

Growing Pains

Rachel Chung

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Terence Cardinal Cooke and the Columbia Center for the Study of Science and Religion

There is nothing like pain. Pain, though deeply subjective and unique among individuals, is experienced by all people. Our pain can take many forms—the pain of physical injury, of loss, of boredom—the list goes on. When we are little, everything and nothing hurt. We fall and hit our head and in that moment, we are in more pain than we can ever remember, and in the next, we carry on as if it never happened. As we grow older we become burdened with the weight of memory; we hone our ability to learn from our experiences, including—especially, even—the painful ones.

Another unique trait of pain is the wide variety of methods with which we address it. Human creativity knows no bounds, but pain can drown out even the strongest inhibitions. No matter how desperate, we can only be so resourceful. As we grow old and sick and limited, so do our options for tackling our pain. In the confines of a hospital bed, any pain, however slight, can be unbearable. A stomachache that would previously have been easily curable with some Tums and the new season of *Law and Order* becomes the sole occupant of our thoughts. When we are bedridden, incontinent, and incapacitated, pain is sometimes all we have.

The Problem

The residents of Terence Cardinal Cooke face an odd catch-22. At the risk of making a generalization, it seems that those who are fully capacitated, functional, and credible rarely complain of pain to staff and generally encounter fewer conflicts. Those who are incapacitated, needy, sometimes non-communicative, wrack the halls with moans and shrieks. Or have we got it backwards? Perhaps staff subconsciously favor the patients who are less needy and, in some cases, less sick. The other patients—the “complainers”—abuse the time of the physicians and wear unnecessarily on the patience of the nurses. It is a dilemma that is most likely beyond the purview of an undergraduate summer intern. However, it is not so difficult to trace back this chicken-and-egg dilemma to the pervasive idea that pain is a behavior, rather than a symptom, of advanced illness.

A sub-acute patient once told me she was in pain.

“I stupidly refused Tylenol a few minutes ago, so now I have to wait until they offer it again to accept it,” she lamented.

She was not willing to request medication, lest she be tossed into the category of “problem patients:” the ones who ask too much too frequently. Another day, I heard the moans of a patient from three doors away.

“Please help me, I’m in so much pain,” she managed through profuse tears and gasps, “I’m meant to be turned every now and then, but they haven’t been today; I’m in so much pain.”

Her tears and wails could have been mistaken for the melodramatic stylings of an Oscar-winning actress. I looked from her hospital gown to the grimace on her face and judged that this, however histrionic, was not an act.

I gently extracted my hand from hers and flew out into the hallway. When I found the nurse covering my new patient, I put on my best impression of the kind but direct physician I hope to someday become:

“Ms. W in room XXX is in a great deal of pain. Does she have orders for as-needed pain medication?”

It was enough to convince the nurse of the apparent urgency of the situation. He turned Ms. W in her bed and as he was removing his gloves said,

“I’ll see if she has any orders for as-needed pain meds. She has to be turned every few hours, so this is a pretty regular behavior for her.”

I nodded in assent and took down some notes. It wasn’t until later, when I was mulling over the experience in my head, that I noticed what a strange choice of words “behavior” was for the pain Ms. W was experiencing. Once pain takes control of our mind, every thought we have contends with our pain. So when a patient is as desperate as Ms. W, we have in many ways failed her. We have allowed her pain to progress to the point at which it gains governance over all her other faculties. But, instead of taking it upon ourselves to rectify this error, we note that Ms. W makes “frequent complaints of pain.” Several more factors contribute to this endlessly complex phrase: Ms. W could be manipulative, delusional, addicted. Kaasalainen et al. write that one of the highest barriers to the effective management of pain in nursing homes is the reluctance of physicians to treat pain aggressively for fear of addiction or over-dosage (Kaasalainen S, 2007). The “problem patient” label

we may affix to the records of patients like Ms. W is not necessarily a dismissal or deliberate neglect of our sworn duties as caregivers—it is our resignation. We have thrown our hands in the air and surrendered to the monstrous, unimaginable pain experienced by our patients. For it is unimaginable; there is no magical number that appears on the patient’s forehead on a scale from 1-10 indicating how bad the pain is. Even if there were, it might not erase the doubt in a physician’s mind. Pain is subjective. Pain is relative. We cannot quantify pain any more than we can quantify the taste of a certain food.

Recent studies have made attempts to standardize pain assessment in nursing homes with varying success. Researchers Russel et al. actually found that an increased focus on quality of pain management was met with a decrease in overall quality of care (Russell, Madsen, Flesner, & Rantz, 2010). This is not to say that there is no utility in measuring pain. A study done by researchers de Rond et al. showed improvement in quality of care with the implementation of a Pain Monitoring Program, or PMP (de Rond ME, 2000). The attitude of caregivers was noted as a pervasive issue in several of these projects. de Rond et al. write that nurses often have “knowledge deficits and prejudices” that can influence the way pain is recognized and addressed. Sengstaken et al. found that, from their sample, 66% of communicative residents had chronic pain, but physicians failed to identify chronic pain in 34% of these patients.

These studies address pain management in the hope that there is a better way than simply “taking the resident’s word for it.” In an essay from the compilation *At the End of Life: True Stories About How We Die*, writer Eugenia Smith gives an intensely personal account of her mother’s suicide, in which she recalls that a physician once suggested that a “low pain threshold” was to blame for her mother’s agony (Smith, 2012). Maybe Ms. W suffered from the same disease—low pain tolerance. When a child is sick, some parents may argue against a continuous morphine drip to treat a persistent stomachache. It builds character and teaches the child any number of valuable life lessons. However, nursing home residents are seldom children. These residents are not looking for more lessons. They are not looking to improve their strength of character. Ms. W is not looking for a cure for her low pain tolerance. She is looking for a cure for her pain, which, however trivial to some, is colossal to her.

Smith's story and others in the book, edited by Lee Gutkind, paint a deeply emotional picture of pain at the end of life. Many of the anecdotes recount conflicts with nursing home staff, be it physicians, nursing aids, social workers, or anyone in between, in which a loved one or caregiver felt that the patient's needs were not properly considered. The simple hesitation of one physician can mean an excruciating death for a patient; a dismissal by one nursing aide can mean decades of inner turmoil for a surviving loved one.

The Details

Unlike treating pain itself, treating the problem of how we handle pain is not as easy as matching a symptom to a drug. We have to attack the problem at its source. We have to examine how we view and are affected by the pain of others. To do this, I conducted interviews with the patients in sub-acute rehabilitation: those who require long-term assistance in recovering from any out of a wide range of ailments. These patients come into TCC expecting to go home, usually within a month of admission. Their stays here are (relatively) short and intense, being shuttled back and forth between physical therapy and follow-up appointments. The sub-acute floors are understandably hectic. With one physician covering around 110 patients each, there is not a lot of time for deep, philosophical proliferation over how a patient is experiencing pain and recovery. On the other hand, for any single task to be accomplished each member of the care team must jump through a variety of administrative hoops. If Ms. W were in more pain than her current medicinal regimen could manage, her attending physician would have to see her and enter an order for more medication. The nurse would then have to update her care plan with the new information and remember to administer the new medication while also attending to the needs of 25 or so other patients.

Not only is this system hardly sustainable, but it is riddled with human error. Audits of the ways staff communicate with each other regarding pain management portray a system riddled with inconsistencies, instances where we "dropped the ball" on a particular patient. The most basic disconnect is when a caregiver fails to recognize pain in a patient. A 2005 study by Roy and Mor identifies the subjectivity of pain recognition as a key issue in treatment. The way pain is identified and measured varies widely amongst caregivers, leaving any information subject to ascertainment bias caused by discrepancies in the ways staff measure items that indicate quality of care (Roy J,

2005). These findings support my backwards hypothesis that caregivers identify pain based on the way they view patients: caregivers are more likely to identify and “believe” complaints of pain in patients whom they view as credible. Patients should be innocent until proven guilty—credible until proven incapacitated. But it is the other way around. It is too easy to fall from grace; any momentary loss of temper, any period of confusion at waking up in a new hospital surrounded by new faces can land a patient in the ever-growing pile of unreliable narrators. We justify our dismissal of these patients’ requests by labeling their pain as a behavior, as a personality flaw. It is as if to say,

“Don’t trust this patient. He’s making it up.”

The Data

To get a better sense of the specific ways in which patients experience pain management at TCC, I conducted a series of interviews with sub-acute patients. These interviews contributed to a base of purely qualitative data that allows me to view each patient as a whole person. This project is not the sterile, carefully controlled survey after which many of the preexisting studies have been modeled. I hope it not only adds color and life to dense medical records but also provides a jumping-off point for future in-depth studies. Other limitations of this project include a small sample size and possible investigator and narrator biases, which I have found to be unavoidable when dealing with something as subjective as pain.

As Sandelowski writes, “Qualitative descriptive studies have as their goal a comprehensive summary of events in the everyday terms of those events” (Sandelowski, 2000). I want to examine suffering from the perspective of the sufferer. The purpose of this project is not to provide more data expressing the ways in which our system is flawed. This project is a highly qualitative, deeply emotional window into the way we think about pain. The utility of expressing responses as percentages is limited to the basic conveyance of information—a cursory look at the surface of the population. I wrote ten questions, but I followed them loosely and asked follow up questions or omitted items based on the apparent direction of the conversation. It was important to me that the patients lead our conversations while I simply recorded their thoughts¹. As evidenced by the responses, which can be found in the Appendix, sub-acute patients are generally satisfied with the

¹ The sample of size seventeen is not meant to be representative. The purpose of the survey was to collect qualitative information only.

care they have received. Satisfaction here is contingent upon a patient's expectations being met by staff; for example, several patients regularly wait up to two hours to receive requested medication, but few expressed discontent with this standard of care. The common thread among the satisfied patients was not that they were all receiving speedy and consistent care—several of them weren't—but that they all felt that the caregivers were doing their best. They felt that the staff listened to and respected them, and they understood how much effort the nurses exert to ensure that they receive the highest possible quality of care. A brief overview of the key responses can be found below:

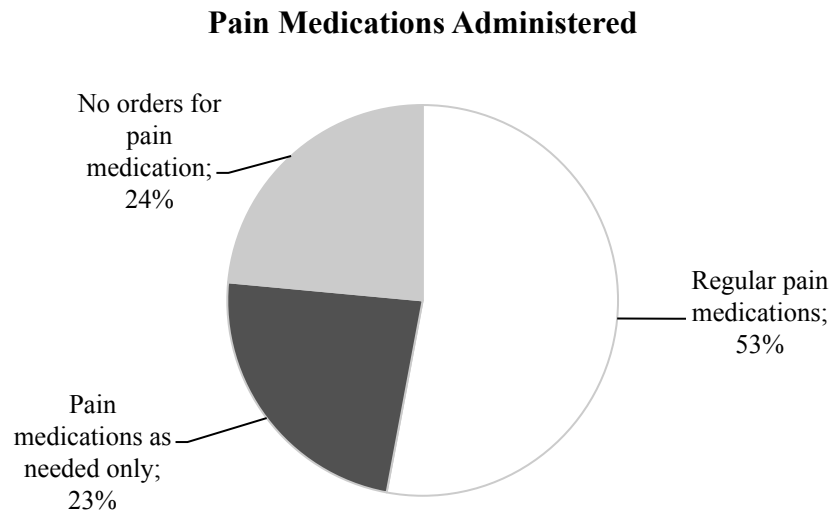


Chart 1: A breakdown by percentage of style of medication administration

17.6%

Percentage of patients who reported having to request their regular dose of pain medication more than once per week

38²

Average minutes waited by patients who request medication

82.3%³

Percentage of patients who felt that their needs were being met with regards to pain management

One patient, Ms. L, addressed the gap between patient satisfaction and staff performance. A nurse herself, Ms. L knows how much food she needs in her stomach before taking her medication.

² Time was estimated based on categories “not long,” “up to 30 minutes,” and “between 30 minutes and 2 hours” from patient responses.

³ 11.8% of patients surveyed felt that only some of their needs were being met or that their needs were being met only some of the time.

She knows what her pills look like, and she knows when she is to receive them. When I spoke to her, Ms. L had been un-medicated for twelve hours, having vomited after each attempt by staff to administer her medications. While an extreme example, it was clear that Ms. L was in a great deal of physical and mental pain. Exceptional pain is not an outlier on a box and whiskers plot. Ms. L, though demanding in the eyes of her care providers, deserves the same attention and responsiveness as every other patient. However, Ms. L's frustration was not just with her own care. She said,

"I'm not taking it personally. I'm taking it for the people that can't fight for themselves."

Ms. L felt that every request was a fight. She had to fight to receive her medication after she had eaten. She had to fight to earn the image of a credible patient in the eyes of her caregivers. In that moment, I felt her frustration. I felt her humiliation at being a skilled caregiver turned patient; I felt her shame at being suddenly dependent on people who, by an apparent lack of investment in the correctness of her care, did not respect her. When I left her, she thanked me. I could see that she felt better; her shoulders had relaxed, and she breathed more deeply. I had not given her any medication. I had neither turned her in her bed nor given her ice for her shoulder. But I gave her the benefit of the doubt. I showed her, just by listening, that I respected her. That I saw her.

"That's all anybody asks," she said, "Just to be listened to."

I wanted to see pain management in action. This proved difficult, as the pain specialist comes in once a week but flies mostly under the radar. Most of the daily pain experienced by the patients is handled by their attending physicians. I followed one of these physicians on daily wound rounds. When we were almost finished, a nurse caught the doctor in the hall.

"Dr. C, Ms. J wants to see you."

Dr. C asked me if I wanted to see Ms. J with her.

"I don't know, do I?"

"Definitely not."

I went anyway. Dr. C explained to me that Ms. J suffers from severe anxiety and chronic pain. Her pain is exacerbated, caused even, by her panic attacks. The room showed all the signs of intended permanence: paintings hung on the wall, memorabilia lining the windowsill, and blankets and trinkets from home littering the furniture and the floor. An alarmingly lifelike baby doll lay in a

heap on the bed. At a glance, the room could almost be mistaken for one in someone's lifelong home.

"I'm in so much pain, doctor," Ms. J wailed.

In response, Dr. C asked,

"Do you want me to prescribe you some more painkillers?"

So far, so good.

"I don't want any more pills, I want to know what's wrong."

One of the most common conflicts between patient and physician that I have seen stems from some misconception that, once they know "what's wrong," physicians can cure even the most serious ailment.

Ms. J's chest heaved in panic.

"No one tells me anything," Ms. J said, "They did a test on my leg weeks ago and never told me what was wrong."

Bingo. Lack of information causes anxiety. Anxiety causes panic attacks. Panic attacks exacerbate the pain. It was clear by Dr. C's reaction that this was a regular occurrence. Dr. C offered to obtain the test results and review them personally with Ms. J, which seemed to calm her. She stopped crying and her breathing slowed. For a moment, her pain was also under control. Dr. C showed that she cared; she listened. She promised to follow up. It is little things like this that, no matter how reluctant we are, make a difference in the way patients view their care.

The Solution

If I were ordered one month ago to make use of my limited experience to help these patients feel better, I would have balked. How could I, with no college degree, no formal training, and no published papers assess and treat something as serious as chronic pain? Now I know that I possess the most useful weapon possible: I have time to listen. Feeling unheard is the most painful experience a patient can live in a skilled nursing facility. The most I can do is sit with these patients, like I did with Ms. W, until reinforcements arrive. I cannot give these patients a pill to block the transmission of pain signals to their brains—I couldn't even turn Ms. W in her bed—but I can alleviate the mental pain that takes over. I can pull the patient back from the brink over which the pain can envelop and

consume the sufferer. Recognizing pain in a patient requires that we recognize that patient as a person. If pain is in the mind, we have to notice the mind to notice the pain.

But how do we convince caregivers to take the time to examine patients' minds? In recent years, leaders in the medical field have developed what could be the solution. Palliative care is not hospice care. The little pink heart on a palliative care patient's chart reminds the reader to keep in mind that this patient has a serious, terminal ailment. Patients on palliative care at TCC receive an additional care plan and medical order that remind caregivers that they require—that they deserve—a little extra attention. Very few of the patients I interviewed, if any, are on palliative care. Sub-acute patients may not have terminal illnesses or even chronic pain. They don't have little pink hearts on their electronic medical records to remind us to be gentle. They just have pain. Pain from a fall, or a stroke, or an amputation. Contrary to popular belief, the science of pain management requires that the physician do more than scribble orders for Percocet on a prescription pad. It requires that the entire care team get to know the patient. What does an 8 out of 10 mean to that patient? Does being in pain cause the patient an exorbitant amount of anxiety? Of fear?

It is at this juncture of philosophy and practice that the distinction between symptom and behavior comes into play. The relationship between symptom and behavior is infinitely complicated. They can be the same, so they cannot be part of a spectrum. They can cause each other, or they can be completely isolated. The way we use the word "behavior" when we really mean "symptom" to describe pain is evidence of the way we view our patient and the pain itself. While the state of being in pain has little attached stigma, the act of expressing your pain is often associated with weakness. From an early age, our parents and coaches tell us to "suck it up" and keep going. Being in pain builds character. A high pain tolerance is evidence of great courage and strength. Somewhere along the line of human history, expressing pain became synonymous with expressing weakness.

This is not to say that caregivers believe weaker patients deserve less intense care. However, if a caregiver sees a patient as weak, any action or request becomes a byproduct of that weakness. Weakness is less a trait than it is a behavior. When a physician labels a patient's pain as behavioral, it means that something else is contributing to this pain—anxiety, depression, schizophrenia, general closed-mindedness. Ms. J's pain could have been dealt with easily, but she refused medication. Her conviction, however ambitious, that her physician could pinpoint the problem and cure her of her neuropathy prevented treatment of her pain, while her anxiety only made the pain worse.

Ms. J's case will require more than a philosophical understanding of pain to solve. As much as it is possible for a physician's bias to get in the way of pain management, it is equally possible for a patient to obstruct the path to his or her own care. Care planning, especially pain management, seems to be a constant tug-of-war for control between the physician and the patient. When patients feel helpless, they tend to lash out, refuse medication—behave badly. It becomes nearly impossible to treat the patient at all, much less get to know the patient as a contributing member of society. Physicians must earn the trust of their patients on a personal level, a level at which they can be clear that simply treating the pain is as close to a cure as they can get. The physician cannot always rely on the patient to communicate his or her needs clearly.

To better understand the patient's needs, the physician must first become familiar with the patient free from pain. If we can understand as much as possible the way the patient was before he or she became sick, we can better gauge the severity of this patient's pain later on. The physician must consider the pain separately from the patient—it is something that holds the mind hostage, not something that comes from the patient. Part of believing in a person's pain is believing, in a sense, that he or she exists in a full capacity. My job at times has been to remind staff that their patients exist in a realm just as rich and complex as their own. It can be difficult to imagine a patient any way other than bedridden, sick, and in need of constant care, but that is not who they are. If we surrender and tell ourselves that the pain is just another bad behavior, we are allowing our patients to be defined by their pain, by their illness.

The Conclusion

The majority of the responses I received paint a remarkably positive picture of care at TCC. Patients feel heard, respected, and well cared-for. As one patient said, "I think you have a very beautiful crew." The general consensus seems to be positive. Most of the issues with pain recognition and management appear in patients who are in the most pain, which can inspire them to be more vocal than average. These patients make up the bulk of my case studies, because they are able to describe their pain as it is currently present. However, we cannot view these patients the same way we view statistical outliers; that is, we cannot ignore them.

No one deserves to be in pain. Even inmates on Death Row are provided the option of a painless, "humane" execution. Understanding another person's pain requires that we step outside

ourselves, away from our own experiences and biases. I hope that in my time here, I've laid the groundwork for that skill. When I see patients as a physician, I will not weigh my experiences against those of my patients in an adversarial way, but I will use them to empathize. When I meet patients here at TCC, I do my best to look beyond the information entered in their medical records. Pain, while a symptom of illness, cannot be identified the same way we identify other symptoms. Monitoring pain requires communication; it requires empathy. Pain is as much an emotion as it is a symptom. I want to know my patients like I would know a friend; I want to know when they're in pain before they are begging for medication. This experience has taught me how to listen to and understand patients as people; I have learned how to make their needs my needs. I have learned how to close the gap between patient and caregiver, always keeping in mind the hope that someday someone will do the same for me.

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Appendix I: Patient Responses

I developed a survey of ten questions, but I tried to avoid pushing the patients to answer lest I inadvertently influence their responses. As a result, I did not adhere strictly to the questions but allowed the patients to direct the conversation themselves, and I asked my questions where I found the opportunity.

Patient 1 (new admission)

Are you having any pain?

None reported at present

Do you receive daily pain medication?

None reported at present

How is the quality of care provided by nursing staff with regards to pain?

Pretty good

Do you feel that your needs are being met with regards to pain?

Feels that some needs are not being met

Patient 2

Are you in pain now?

Not at the moment

Have you experienced any pain since you were admitted?

Experiences occasional pain in ankle

Has that pain been addressed by a physician?

Periodically, but has to “beg them” sometimes

Do you receive daily pain medication?

Yes

How often would you say you have to ask for pain medication, supplementary or otherwise?

1-2 times per week

When you ask for medication, how long does it usually take to receive it?

Usually none, sometimes 1-1.5 hours

How do you feel when you are in pain?

“The pain’s all I know.”

How do you feel when you ask for medication?

Very positive about physicians and nurses

“When you’re in pain, you’re in pain.”

Do you feel that your needs are being met with regards to pain?

“Sometimes yes, sometimes no.”

Feels that delivery takes too long

“All I’m asking for is help.”

Patient 3

Are you in pain now?

No

Have you experienced any pain since you were admitted?

Yes; admitted for broken ankle

Has that pain been addressed by a physician?

Yes

Do you receive daily pain medication?

Unsure

How often would you say you have to ask for pain medication, supplementary or otherwise?

Unsure

When you ask for medication, how long does it usually take to receive it?

Half an hour or more

How do you feel when you ask for medication?

“Getting attention is the hard part.”

No other complaints

How is the quality of care provided by nursing staff with regards to pain?

No complaints

Do you feel that your needs are being met with regards to pain?

No complaints

Patient 4

Are you in pain now?

Not much

Have you experienced any pain since you were admitted?

Some

Has that pain been addressed by a physician?

Yes

Do you receive daily pain medication?

Yes

How often would you say you have to ask for pain medication, supplementary or otherwise?

Not too often

When you ask for medication, how long does it usually take to receive it?

“Sometimes a long time.”

How do you feel when you ask for medication?

Doesn’t like having to ask

How is the quality of care provided by nursing staff with regards to pain?

Says the staff are all very nice

Do you feel that your needs are being met with regards to pain?

Yes

Patient 5

Are you in pain now?

Yes

Have you experienced any pain since you were admitted?

Yes

Has that pain been addressed by a physician?

Yes

Do you receive daily pain medication?

Yes; occasionally the pain returns before next dose is administered

How often would you say you have to ask for pain medication, supplementary or otherwise?

Varies; son brought over-the-counter pain medication himself

When you ask for medication, how long does it usually take to receive it?

1.5 hours (reason why the son brought medication)

How do you feel when you are in pain?

“Horrible...I want to knock people’s heads off.”

Feels as though she is “left in pain.”

How do you feel when you ask for medication?

"I don't mind...but to have to beg for your pain medication is the worst thing in the world, and I have had to do that."

How is the quality of care provided by nursing staff with regards to pain?

Generally attentive and respectful

Do you feel that your needs are being met with regards to pain?

Most of the time, with some issues

Patient 6

Are you in pain now?

Yes

How long have you had this particular pain?

All day; getting worse

Has that pain been addressed by a physician?

No; has not alerted staff.

Do you receive daily pain medication?

Unsure

How often would you say you have to ask for pain medication, supplementary or otherwise?

Few times per month

When you ask for medication, how long does it usually take to receive it?

Not long

How do you feel when you are in pain?

Confused, disoriented

How is the quality of care provided by nursing staff with regards to pain?

Says nurses are nice

Do you feel that your needs are being met with regards to pain?

Yes, despite pain

Patient did not display signs of distress but reported being in pain when asked

Patient 7

Are you in pain now?

No

Have you experienced any pain since you were admitted?

Occasional discomfort

Has that pain been addressed by a physician?

Yes

Do you receive daily pain medication?

Yes

How often would you say you have to ask for pain medication, supplementary or otherwise?

Once per day

When you ask for medication, how long does it usually take to receive it?

Not long, depending on how busy the staff are

How do you feel when you are in pain?

Hopes it goes away

How do you feel when you ask for medication?

"It has to be done."

How is the quality of care provided by nursing staff with regards to pain?

Feels that the staff "don't care one way or the other," but has no complaints.

Do you feel that your needs are being met with regards to pain?

Yes

Patient 8

Are you in pain now?

No

Have you experienced any pain since you were admitted?

Some shoulder pain

Has that pain been addressed by a physician?

Yes

Do you receive daily pain medication?

No

How often would you say you have to ask for pain medication, supplementary or otherwise?

Two times the whole stay here

When you ask for medication, how long does it usually take to receive it?

Roughly 15 minutes

How do you feel when you are in pain?

No thoughts in particular

How do you feel when you ask for medication?

"Fine."

How is the quality of care provided by nursing staff with regards to pain?

No complaints

Do you feel that your needs are being met with regards to pain?

No complaints

Patient 9

Are you in pain now?

No

Have you experienced any pain since you were admitted?

Sometimes in hand/arm

Has that pain been addressed by a physician?

Yes

Do you receive daily pain medication?

As needed

How often would you say you have to ask for pain medication, supplementary or otherwise?

Two times per day as needed

When you ask for medication, how long does it usually take to receive it?

Up to 30 minutes

How do you feel when you are in pain?

No complaints

How is the quality of care provided by nursing staff with regards to pain?

No complaints

Do you feel that your needs are being met with regards to pain?

Yes, feels that nurses listen

"I think *mine* are." (emphasis as such)

Patient 10

Are you in pain now?

Yes; no medication administered since 9 am (roughly 7 hour gap)

Have you experienced any pain since you were admitted?

Yes

Has that pain been addressed by a physician?

No (until a nurse came in to notify that physician had been contacted during interview)

Do you receive daily pain medication?

Yes, every 3 hours

How often would you say you have to ask for pain medication, supplementary or otherwise?

1-2 times per day

When you ask for medication, how long does it usually take to receive it?

Varies by individual caregiver; between a few hours and never

How do you feel when you are in pain?

Helpless, hopeless

"It just makes me so mad."

How do you feel when you ask for medication?

"When you ask someone for medicine you feel like you're begging."

"Have I made [the nurse] mad?"

Feels humiliated

How is the quality of care provided by nursing staff with regards to pain?

Feels that nurse is exasperated

"It's what they tell us to do, but we shouldn't have to ask."

Nurses are not familiar with medications/usage directions

Do you feel that your needs are being met with regards to pain?

"I'm not taking it personally, I'm taking it for the people that can't fight for themselves."

Says that not all patients know their own medical regimen or are not able to communicate their needs and frustrations.

"That's all anybody asks, just to be listened to."

"I wouldn't send a dog here."

Patient 11

Are you in pain now?

No

Have you experienced any pain since you were admitted?

Occasional knee pain

Has that pain been addressed by a physician?

Yes

Do you receive daily pain medication?

Yes

How often would you say you have to ask for pain medication, supplementary or otherwise?

Never

How do you feel when you are in pain?

Just in pain

How is the quality of care provided by nursing staff with regards to pain?

Nurses are good, very kind

Do you feel that your needs are being met with regards to pain?

Yes

Patient 12

Are you in pain now?

No

Have you experienced any pain since you were admitted?

Yes, nightly pain

Has that pain been addressed by a physician?

Not that she knows of—has not alerted staff of pain

Do you receive daily pain medication?

Yes; has not found it effective

How often would you say you have to ask for pain medication, supplementary or otherwise?

Never alerted staff to pain/never asked for medication

How is the quality of care provided by nursing staff with regards to pain?

No complaints

Do you feel that your needs are being met with regards to pain?

No complaints

Patient 13

Are you in pain now?

No

Have you experienced any pain since you were admitted?

Yes, occasional arm pain

Has that pain been addressed by a physician?

“No, I bear it...Because I’m sick of people going on Tylenol for nothing.”

Concerned about addiction

Depends on mood

Do you receive daily pain medication?

Unsure

How is the quality of care provided by nursing staff with regards to pain?

Very good

Do you feel that your needs are being met with regards to pain?

Yes, likes the food

Patient 14

Are you in pain now?

No

Have you experienced any pain since you were admitted?

Yes, occasional knee pain, in physical therapy for rehabilitation

Do you receive daily pain medication?

No

How often would you say you have to ask for pain medication, supplementary or otherwise?

Not applicable, sometimes requests sleeping pills, itching due to dialysis

How is the quality of care provided by nursing staff with regards to pain?

“They couldn’t be better.”

Patient 15

Are you in pain now?

No

Have you experienced any pain since you were admitted?

No

Do you receive daily pain medication?

No

How is the quality of care provided by nursing staff with regards to pain?

Says staff are respectful.

Do you feel that your needs are being met with regards to pain?

Yes

Patient 16-language barrier

Are you in pain now?

No

How often would you say you have to ask for pain medication, supplementary or otherwise?

Never asks for medication

"I think I am powerful to fight the pain. I don't depend on people."

Patient 17

Are you in pain now?

Yes

Have you experienced any pain since you were admitted?

Yes, recently

Has this current pain been addressed by a physician?

"No, but she knows."—not reflected in medical record

Do you receive daily pain medication?

Yes

How do you feel asking for pain medication?

Fine, pretty good.

How is the quality of care provided by nursing staff with regards to pain?

Nurses are very nice.

Do you feel that your needs are being met with regards to pain?

No complaints

"I think you have a very beautiful crew."

Appendix II: Literature Review

“A pain monitoring program for nurses: effects on nurses’ pain knowledge and attitude”

De Rond et al. found that one of the primary reasons for inadequate pain management in nursing homes is insufficient knowledge in nurses regarding ways to recognize and monitor pain. The researchers designed a Pain Monitoring Program (PMP) by which to educate nurses. They implemented a daily pain assessment using a standardized rating scale and studied the effectiveness of this program. The results showed that nurses have “knowledge deficits and prejudices” that obstruct the provision of quality care. The researchers found that with the PMP, nurse attitudes changed with respect to knowledge and applicable skills, willingness to assess pain levels daily, and attention to patient complaints.

“Pain management and decision making among long-term care physicians and nurses”

Kaasalainen et al. designed a study with emphasis on cognitively impaired patients, examining physicians, registered nurses, and registered practical nurses. The researchers found that pain management can be broken into assessment and treatment. Recognition and uncertainty in evaluating pain contribute to issues in assessing pain, and reluctance to use opioids, difficulty individualizing care, and lack of trust between physicians and nurses contribute to issues in treating pain.

“The effect of provider-level ascertainment bias on profiling nursing homes”

Roy et al. found that ascertainment bias, which is caused by variation in ways quality is measured by staff, can be responsible for inconsistencies in the evaluation of residents in nursing homes.

“Pain Management in Nursing Homes: What Do Quality Measure Scores Tell Us?”

Russell et al. describe the myriad ways in which pain can negatively affect a patient’s quality of life. They write that barriers to pain relief can include “inadequate knowledge,” fear of overdose or addiction, and difficulty choosing proper medication. The researchers write that many physicians do not have the available time to devote to patients or do not recognize the importance of regular pain monitoring by multiple caregivers. Their study found that their implemented plan did not improve quality of life on paper, but staff with the plan did report improved staff morale and a higher quality work environment as a result of more concerted efforts by the entire team. Russell et al. suggest that pain management can be reformed through the improvement of key structural elements, which must be demonstrated by a present authority to remind and encourage staff.

“Whatever happened to qualitative description?”

Sandelowski et al. write that “qualitative descriptive studies have as their goal a comprehensive summary of events in the everyday terms of those events.”

“The problems of pain and its detection among geriatric nursing home residents”

Sengstaken et al. conducted a study in which they found that 66% of “communicative residents” experienced chronic pain, but physicians failed to recognize pain in 34% of these patients. They also found that patients in whom pain went unidentified were more likely to suffer from neurologic disorders other than dementia. Sengstaken et al. write that pain was identified even less frequently in non-communicative residents. The consistency of pain evaluation can be improved through “direct questioning about this problem at frequent intervals.” Sengstaken et al. also suggest the development of new and different methods of assessing pain in non-communicative residents.