Pain in Perspective: A Qualitative Study of Chronic Pain Patients’ Experience with Pain and Pain Management

Clendening Summer Fellowship Proposal

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Introduction:

With approximately 100 million adults affected, chronic pain represents a national crisis of public health. Unfortunately, there are no easy solutions. Treating chronic pain is a complex task and the barriers to effective treatment are numerous. Among those barriers is the marginalization of the patient’s perspective in the management and treatment of chronic pain. For instance, practitioners frequently adopt attitudes and goals that are different from those of their patients living with chronic pain (Frantsve and Kerns 2007), and practitioners often encourage patients to describe their experience with chronic pain only briefly, rather than present a narrative that fully explains the impact of pain on their lives (Morris 2002). Patients report that these experiences leave them with the feeling that their pain is trivial or, worse, illegitimate (IOM 2011). The aim of this study is to gain an understanding of the impact that chronic pain has on patients’ lives by providing a context in which they may give voice to their personal narratives. Through qualitative interviews with chronic pain patients in Kansas City, I aim to gain an understanding of these patients’ perspectives, their struggles with pain, and their efforts to manage chronic illness. The results and analysis of these interviews will be provided to local organizers of the PAINS project, an initiative of the Center for Practical Bioethics, to help them in their efforts to foster better understanding between practitioners and chronic pain patients.

Background:

In 2011, the Institute of Medicine published a seminal report concerning pain in the United States. Relieving Pain in America: A Blueprint for Transforming Prevention, Care, Education, and Research (2011) revealed that acute and chronic pain represent nothing short of a national crisis of public health. The scale of the problem is alarming. Chronic pain alone affects approximately 100 million Americans at a cost of $560-635 billion annually. But the crisis of chronic pain is also complex: it is colored by under-treatment and under-diagnosis, substantial disparities in treatment and management of chronic pain, and social stigma.

Among the barriers to improved treatment of chronic pain is the marginalization of the patient’s perspective in the management and treatment of chronic pain. People with chronic pain, especially women, have been shown to often have attitudes and goals that are at odds with the attitudes and goals of providers; while patients seek to have their pain legitimized, providers focus on therapy (Frantsve and Kerns 2007). Additionally, researchers working with patient focus groups have noted “perceived failures of providers to fully respect, trust, and accept the patient, to offer positive feedback and support, and to believe the patient’s reports of the severity and adverse effects of their pain” (Upshur et al. 2010). Others have noted that “patients are encouraged to describe their experience only briefly and in terms most familiar to physicians, rather than present a narrative that fully explains the impact of pain in their lives” (Morris 2002). Finally, consumers who testified before the IOM committee reported that patients often believe practitioners trivialize pain, which makes patients feel worse (IOM 2011, pp. 154).

The marginalization of the patient’s perspective in the treatment of chronic pain is lamentable. But it also represents a barrier to treatment. To overcome this barrier, we must begin to appreciate with greater clarity the extent to which chronic pain burdens and disrupts patients’ lives. By listening to patients’ perspective, we may foster better understanding between practitioners and patients and thereby reduce under-treatment, under-diagnosis, and disparities in the treatment and management of chronic pain.
With the Clendening Summer Fellowship, I aim to gain insight into chronic pain patients’ experience of living with chronic pain. In the clinic, the narratives of patients with chronic pain are, for various reasons, cut short. Through interviews, I propose to provide a context in which these patients may give voice to their narratives. Each interview will be documented and, through quantitative methods, I will analyze the patients’ narratives and descriptions. The analysis of these interviews will be provided to local organizers of the PAINS project, an initiative of the Center for Practical Bioethics, to help them in their efforts to foster better understanding between practitioners and chronic pain patients, thereby improving the management and treatment of people suffering from chronic pain.

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The purpose of this project is to feature patients’ perspectives on chronic pain and pain management as part of a larger effort to improve the delivery of care to patients with chronic pain in Kansas City and across the country. Having taken an interest in the topic of pain and pain management, I arranged a meeting with Myra Christopher, the Kathleen M. Foley Chair for Pain and Palliative Care at the Center for Practical Bioethics. Based at the Center, Ms. Christopher leads the Pain Action Alliance to Implement a National Strategy (PAINS) and, through her work, is building a national movement to change the way pain is perceived, judged and treated. My enthusiasm and admiration for Ms. Christopher’s work led me to inquire about areas of research that would contribute to the mission of PAINS. This led to discussions with Dr. Joseph LeMaster and Dr. Kim Kimminau of the Department of Family Medicine at the University of Kansas, School of Medicine, who also have interest in chronic pain research, and I began developing a Clendening Summer Fellowship proposal under their guidance.

My goals for the Clendening Summer Fellowship are three-fold. For starters, I aim to gain insight into the lives of patients living with chronic pain. Developing a deeper appreciation for the challenges they face will no doubt prepare me to deliver compassionate, informed, and sensitive care to patients with chronic pain in the future. Given the prevalence of chronic pain in the United States, gaining this insight will be invaluable. Second, through working with the PAINS project and the Center for Practical Bioethics, I aim to gain practical experience in patient advocacy at a local and national level. I have accounted for time spent at the Center and for working with local organizers of the PAINS project in the timeline outlined below. Finally, I hope to conduct research that will make a meaningful contribution to the efforts of PAINS. By giving voice to patients with chronic pain and characterizing their experience with pain and pain management, this research may help to shape future PAINS endeavors in Kansas City and improve the lives of people living with chronic pain.

Description:

*Relieving Pain in Kansas City*, a community-based initiative involving PAINS, is a monthly meeting of patients living with chronic pain in the Kansas City area. Over the next several months I plan to attend these meetings in order to become involved with this local initiative of PAINS and become acquainted with the population of patients suffering from chronic pain in Kansas City. The patients suffer from a variety of illnesses, and each has a unique story to tell.

At the conclusion of the school year, I will begin learning the skills and techniques required for qualitative interviews and analysis with Dr. Kimminau, director of community health research and associate professor in the Department of Family Medicine at the University of Kansas Medical Center. I will also begin to review the relevant literature on pain and pain management. After this time, I will work
with Dr. Kimminau to select interview subjects from the *Relieving Pain in Kansas City* group and begin interviewing patients. The aim of these interviews is to gain an understanding of chronic pain patients’ perspectives on pain and pain management. A set of sample questions may be found in Appendix B.

In addition to interviewing patients, I will work with local PAINS organizers at the Center for Practical Bioethics in order to gain practical experience in patient advocacy. The mission of PAINS is to advocate for and act collectively to actualize the recommendations set forth in the Institute of Medicine report, *Relieving Pain in America*. Carrying out this mission involves working on behalf of patients at a local and national level. Under the guidance of local organizers of PAINS, and in particular Myra Christopher of the Center for Practical Bioethics, I aim to become involved in various aspects of patient advocacy. Learning these skills will no doubt improve my skill and capacity for patient advocacy for future patients.

After a thorough review of the relevant literature and after completing patient interviews, I will compile and analyze the data using qualitative methods. The findings of the qualitative study will be included in a report for the Clendening Summer Fellowship. Additionally, the findings will be provided to local organizers of the PAINS project, an initiative of the Center for Practical Bioethics, to help them in their efforts to foster better understanding between practitioners and chronic pain patients, thereby improving the management and treatment of people suffering from chronic pain.

**Timeline:**

February – May: Attend monthly meetings of *Relieving Pain in Kansas City* in order to become acquainted with the local organizers of the PAINS initiative and the local network of patients with chronic pain.

May 17, 2014: End of Academic Year.

May 18 – 31: Develop skills and techniques required for qualitative interviews with Dr. Kim Kimminau and her staff. Review relevant literature on pain, pain management, and qualitative research methods.

June: Conduct interviews. Work with local PAINS project organizers at the Center for Practical Bioethics. Continue to review relevant literature on pain and qualitative research methods.

July: Analyze data. Continue to work with PAINS project organizers. Continue to review relevant literature. Write Clendening Summer Fellowship report.

August: Submit reports.

**Methods:**

Pending IRB approval, data will be collected through interviews with chronic pain patients associated with *Relieving Pain in Kansas City*, a local initiative of the PAINS project. All interviews will be conducted on a voluntary basis in private rooms at the University of Kansas Clinical Research Center at 4350 Shawnee Mission Parkway, Fairway, KS 66205; the CRC is the site of *Relieving Pain in Kansas City* meetings, so prospective interviewees will be familiar with the setting. Interviewees will be provided remuneration in the form of gift cards. Potential interviewees will be approached at meetings of *Relieving Pain in Kansas City*, given a description the project, and allowed to decide if they wish to
participate. Written consent will be obtained from each participant (see Appendix A). Audio recording will be employed in order to ensure accurate recording of the information obtained via interview.

The goal of the interview process is to obtain detailed, in-depth narratives and descriptions of patients’ perspectives on living with chronic pain as well as the management of chronic pain. As such, lengthy interviews with fewer patients will be favored over short interviews with a large number of patients. Approximately 10-15 interviewees will be selected for interviews. Interviews with each patient will consist of at least one extended interview session and may include follow-up sessions as needed.

Under the guidance of Dr. Kim Kimminau, I have completed a preliminary review of qualitative methodologies, and on the basis of this review I plan to employ crystallization methods as articulated by Ellingson (2009) in the analysis of patient interviews. Qualitative interview methods and techniques will be practiced with Dr. Kimminau and her staff prior to interviewing patients. Additionally, medical literature pertaining to chronic pain and pain management will be reviewed and, when pertinent, included in the report.

For the duration of the project I will maintain residence in Kansas City. This expense, along with the cost of travel to and from interviews, monthly meetings of Relieving Pain in Kansas City, and work with PAINS organizers at the Center for Practical Bioethics in Kansas City has been detailed in the proposed budget below.

**Contacts:**

Myra Christopher  
Kathleen M. Foley Chair for Pain and Palliative Care  
Center for Practical Bioethics  
Steering Committee Chair: The Pain Action Alliance to Implement a National Strategy (PAINS)  
mchristopher@practicalbioethics.org

Dr. Kim Kimminau, PhD  
Associate Professor  
Director, Center for Community Health Improvement  
University of Kansas, School of Medicine  
kkimminau@kumc.edu

Dr. Joseph LeMaster, MD, MPH  
Associate Professor  
Department of Family Medicine  
University of Kansas, School of Medicine  
jlemaster@kumc.edu

**Budget:**

- Housing: $600.00/month x 3 months………………………………………………..$1800.00
- Utilities: $60.00/month x 3 months………………………………………………..$180.00
Budget (cont.):

Food: $150.00/month x 3 months................................................................. $450.00
Transportation (gas): $75.00/month ............................................................... $225.00
Subject Remuneration: $20.00/person x 10-15 persons....................................... $200.00 - $250.00
Audio Recorder: $50.00...................................................................................... $50.00
Total....................................................................................................................... $2905.00-2955.00

$2500 of the proposed budget will be financed via funds provided by the Clendening Summer Fellowship. Additional costs, beyond $2500, will be financed personally.

Bibliography


Appendix A: Consent Form

I am a medical student at the University of Kansas, School of Medicine, and I am conducting interviews as part of a Clendening Summer Fellowship research project. The goal of the project is to study the perspectives of people living with chronic pain, especially their perspectives on healthcare.

If you choose to participate in this study, you will be asked some questions about the care you currently receive for chronic pain or the care you have received in the past. You will also be asked about your disease(s) and other factors that contribute to the nature of your experience with healthcare as it relates to your pain. Please take as much time as you need to answer the questions, and feel free to expand on any idea or related ideas that may occur to you. If at any point during the interview you are asked a question that you do not wish to answer, please express this and we will stop the interview or proceed to another question. All information will be kept confidential, and you will not be asked to give identifying information (e.g. name, address, telephone number) of any sort.

Participant’s Agreement:

I am aware that my participation in this interview is voluntary. I understand the purpose and intent of the research. If, for any reason, I wish to stop the interview at any time, I may do so without having to give an explanation. I am aware that information obtained from this interview will be used in a Clendening Summer Fellowship research project and may be used in a presentation at the University of Kansas, School of Medicine. I have the right to review, comment on, and/or withdraw information prior to the project’s submission. The information gathered in this interview is confidential with respect to my personal identity unless I specify otherwise. I understand that the audio from this interview is being recorded.

If I have any questions about this study I am free to contact the student researcher (Joel Burnett, jburnett2@kumc.edu, 816-547-9446). I have been offered a copy of this consent form, which I may keep for my own reference. I have read the above form and, with the understanding that I can withdraw at any time and for whatever reason, I consent to participate in today’s interview.

_________________________________________  __________________
Participant’s Signature                                                                       Date

_________________________________________
Interviewer’s Signature

Adapted from http://inside.bard.edu/irb/consent/
Appendix B: Interview Questions

Note that the set of questions here constitutes a draft that is subject to revision following additional research into medical literature concerning chronic pain and pain management as well as additional training in qualitative interview methods.

1. How long have you lived with chronic pain? What do you understand the source of this pain to be?

2. Describe your typical day. How is it impacted when your pain is mild? Moderate? Severe?

3. What are you doing to manage your pain (e.g. medications, complementary therapies, etc.)?

4. How did you arrive at the approaches to pain management that you employ?

5. Is your pain management adequate? How could it be improved?

6. Has your attitude toward pain changed as a result of your experience with chronic pain? How?

7. What, in your view, are the barriers to improving your pain management? How might those barriers be overcome?

8. Specifically, what do healthcare providers do to help you in your chronic pain care? What do they do to hinder you?

9. How has chronic pain impacted your family life? Your social life? Your work life?

10. Does the experience of living with chronic pain carry personal meaning or significance for you? Have you discussed this significance with your family? Your healthcare providers?