish their own lives from those of their patients. These nurses acknowledged that their patients' plights might well be their own in the future, but by tempering their involvement they were able to shield themselves from the suffering of others. Maeve's work, like that of Madjar (1999), illustrates well how the avoidance of full engagement with patients can be self-protective for nurses. Regularly entrusting oneself, in an intersubjective sense, to the pain and/or suffering of another may prove ultimately to be unbearable.

The over-estimation of clinical knowledge and fear of opioids also serve to protect clinicians from vulnerability. Watt-Watson et al. (2001) found that most nurses in their study rated their pain knowledge and management competence as excellent, despite moderate knowledge scores and minimal or no recent pain-related service (the sources of their pain information are not known). Clarke et al. (1996) found that hospital orientation programs offered the least information about pain; nurses reported learning more from informal sources, such as personal experience and colleagues, than from formal education. In addition, we live in a culture that fears opioids. There are misconceptions regarding the dosages that are effective and exaggerated fears of addiction, hastening death, and legal reprisal (Madjar, 1999; Rich, 1997, 2000). These misconceptions and fears help clinicians to rationalize their lack of involvement in patients' pain and serve to protect them from the accompanying vulnerability of entrustment.

Conclusions and Recommendations

We have explored various meanings of the concept of trust in patients in order to better understand the phenomenon of unrelieved pain. The concept of trust can entail entrusting oneself to another, or entering into another's experiences, and it can connote evaluating the moral character/goodness of another. Trust can also be epistemic in nature — confidence in certain forms of knowledge and competence. It can also go beyond dyadic trust relationships to encompass a network of trust relationships (Peter & Morgan, 2001). We have examined several types of clinician distrust in patients that result in inadequate pain relief. A lack

of trust in patient subjectivity reveals an epistemic bias that privileges objectivity in a positivistic sense. Unfortunately, the outcome of this epistemological failure is a moral failure: disrespect for patients' bodily experiences and knowledge and, in the end, unnecessary pain and suffering. We have explained that patients' complaints of pain are often not believed, particularly if voiced by members of marginalized or relatively less powerful groups. We hypothesize that this distrust might have a basis in clinicians' judgements concerning patient dishonesty and ignorance. These judgements, too, demonstrate disrespect. Finally, we have described how clinicians shield themselves from patients' pain by distancing themselves in order to resist entrustment.

It would be wrong, however, to hold individual clinicians entirely accountable for these moral and epistemological failings, for such failings have deep cultural and historical roots. They originate in the broader network of trust relationships. Therefore, the focus of change must also go beyond the individual. Broader, societal awareness and reflection are needed. For example, examining the neutrality of scientific knowledge may appear to be purely academic, but this belief in neutrality has ramifications for the delivery of care. Minimally, nursing and medical educators need to be mindful of the ethical implications of wholeheartedly trusting in positivistic science. To distrust the subjective when relieving pain is, often, to disparage the most significant clinical evidence available. It is also important that future and practising clinicians address unconscious racism, ageism, and sexism. In addition, clinicians should be rewarded and held accountable for more than the acute-care needs of their patients; subjective and interpersonal needs should also be valued.

Treating this issue as a systemic one may help to underscore its pervasiveness and may be a less threatening way of confronting it than focusing on the blameworthiness of specific individuals. Research findings regarding the lack of pain relief among the marginalized and relatively less powerful provide grounds for discussion as well as evidence of the everydayness of this issue. Furthermore, clinicians need to be supported in their work such that the moral significance of their own vulnerability and suffering is acknowledged. We realize that this suggestion is highly idealistic. However, clinicians may become depleted through continual exposure to pain and suffering. Finally, we recommend that both clinicians and the public be educated. In an effort to enhance clinicians' understanding of pain theories, assessment, and appropriate management, organizations such as the US Agency for Health Care Policy and Research, the Canadian Pain Society, and the American Pain Society have published position statements and guide-

lines for optimal practice. Almost all acute and cancer pain can be relieved, and many patients with chronic non-cancer pain can also be helped (Watt-Watson, Clark, Finley, & Watson, 1999). While fears of regulatory scrutiny related to opioids are valid, admonitions against drug use do not always differentiate between illegal abuse and therapeutic use. With time, clinicians can become more knowledgeable and feel less vulnerable in prescribing and administering appropriate analgesia, particularly opioids. Patients, too, should become more knowledgeable about pain management and learn to expect more from clinicians. Rich (2000) describes patients misguidedly trusting physicians and nurses to not allow them to suffer unnecessarily. Ironically, however, patients ought to trust clinicians less.

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