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Using qualitative methods to access the pain experience

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Abstract

Qualitative methods provide us with techniques to access the pain experience of patients in ways that provide explanation for apparent contradictions and idiosyncrasies that are difficult to access. In this article, I review three such strategies and the application of qualitative research to practice: (1) the analysis of the ways participants speak about agonizing pain using narrative inquiry, (2) comparisons of childbirth pain in two cultural groups using ethnography and (3) present a qualitative theory, the *Praxis Theory of Suffering*. This theory provides a theoretical explanation for behaviours that presently confound the understanding of distress using the Distress Thermometer. An alternative approach, 'reading' patients' behavioural manifestations of distress, is recommended.

Keywords

Acute pain, chronic pain, labour pain, intractable pain, pain perception

Pain is a subjective sensation that continues to challenge researchers, clinicians and caregivers. We have known for decades that the pain experience is contextualized, often internalized and, if severe, engulfs the person. Yet clinically, when patients complain of pain, they are asked to rate it numerically on a scale from 1 to 10 before an analgesic is administered. We have quantified pain and diminished the experience to a number that may be manipulated by patients (they all know that to get 'something' (i.e. an analgesic) to answer 7 or above), yet our understanding of the pain experience, the resolution of the pain epidemic and our methods for handling pain remain primitive.

While we agree that those who are experiencing the pain best assess the intensity of the pain, yet we continue to measure pain simplistically. We ask children to identify the pain intensity by identifying with cartoon faces and adults by estimating a value from 1 to 10, which may measure intensity but not pain sensation.¹ Clearly, our 'measurement' of the pain experience only approximates the experience. Although we understand body language and physiological signs,² this knowledge is not incorporated into our formal pain assessments. We must find other ways to elicit an understanding of pain.

The major qualitative method presently used in medical research is the focus group. Yet, we know that focus group data merely give us opinions, 'comment data', that is, data that fall somewhere between our own observations and what we 'know', and those responses obtained from using a survey. Focus groups provide superficial knowledge at best; they may help to highlight issues, allow the researcher to get a feel of the research domain, obtain relevant items for a questionnaire or provide a rapid form of evaluation.³ For qualitative research to be useful in health care, we need to move beyond this level of data (and analysis) to interpretive methods. We need to move beyond the small-scale, small-sample, descriptive methods to reflective, interpretative, multidimensional approaches. We need to attend to context.⁴

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We need to attend to theory as well as to what we are doing in practice.⁵ Funding agencies must recognize the value of qualitative inquiry, fund methodological development and fund research that challenges the status quo and attends to paradigm shifts. These shifts, both methodological and theoretical, however uncomfortable and however costly in patient care time, challenge orthodox research methods. But we owe responses to these challenges to our clinicians, to the public and, most of all, to our patients.

In this short article, I review some descriptive and interpretative qualitative approaches of these ‘other ways’, research projects that qualitatively elicit understandings of pain and distress, patient pain expressions and how qualitative research fills in the gaps of our understanding of pain. The first example is using narrative inquiry, exploring ways those people who have experience agonizing pain talk about their bodies during and after the pain event.⁶

The second example uses ethnography, that is, a descriptive/interpretative method developed in anthropology, using a cultural lens.⁷ I was fascinated by the differences in the perceived painfulness of childbirth. In the case of the Fijians and the Fiji Indians, the two cultural groups shared the same healthcare system.⁸

The third example is a discussion of ‘distress’ using the Distress Thermometer, and I present an alternative theoretical explanation, a theory of suffering behaviour that accounts for the absence of expected distress in women when undergoing the diagnostic procedures for breast cancer.⁹

Each of these examples illustrates different perspectives about the expression of pain, the uniqueness of pain and the difficulties we have as caregivers assessing pain.

Narrative inquiry

Narrative inquiry elicits data by recording and analysing participant’s stories and recollections of events and uses the text as units of analysis to understand the ways people make meaning of their lives. It provides us with ‘alternative stories’,¹⁰ stories behind the one being told. In this case, I used the text to elicit linguistic signals of embodiment and disembodiment as the participants described experiences of agonizing pain. The initial data set included six participants who had experienced agonizing pain.

Linguistic signals of agonizing pain: disembodiment of the self

Look carefully at the text of an interview conducted with the first participant, a lineman who received electrical burns. His interview reads,

... *both hands and wrists* were burnt, which were the [electrical] entry sites. And ... *both feet* were burnt ... *the right side* being the worst ... *right side of both hands and feet* because – my right hand was up high – so naturally it entered *the right* the most ... whatever was left over came down and went into *the left* ... it still sustained some damage ... *the right hand* had to be removed ... And *the right leg* was burnt quite badly, and the whole outside of *the leg* was burnt down to *the bone* – you could see *bones and sinews* in there, and at the very bottom – it also exited – not on the bottom of the foot – but ... on the bottom of the leg, like right at the side of *the* foot was really burnt bad, too. (p. 669)⁶

In this case, the lineman is talking about his own body, yet using the definitive article (italicized in the text above).

Not satisfied, we now ask questions of this text: is it used to distance himself from the pain? In what circumstances does this language occur?

We note that it does not occur uniformly. Before the electric shock, the hands are his; he uses the possessive pronoun: ‘*my* right hand was up high’. We follow his story through, tracing these signals of disembodiment. We see that he speaks of his surgeries and his rehabilitation. Gradually, the personal pronouns are again used in reference to himself. He is ‘taking his body back’. Furthermore, he does not disembody himself totally, but rather relinquishes *parts* of his body. In this burn patient’s description of his intensive care unit (ICU) experience, he uses ‘I’ in reference to himself (i.e. the confusion is still *his*), but he uses indicators of detachment when speaking of his injured extremities:

But the time, the month of October was very hazy, *I* was in and out of it. As soon as *I* would get better, *one* limb would turn bad, toxic, and *I* would get confused; then they would amputate *one* more, and then *it* would clear up ... (p. 670)⁶

So far, we have only one interesting case. We proceeded by examining the other five interviews from burn victims.

Next, we develop conjectures for this disembodiment language, examining other data sets that would permit us to ‘test’ our conjectures by the presence or absence of the disembodiment language.

The conjectures tested were as follows:

1. *When individuals lose control of a body part, some disembody that part to maintain control of the self.*
2. *When individuals lose sensation in a body part, disembodiment can be a psychological strategy for ‘disengaging’ the body part from the self.*

Conjectures 1 and 2 were tested by systematically comparing burn patient transcripts with patient groups who have and have not lost sensation and control.

Table 1. Comparison of four groups to determine the characteristics of pain responses.

Conjectures	Sample/responses			
	Burn (<i>n</i> = 6)	SCI (<i>n</i> = 11)	Transplant (<i>n</i> = 8)	Myocardial infarction (<i>n</i> = 13)
Loss of control of body part?	Some loss of movement	Yes	No	No
Loss of sensation?	Some loss if prostheses is used	Yes	No	No
Need to protect the self?	Yes	Yes	Yes	Yes
Opportunity to learn from physicians?	Yes	Yes	Yes	Yes
Extreme pain?	Yes	No	No	No

SCI: spinal cord injury.

Source: adapted from Morse and Mitcham [p. 669].⁶

3. *Patients learn disembodied language from physicians.* Physicians use disembodied language, perhaps to reduce their own anxiety or that of the patient ('I am afraid we will have to amputate the leg').
4. *Disembodiment is used in life-threatening trauma, in an effort to protect the self.* If this statement were to be supported, disembodiment would occur in all people who experience a sudden and life-threatening event, and linguistic signals of disembodiment would be present at the time a patient's life is in jeopardy.
5. *Disembodiment is a strategy used to remove the body part, hence to remove the pain when the agony is overwhelming.* We suggest that by disembodied the pain, the patient also 'removes' the painful limb or organ, detaching 'it' from his or her body, and thereby removing the pain (p. 669).⁶

These six burn patient interviews were then compared with spinal cord injury patients (*n* = 11), myocardial infarction patients (*n* = 13) and heart transplant patients (*n* = 8), looking for the presence or absence of each characteristic in the way each person spoke about his or her body in their interview. The results are shown in Table 1.

Thus, in the search for the presence or absence of each characteristic in the interviews, alternative conjectures for the use of disembodied language were systematically excluded. The interpretation was advanced that the use of disembodied language by burn patients indicates a special human capacity to maintain the integrity of the self during prolonged agonizing experiences. Although the confirmability of the findings qualitatively does not constitute the same hypothesis testing used in experimental design, it does increase the certainty of results. This study thus presents a phenomenological interpretation of the body

and its experience by deepening our understanding of the experience of living through excruciating pain.

Ethnography

Ethnographic methods are used for the study of culture, using the emic perspective (i.e. the perspective from the people themselves, rather than the ethnographers). Ethnographies comprise three core strategies: unstructured interview, observations and a diary. Other methods added to this core – in this case, physiological measures and a psychological pain rating scale used at the community level – make this study a qualitatively driven mixed-methods design.

Ethnographic evaluation of the painfulness of painful conditions⁸

When doing ethnography, one 'follows one's nose', solving a puzzle – in this case, the cultural painfulness of painful conditions. Zborowski,¹¹ in a now classic study, wrote that pain expression (using back pain in four cultural groups in New York) was culturally learned and differed between cultures. My study of childbirth comparing Fijians and Fiji Indians⁸ extended Zborowski's findings by informing us that each cultural group had a 'template' of *how painful* pain conditions were, and this degree of painfulness was consistent with (1) traditional ethnographic treatments and patterns of care and (2) how these conditions were treated medically, attended to, medically managed and evaluated. This included whether the pain signals were 'real' and legitimated, or 'put on' and exaggerated pain displays, how analgesics were administered and how patients were treated. In this case, we considered a 'naughty', uncooperative patient or a 'good', quiet and cooperative patient during labour.

Using childbirth as an exemplar, I commenced the study in Fiji by conducting interviews of primiparous women in early labour – observing delivery (including

reporting pain expression during delivery and analgesics administered) and conducting postpartum interviews with nurses and the new mothers. The cultural context of childbirth was elicited with interviews with traditional birth attendants. Once I recognized the culturally embedded frameworks of childbirth normative behaviours and how these were related to the patients' pain expressions, I realized I could quantitatively measure *how painful* each group rated the pain of childbirth. Using Thurstone's paired comparison technique (described in Nunnally¹²) to elicit the painfulness of pain events in both cultures, I administered the questionnaire to newly delivered mothers, multipara who had delivered previously and males, from both the Fijian and Fiji Indian cultures, rating the perceived pain of childbirth with other painful events. The painful events common to each cultural group were broken leg, crushed thumbnail, toothache, migraine headache, heart attack, eye injury, gallstones, kidney stones and childbirth.⁸

Thus, pain expression consists of the communication of pain signals and pain behaviours (which we know from Zborowski¹¹ are culturally transmitted and vary inter-culturally) and may be misinterpreted by caregivers from a different cultural group.⁷ This study of childbirth in Fiji⁸ makes the assessment of cross-cultural pain even more complex by including *how painful one's own culture evaluates the pain* of the condition – and this also varies between cultures.

Those who practise cross-cultural care have a vast task in documenting normative illness behaviours (including pain behaviours) cross-culturally. I continued this work measuring pain estimation in various cultural groups in Western Canada¹³ and also compared the pain expectation of mothers who had home births with those who delivered in hospital.¹⁴

Applying qualitative theory to practice

Theory derived from qualitative studies can provide us with understanding of 'what is going on' for appropriate care. I have conducted a large number of qualitative studies with 'distressed' patients, including those undergoing diagnosis for breast cancer and those who were dying from cancer,⁹ and conducted qualitative synthesis of interrelated projects, a technique called *theoretical coalescence*,¹⁵ fitting these studies together, to form the *Praxis Theory of Suffering*.^{16,17}

The clinical validity of the Distress Thermometer

Recently, there has been a trend towards measuring 'distress' in cancer patients using the Distress Thermometer.¹⁸ Parallel to rating patients using the

pain scale, patients who are distressed are asked to rate their degree of distress on a scale from 1 to 10. The problem for practitioners is that the Distress Thermometer does not provide expected results.¹⁹ Some patients for whom circumstances indicate they should be distressed do not appear distressed; in fact, they appear devoid of emotion. But the fact that the Distress Thermometer does not work with all patients has not halted its implementation and acceptance into practice.

Understanding suffering behaviours

Briefly, suffering consists of two states: enduring and emotional suffering.^{16,17} When enduring, the person suppresses emotion in order to 'keep going', to cognitively suppress the fear of cancer, until able to accept the notion (or 'come to terms') that they may indeed have cancer.⁹ This state of emotional suppression is evident behaviourally. When the enduring is 'acute', sufferers walk stiffly and upright, without spontaneous movement. They do not initiate conversation and may respond in short sentences; they gaze into the distance with dry eyes. We see this not only in the medical setting; we see enduring behaviour most often with the bereaved at funerals and even with the intense concentration of adolescents at spelling bees (or spelling competitions). We see it when people are bearing intense pain; we see it with women going through the experience of diagnosis for a breast biopsy.⁹ It is when people are enduring they do not appear 'distressed', and the Distress Thermometer scores fail. This response, which research has shown to be a normal response, has been labelled 'passive coping',¹⁹ 'emotional inhibition',²⁰ 'negative',^{21,22} and even alexithymia.²³

Emotional suffering may 'break through' with the person *transitioning* from enduring;²⁴ the facial expression becomes one of sorrow. Tears fall. Behaviourally, the person crumples and talks incessantly about what has happened. When in a state of emotional suffering, the Distress Thermometer 'works'. But in this state, we can see the distress. Why do we need a score?

Discussion

The power of qualitative methods is that they enable us to get beyond the obvious, superficial layer. When used interpretatively, qualitative methods show us what is really going on. In this first example,⁶ by observing the way a person who had experienced agonizing electrical burns spoke about his burned extremities, and following his story through rehabilitation, we could see he metaphorically managed the pain within himself by psychologically disembodimenting his hands and feet. By comparing his use of language with patients who had

experienced other conditions, but not such intense pain, we could eliminate alternative explanations and accept that disembodied patterns of speech may be attributed to agonizing pain experiences.

In the second example,⁸ I used ethnographic methods at the population level to explore the behavioural manifestations of childbirth pain by comparing two cultural groups, the Fijians and the Fiji Indians. The influence of culture is profound: not only are we instructed how to express our pain and appropriate ways to behave when we are in pain, culturally we are also taught how painful something is and what condition is more painful than others.

This has profound message clinically: it influences how often someone with a certain condition may be given an analgesic and how solicitous we are towards those with conditions we consider to be very painful. Importantly, when our cultural perceptions differ from those with another 'cultural evaluation of its painfulness', cultural dissonance in care occurs. While this area of understanding pain perceptions has been investigated for more than 50 years, there is still much that is not understood.

The last study used the *Praxis Theory of Suffering*,^{16,17} and what is known about behaviours of suffering, to assess suffering clinically.⁹ The paradox of the lack of understanding about the Distress Thermometer worked, and why valid, interpretable results were not being obtained is clear when one understands suffering behaviour as two stages: enduring and emotional suffering.

From these examples, it is clear that qualitative inquiry has much to offer to the understanding of pain, both as the basis of a research programme and as a means to reveal 'what is going on'. Used interpretatively, it provides access to areas that may not be otherwise accessible using quantitative methods.

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