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TOWARDS AN UNDERSTANDING OF THE CHRONIC PAIN EXPERIENCE
FOR SIX FORMER PATIENTS OF A CHRONIC PAIN PROGRAM

DISSERTATION

Presented in Partial Fulfillment of the Requirements for
the Degree Doctor of Philosophy in the Graduate
School of the Ohio State University

By

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1997

The Ohio State University

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ABSTRACT

Chronic pain lasts three months or longer and correlates with stresses such as loss of valued roles, income, marital discord, and confinement. Chronic pain has been investigated through different theoretical approaches such as: (a) the operant approach, which views pain as learned operant behavior; (b) the transactional approach, which views pain as expressed in pain games; and (c) the cognitive-behavioral approach, which views pain as partly influenced by cognition and under self-regulation. These three approaches acknowledge the psychological realm of pain and give the patient an active role in pain management. How patients personally experience chronic pain remains to be adequately studied. The intent of this study was to develop a grounded theory of personal experiences and processes associated with chronic pain. Six former patients of a chronic pain program, (two men and four women, Caucasian, age range 34-66 with mean of 49), were interviewed. Audiotaped interviews were transcribed, and data from the interviews were analyzed using grounded theory. Grounded theory is a qualitative research method that oscillates between analysis and data collection throughout the research process in order to (a) generate theory from data, and (b) modify the theory in light of new data. Analysis of the data resulted in five themes: (a) self-concept pre-injury; (b) self-regard post-injury; (c) control over one's life; (d) exploring the self-concept; and (e) the need to be accepted by others. A grounded theory, derived from these themes, centered around the self-concept. The model,
supported by participants' direct quotations, includes three phases: (a) making pain/injury experiences congruent with the pre-injury self-concept (using denial and defense mechanisms); (b) experiencing significant life changes due to chronic pain and, therefore, having difficulty maintaining one's pre-injury self-concept; and (c) reformulating the self-concept that incorporates injury/pain. Limitations of the study and implications for the field are discussed.
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Finally, a sincere thank-you to those men and women who unselfishly shared their time and personal stories. I hope that your participation in the study has helped you feel heard. I hope that this document will help others understand your experiences with chronic pain.
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CHAPTER 1

INTRODUCTION

The following quotes are from people who live with chronic pain who participated in this study:

Chronic pain is kind of like a black cloud floating around you following you around in a lot of ways... the pain just kind of sucks the life out of your life. (Sam)

...I always thought I’d work ‘till I was 70... I never thought of having to retire and it really, really shocked me... Sometimes I get the feeling where like I’m on welfare or... getting something that I don’t deserve. (Kelly)

... in the beginning everything was painful. Walking was painful, breathing, sneezing, and coughing. It did feel like it had control over me because I was just so overwhelmed by it. There were just so many things that hurt. (Bonnie)

I don’t feel I have control over making my body do what my mind tells me I have to. Everyday it’s a battle to get out of bed. Do the things that have to be done. I feel like I’m just existing right now just to do what I have to do. Not a very good life right now. (Jennifer)

Chronic pain is defined as pain that lasts three months or longer (International Association for the Study of Pain, Subcommittee on Taxonomy, 1986). It is a subjective and complex phenomenon that affects 11% of the population at any given time (Merskey, 1988), and as Mikail, Henderson, and Taska (1994) state, "[p]ain is a necessary but not sufficient condition in the development of chronic pain syndrome" (p. 7). Much more than physical pain is being experienced by those in chronic pain -- but what factors are associated with chronic physical
pain? Turk, Meichenbaum, and Genest (1983) state that chronic pain frequently results in loss of valued roles. Keefe, Salley and Lefebvre (1992) maintain that stressors such as loss of income, confinement, and marital discord can occur simultaneously. Due to the complexity of the chronic pain experience, researchers have approached this phenomena through several different routes.

Different dimensions of the chronic pain spectrum have been researched. The three most prominent dimensions are the (a) physiological aspects (Chapman, Casey, Dubner, Floey, Gracely, & Reading, 1985), (b) psychological factors (Davis, 1989; Gamsa, 1990; Kleinke, 1994), and (c) multidimensional blend of subjective, objective, and behavioral components (Sullivan, 1991). A fourth dimension, which has only recently been examined, focuses on the phenomenological experience of chronic pain (Davis, 1989). Overall, it seems that the literature on chronic pain has been progressing towards a more holistic understanding of the person.

History of Pain Research

The first physiological explanation for the pain experience came from the physiologists and psychophysicists of the 19th century. They understood pain as solely the function of sensory input; thus, the amount of pain experienced was directly proportional to the amount of tissue damage. This direct-transmission-model assumed that pain could be eliminated or reduced by interfering anywhere in the transmission process (Turk, Meichenbaum, & Genest, 1983).

Researchers began to take interest in the psychological aspects of pain in the early 1970's (Weisenberg, 1977). Some of these
investigators were interested in the perception of pain; that is, how individuals actually interpret the sensation of pain (Turk, 1975; Weisenberg, 1977). They suggested that pain was a multidimensional subjective experience defined by the person and that a proper conceptualization of this experience must have several dimensions as well. A multidimensional perspective incorporates cognition, affect, and physical/sensory components. Several case studies kept records of an individual's progress in a multidimensional rehabilitation program (Sullivan, 1991, May). These case studies are the therapists' descriptions of how the patient was progressing. The psychotherapist's description was similar to the case history conducted in an intake session and did not include the client's subjective experiences.

Other researchers interested in the psychological aspect of the chronic pain experience focused on how personality influences and is influenced by pain. Several of these studies used personality tests, such as the Minnesota Multiphasic Personality Inventory (MMPI), to elucidate the relationship between pain, ways of coping, and personality factors (Davis, 1989). Davis noted that the personality factors of hysteria, depression, and hypochondriasis were frequently associated with pain (1989). The validity of using the MMPI with chronic pain patients has been questioned (Karoly, 1985) due to its original intent of diagnosing psychiatric populations (Welsh & Dahlstrom, 1956).

Recently, studies on chronic pain focused on the unique chronic pain experience of the individual from his/her perspective (Davis, 1989). This phenomenological focus is an important addition, since past studies have segmented the chronic pain experience into different
dimensions and generalized the findings. The tests and questionnaires
did not capture the full essence of unique human life experiences.
Methodology congruent with the phenomenological focus is necessary to
fully examine chronic pain from the client's perspective. Keefe et al.
(1992) phrased it well,

[we believe that the time has come for a second generation of
studies [using new methodologies other than questionnaires],
informed by the successes and mistakes of earlier research, is
likely to further advance our understanding of the complex process
of coping with chronic pain. (p. 134)

Several psychological approaches have been used to study and treat
chronic pain. Researchers and practitioners have utilized operant,
transactional, and cognitive-behavioral lenses. Each of these lenses is
capable of observing certain phenomena and not others. To get the
bigger picture, a lens with increased depth is needed. An emic
phenomenological perspective is, therefore, required.

Qualitative research is phenomenological in that reality is found
in an individual's personal experience. Qualitative research takes an
emic (insider) approach by looking at behavior from the context in which
it occurs. The emic approach is contrasted with the etic (outsider)
approach of quantitative research which "strips" context from behavior
(Guba & Lincoln, 1994). Researchers using an emic approach do not
passively observe, but are interactively engaged in understanding the
perspective of the people they study. Strauss and Corbin (1990)
underscored the importance of viewing behavior from people's positions.
The goal is to understand how people give meaning to their behavior, as
well as to the behavior of others.
One method of doing qualitative research is grounded theory (Strauss & Corbin, 1994). Through grounded theory, theory emerges from the data. Grounded theory is a qualitative research method that oscillates between analysis and data collection throughout the research process in order to (a) generate theory from data, and (b) modify the theory in light of new data (Strauss & Corbin, 1994).

Research that focuses on understanding the chronic pain experience from the person's perspective will provide knowledge to inform theory and will help practitioners, family, and friends more effectively relate with people who live with chronic pain.

Objective

The objective of this study was to explore and understand the personal experiences of those who live with chronic pain. More specifically, the purpose was to understand commonalties and differences in their experiences. Former patients of a chronic pain management program were invited to participate in two in-depth individual interviews and one group discussion in order to explore how chronic pain has affected their lives.

Having worked with chronic pain patients for six months, I have come to realize that living with chronic pain involves more than taking pain pills and being uncomfortable. Pain affects all aspects of a person's life and often takes on a life of its own. Those living with chronic pain are continuously trying to get others to hear them. The purpose of this phenomenological study was to give a voice to this unheard and misunderstood population.
CHAPTER 2

LITERATURE REVIEW

The literature review will first focus on how the study of pain has changed through time. Second, several schools of thought will be compared regarding their contribution to the understanding of chronic pain. Third, dimensional analysis, based on grounded theory, will be discussed as a viable method for understanding the chronic pain experience. Fourth, research objectives will be proposed.

The Nature of Chronic Pain

**A direct relationship.** The direct-transmission-model, generated in the 19th century, claimed a direct relationship between the amount of pain experienced and the amount of tissue damage. For example, a more severe wound would cause more intense pain. The physiological path of the "pain" was discovered, and it was used to interrupt the transmission of pain. Pain could be eliminated or reduced by removing the pain stimulus, blocking the pain pathways, severing these pathways, or removing parts of the brain where the pain signals register (Turk et al., 1983).

**An indirect relationship.** Beecher's research with wounded combat soldiers (1946, 1959) initiated the concept that the relationship between the wound and the pain experienced may not be direct. Beecher
observed that soldiers who saw their wound as a "ticket home" did not complain of severe pain, but instead were actually relieved. Therefore, the severity of the wound did not directly relate to the intensity of the pain. Beecher claimed, "[t]he pain is in very large part determined by other factors, and of great importance here is the significance of the wound" (1959, P. 165).

Laboratory studies confirmed Beecher's observations, and several of the following methods are still used to investigate the subjective experience of pain. These studies used volunteers, and pain was intentionally induced by the experimenter. Pain can be induced by ice water (immersing one's hand in ice water for five minutes), electric shock (many brief non-damaging shocks of increasing amperage), heat pressure (focusing a high-intensity light against skin blackened with India ink), and muscle ischemia (inflating a high pressure cuff on one's arm to a high degree and then doing moderate exercise with that arm) (Turk et al., 1983). Cognitive strategies on the tolerance of laboratory-induced pain either alter the appraisal of the painful situation or divert attention away from the pain (Genest & Turk, 1979). These tactics include imaginative inattention, imaginative transformation of context, focusing attention on physical characteristics of the environment, mental distraction, and somatization (Turk et al., 1983). Existing evidence does not support the use of one strategy over another (Turk et al., 1983).

The personality component of the indirect relationship. Studies that focus on the psychological component of the pain have examined how personality factors affect and are affected by the pain experience
(Davis, 1989). Gamsa (1990) assessed the contribution of emotional disturbance to the perpetuation of pain. An experimental group of 163 chronic pain sufferers was compared with 81 controls on measures of personal history, before the onset of the pain, and measures of current emotional disturbance. Personal history was examined through seven antecedent measures of 'solid citizen,' unmet childhood dependency needs, adult difficulties, and four measures of parental bonding. Pain was related more to current depression and less to current life satisfaction, but was not associated with most of the personal history variables. Thus, Gamsa suggested that emotional disturbance in pain patients is more likely to be a consequence than a cause of chronic pain. Kleinke (1994) investigated MMPI scales to assess if they can predict the pain-coping strategies preferred by chronic pain patients. The MMPI scores of 300 chronic pain patients in a multidisciplinary chronic pain program were correlated with their pain-coping strategies. Results indicated that self-management and social support were related to good adjustment and that helplessness and the use of pain medications were related to poor adjustment. Along the same lines, Ashby and Lenhart (1994) examined the use of prayer as a coping strategy. They gave 105 people, who had reported chronic pain, several questionnaires. Results indicated that prayer was associated with avoidance, a passive coping response. Those individuals who used a greater degree of prayer reported less self-control and higher levels of interference in their lives due to pain.

A multidimensional relationship. No doubt exists that psychological factors are major contributors to the chronic pain
This experience, though, is not only psychological, but is multidimensional. Schramm (1995) noted that, "... chronic pain is a syndrome; associated disabilities include inactivity, deconditioning, insomnia, polypharmacy, iatrogenic narcotic dependence and other adverse drug reactions and interactions, psychological and spousal discord, and unemployment" (p. 45). Sullivan (1991) notes that, "... treatment that focuses only on these [psychiatric and psychological] factors is often inadequate. The cycle of disuse, pain, and disability usually cannot be broken without physical therapy" (p. 475). It would logically hold, then, that the best evaluation and treatment for such a syndrome would be one that included each of these dimensions. Treatment teams have used this multidimensional approach. A team may consist of an occupational therapist, a physical therapist, a speech therapist, a psychologist, a nurse, and a physician. In team treatments, the reduction of pain, as opposed to its eradication, is the goal (Schramm, 1995, June/July). Considerable evidence exists that multidisciplinary chronic pain programs improve psychological and physical functioning, although little is known about which specific programmatic components of the program are associated with improvement (Jensen, Turner, & Romano, 1994). Multidisciplinary treatment has the advantage of comprehensive treatment, utilizing a specialist for each concern. One aspect is lacking, though. The person's holistic experience is lost in a broad and compartmentalized treatment plan, since phenomenology does not neatly fit into any one of these specialized domains.

A phenomenological perspective. Effects of chronic pain on the individual are physiological, emotional, social, and economic (Davis,
Undoubtedly, other effects of chronic pain exist that have not been systematically investigated. Although these components appear separate, these effects occur simultaneously. From this holistic experience comes one's self-concept, values, and goals. Focusing on only one aspect of the complete experience does not adequately capture the chronic pain patient's reality. The author of this paper notes that part of the purpose of weekly team meetings in chronic pain programs is for the therapists to get a complete picture of the patient's condition. In actuality, the final representation seems to consist of the therapists' combined notes and perceptions. No matter how insightful this picture may be, the author believes it cannot replace the patient's own subjective experience. The patient is present at the end of the team meeting to get feedback from all the therapists, but this only lasts for several minutes and can be overwhelming for the patient.

Davis (1989) developed an instrument that measures the chronic pain experience. Its purpose is to understand how "persistent pain" is experienced and personally responded to by patients. For example, one question on the instrument is "I feel guilty about the ways in which my pain affects others." This question can only be answered with a close-ended response. A more effective question might be, "How do you feel about how your pain affects others?".

To date, it appears that no systematic qualitative research has been conducted with chronic pain patients. Qualitative interviews with chronic pain patients might generate theory that would illuminate treatment interventions.
Theories of Chronic Pain

Currently, the major treatment programs offered to chronic pain patients come from several different theoretical orientations. The utility of each of these theories differs, with each having advantages and disadvantages. The theories of operant, transactional, and cognitive-behavioral approaches will be reviewed.

Operant approach. According to Fordyce (1973), the behavior repertoire of a person with chronic pain includes adaptive (well behaviors), as well as maladaptive behaviors (pain behaviors). Maladaptive behaviors are those that express pain, such as moaning, grimacing, and limping. Fordyce described the need to reduce these behaviors through ignoring them and to increase adaptive behaviors, such as physical activity, through reinforcement. Overall, the behaviors to be increased, decreased, or eliminated are identified and then the appropriate reinforcements are put into effect. Fordyce, Fowler, Lehmann, DeLateur, Sand, and Trieschmann (1973) examined the efficacy of Fordyce’s theory conducting a study with 36 chronic pain patients referred to a pain clinic at the University of Washington. They were treated by the operant conditioning approach, meaning that pain behaviors were ignored and non-pain behaviors were reinforced. The spouses of the patients were taught to do this as well. Fordyce et al. reported that the pain decreased; less interference with daily activities was reported; a reduction in medication occurred, and less time was spent reclining. A methodological problem was that patients were asked to report retrospectively how much pain they had experienced prior to treatment.
Transactional approach. Strenbach & Rusk (1973) also focused on pain behaviors, but saw them as part of the patient's "pain games" (behaving in such a way as to get attention, sympathy, and avoid doing certain things). It is assumed that patients are in full control of their pain games and can give them up if they are motivated. Strenbach used confrontation and realistic goal setting in his therapies. He reported self-report follow-up data on 61 patients examined 6 months after discharge, representing 67% of patients that completed the program, (1974). These patients reported significantly less pain than at the time of hospital admission, increased levels of activity, and reduced medication. Sternbach and his colleagues reported reduced pain and medications and increased activity level after a 3-year follow-up (Ignelzi et al., 1977). Gottlieb et al. (1977) created a treatment program that included self-regulation. Their program included biofeedback, lectures, physical therapy, individual and group therapy, and self-administered medicine-reduction program. Gottlieb et al. reported that 79% of the patients, following treatment for low back pain at a rehabilitation hospital in California, demonstrated unimpaired physical functioning levels, and 82% of the patients were employed or in a job training program.

Cognitive-behavioral approach. The cognitive-behavioral approach also includes client self-regulation, but a large portion of this self-regulation is carried out cognitively. Interventions assume that affect and behavior are largely determined by the way in which the individual construes the world (which includes cognitive structures [i.e., beliefs and meaning systems] and processes [i.e., automatic thoughts and
problem-solving skills]) (Turk et al., 1983). Treatment interventions can occur at the point of cognitive structures, cognitive processes, behavioral acts, and environmental consequences. The first step in using this therapy approach with chronic pain patients is to assess their expectations, beliefs, and attitudes about pain-related issues. The patients' symptoms are then reconceptualized by translating them into solvable problems. Patients are then taught new problem-solving methods for dealing with pain-related complaints. These patients experience reinforcing changes in behavior and affect due to their self-monitoring and coping abilities. For example, a therapist works with a chronic pain patient who turned down a road trip with her family. The therapist and patient together uncover the patient's beliefs: if I went on a road trip, the pain would intensify to such a degree that I would die. Together, they work to reconceptualize the issue into: going on a road trip could increase the pain, which would not kill me, and which could be prevented or alleviated through several means. These means are then negotiated and listed. Consequently, the patient experiences increased efficacy and becomes aware of her thoughts and behaviors.

Turk et al. (1983) summarized laboratory studies that examined the efficacy of cognitive coping strategies. Several different dependent measures (e.g., pain tolerance, threshold, self-report, and physiological indexes) were investigated in relation to a variety of pain stimuli (e.g., radiant heat, cold pressor, pressure, and muscle ischemia). They noted, "it is not clear that the use of any particular cognitive strategy is more effective than a no-treatment control manipulation in altering the pain experience" (p. 91). Turk et al.
state, however, that subjects in the control groups may have actually used cognitive strategies without instruction to do so. It is unclear whether subjects adhere to treatment guidelines. Studies looking at cognitive-behavioral approaches are diverse in their interventions and have many limitations. Turk et al. noted,

> Although several studies have collected follow-up data, each has methodological shortcomings, mainly involving inadequate controls, self-selection biases in follow-up, and the use of questionable dependent measures.

**Summary**

Overall, the operant approach views pain as learned, operant behavior; the transactional approach views pain as expressed in pain games; and the cognitive-behavioral approach views pain as partly influenced by cognition and under self-regulation. All three approaches state that pain is more than physical and that the patient has the power to change it.

These three approaches are beneficial because they acknowledge the psychological realm of pain and give the patient an active role in pain management. How patients experience chronic pain, though, remains to be adequately studied.

**A Computerized Pain Inventory**

Kerns, Turk, and Rudy (1985) developed the West Haven-Yale Multidimensional Pain Inventory (MPI), which operationalizes the experience of living with chronic pain (i.e., how a significant other responds to your pain). This program is based on the responses of over 700 heterogeneous chronic pain patients from five separate pain programs. Forty-two percent of this sample were back pain patients. This program includes a Multiaxial Assessment of Pain (MAP) which
operationalizes correlates of chronic pain into three parts: (a) psychosocial; (b) significant others responses to displays of pain and suffering; and (c) an activities checklist. A total of 52 questions are answered on a Likert-type scale. Part I of the MAP operationalizes the psychosocial axis, and parts II and III operationalize the behavioral axis. Part I is comprised of five scales designed to assess chronic pain patients: (a) pain severity; (b) interference; (c) life control; (d) affective distress; and (e) support. Part II assesses the frequency of the rate of behavioral responses by significant others to their displays of pain and suffering: (a) punishing responses, (b) solicitous responses, and (c) distracting responses. Part III is comprised of an activities checklist: (a) household chores; (b) outdoor work; (c) activities away from home; and (d) social activities. There is also a general activity scale. Patients are classified into one of three prototypes (with estimated probabilities of error) based on their responses: (a) dysfunctional; (b) interpersonally distressed; and (c) adaptive copers. Practitioners then decide the structure of their patient's therapy based on their prototype. A small percentage of patients will have non-prototypic profiles and will be labeled as: (a) a hybrid profile (represent aspects of more than one prototypic profile); (b) an anomalous profile (scores make no sense); and (c) unanalyzable (too much missing data). Kerns et al. noted that this classification system may facilitate patient assessment, professional communication, and treatment planning. These are "average" patient MPI profiles, and the practitioner should review the set of answers to understand each patient as an individual. The MPI program is useful in informing the
practitioner how well the chronic pain patient is coping and the areas of concern, but does not provide insight into the patient’s subjective experience of living with chronic pain.

Phenomenological Research and Grounded Theory

Phenomenological research designs seek to understand how people construct their internal realities. These qualitative designs analyze human awareness to describe, clarify, and understand it (Polkinghorne, 1983). Phenomenological research is done by retaining the perspectives of the people being studied rather than relying on outside observers.

The purpose of this study was to understand the personal experience of living with chronic pain; therefore, a phenomenological research approach was utilized: "It is the comprehension of the meaning of another person’s experience, which requires the special mode of inquiry considered to be phenomenological" (Hoshmand, 1989, p. 22). The meaning attached to behaviors is the focus of inquiry, as opposed to the behaviors themselves (Nielsen, 1990). Human behavior cannot be understood without referring to its meanings and goals. In other words, stripping human behavior of context, invalidates the conclusions. For theories to be valid, they need to be based in qualitative research (Glaser & Strauss, 1967).

The intent of this study was to develop a grounded theory of experiences and processes associated with chronic pain. The general question guiding the research was, "What psychosocial process are associated with chronic pain?". Grounded theory methodology, based on the personal perspectives of those who live with chronic pain, was chosen to identify and describe these experiences. Rennie (1994)
described grounded theory as aiming to understand, discover, and represent the meaning of a phenomenon as experienced by participants. Using both inductive and deductive methodologies, the resulting theory is "grounded" in empirical data (Rose & Jevne, 1993). The grounded theory approach is characterized by the simultaneous ongoing collection, categorization, and interpretation of data (Glaser & Strauss, 1967). Theory is not imposed a priori, but rather is grounded in direct experience. The theory emerges from the data, rather than being verified by the data. No hypotheses are used, and there is no linear plan of investigation. Importance lies in how well the guidelines used are reported, rather than in how closely available guidelines are followed (Patton, 1990). A detailed description of the analysis conducted based on grounded theory methodology will be provided in Chapter III.

Research Objectives

This study explored the following research objectives:

(a) to examine the unique subjective experience of people living with chronic pain;
(b) to identify similarities and differences among the participants' subjective experiences;
(c) to identify and compare specific effects of patients' chronic pain on their life events (i.e., marital relationship, work, and social relations);
(d) to identify and compare coping strategies for dealing with chronic pain.
CHAPTER 3

METHOD

Overview of Study

Participants in this study were former patients of the Chronic Pain Management Program in Dodd Hall, a rehabilitation hospital at The Ohio State University. The Chronic Pain Management Program (CPMP) is a three-week outpatient program that assists people with pain in becoming healthier and more self reliant. General goals of the individualized program are: (a) to improve general physical condition; (b) to eliminate the use of medications; (c) to return to vocational activities; and (d) to learn alternative methods for pain management. This interdisciplinary program includes medical care, psychological services, nursing services, physical therapy, and occupational therapy. The researcher was involved providing psychological services for six months (September-February of 1995); however, the researcher did not interview the clients with whom she worked. Participants considered for the study met the following requirements: (a) living with chronic pain (duration longer than three months); (b) completion of the three-week Chronic Pain Management Program at Dodd Hall during 1993-1995; and (c) not have participated in the Program during the time the researcher was involved in it.
This study was concerned with generalizing the results only to people with similar characteristics as the sample. Therefore, sampling did not follow a random procedure. Instead, the study was concerned with (a) understanding the perspective of each participant; and (b) finding commonalties and differences among their experiences. Depth, rather than breadth, is most appropriate when exploring questions that have not been adequately addressed in previous quantitative research. Therefore, a small heterogeneous sample would be most effective. The researcher intended to use "purposeful" sampling, meaning that participants would be chosen based on how their characteristics and experiences could contribute to understanding the chronic pain experience (Strauss & Corbin, 1994). The characteristics that were focused on were sex, age, ethnicity, race, religion, duration of pain, and location of pain. The preceding criteria were not listed in any order of importance, since each criterion was important. Initially, in order to have a heterogeneous sample, participants who offered diversity to the sample were contacted first. The order and rationale for contacting potential participants were as follows: (a) the first two were a Caucasian male and female; (b) the third was an African American male; (c) the fourth reported that her pain was at a different location; and (d) the number of respondents willing to participate slowed down, and therefore the researcher decided to contact everyone who was interested. The 10 people, from a total of 50, who expressed interest in participating, were contacted. The final sample consisted of six participants. The other four participants were not included because
they could not come to Dodd Hall or could not be reached by phone to schedule a meeting time.

Recruitment Procedure

The Ohio State University guidelines for using human subjects in research were followed, and approval was obtained. In order to access participants' demographic information, permission for research access to medical information was obtained from The Ohio State University Medical Center. Statements, acknowledging the confidentiality of patients' demographic information, were obtained from the director of the program, the secretary, and the secretary's student assistant in order to use their aid in the computer search for demographic information.

Participant recruitment was conducted by the director of the Chronic Pain Management Program. She reviewed her listings of past participants of the program to identify individuals who met criteria for inclusion. Only individuals who participated in the program during the years of 1993 to 1995 were contacted due to (a) unclear coding of previous records (current director took tracking of records over in 1993), and (b) the exclusion of patients who had worked with the researcher (September, 1995+). The secretary obtained potential participant addresses and phone numbers and assigned code numbers (1-50). A preset number of 50 potential participants (number limited by cost of mailing supplies) were contacted from a possible list of 68 (the secretary was asked to go down the list of names until 50 names complete with addresses and phone numbers were obtained). The director sent a recruitment letter to each of these 50 potential participants (see Appendix A). This letter was reviewed and revised by the chronic pain
director and a graduate student intern at Dodd Hall. Through the letter, potential participants were informed of the goals and nature of the study and the time required, their voluntary participation, and their option to withdraw from the study at any time. The letter contained a self-addressed stamped response card which included their code number (see Appendix B). The potential participants were requested to return the card stating whether or not they wished to participate in the study. Once former patients indicated a willingness to participate, the director gave their names and phone numbers to the researcher. Participants were contacted by phone to schedule an interview site and time and to answer any questions (see Appendix C).

Participants

Of the 50 participants who were contacted by mail, 20 replied (40%). Ten (20%) responded that they would like to participate, and ten (20%) declined to participate; 26 (52%) did not respond, and four (8%) envelopes were returned due to resident no longer living at that address. There may have been a possible drug/alcohol problem in the population that did not respond. Of the 10 potential participants, only six (60%) took part in the study. The characteristics of these six participants are outlined in Table 1. As shown in Table 1, four of the participants were females (67%) and two were males (33%). Their ages ranged from 34 to 66 with a mean of 49. All were Caucasian. The African-American male, who volunteered, could not participate due to a medical emergency that resulted in a lengthy hospital stay. Their dates of injury ranged from 1980 to 1992. Four (67%) participated in the program in 1993 and the other two (33%) in 1994. They all had at least
two locations of pain. Although five out of the six participants had back pain, the results of this study are not specific to individuals with chronic back pain. Of the other four potential participants who were not included in the study, one could not come to Dodd Hall for the study; two did not return phone messages, and one did not answer the phone and did not have an answering machine.

<table>
<thead>
<tr>
<th>Names</th>
<th>Gender</th>
<th>Age</th>
<th>Ethnicity</th>
<th>Religion</th>
<th>D.I.</th>
<th>Y.P.</th>
<th>L.P.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brian</td>
<td>M</td>
<td>66</td>
<td>Caucasian</td>
<td>Catholic</td>
<td>88</td>
<td>93</td>
<td>b,rl</td>
</tr>
<tr>
<td>Sam</td>
<td>M</td>
<td>44</td>
<td>Caucasian</td>
<td>Christian</td>
<td>81</td>
<td>93</td>
<td>k,b,h</td>
</tr>
<tr>
<td>Jennifer</td>
<td>F</td>
<td>42</td>
<td>Caucasian</td>
<td>J.W.</td>
<td>80/82</td>
<td>93</td>
<td>djd,b</td>
</tr>
<tr>
<td>Kelly</td>
<td>F</td>
<td>55</td>
<td>Caucasian</td>
<td>None</td>
<td>87</td>
<td>93</td>
<td>b,hi,t</td>
</tr>
<tr>
<td>Tina</td>
<td>F</td>
<td>53</td>
<td>Caucasian</td>
<td>Baptist</td>
<td>90</td>
<td>94</td>
<td>h,n,s</td>
</tr>
<tr>
<td>Bonnie</td>
<td>F</td>
<td>34</td>
<td>Caucasian</td>
<td>None</td>
<td>92</td>
<td>94</td>
<td>b,s,n</td>
</tr>
</tbody>
</table>

Note. Pseudonyms were used for confidentiality.

D.I. = date of injury; Y.P. = year in program; L.P. = location of pain; J.W. = Jehova's Witness; b = back; rl = right leg; k = knee; h = head; djd = degenerative joint disease; hi = hips; t = tailbone; n = neck; s = shoulders.

Table 3.1: Personal characteristics of participants.
Confidentiality was maintained. Any information that could identify participants was omitted when the interviews were transcribed.

**Settings and Characteristics of the Interview Process**

All participants met individually with the researcher or another psychology intern in their respective offices at Dodd Hall. The interview setting was selected due to convenience of scheduling time (interviewer could meet with participants in-between work-related activities) and with a minimal amount of distractions. The other psychology intern, who conducted two interviews with one participant, is a 29-year-old Caucasian female who has a master’s degree in counseling psychology. She is currently working with brain injured patients in Dodd Hall and is completing her Ph.D. in counseling psychology (at The Ohio State University.) The participant she interviewed was determined by mutually convenient dates and times. Interviews were conducted weekdays during business hours. Participants were reimbursed for their parking by the researcher ($2 each time).

The first session lasted approximately 60 minutes and consisted of a semi-structured interview (see Appendix D). The questions and their order were reviewed and revised with the help of the chronic pain program director and a graduate student who was interning in the stroke and orthopedic unit. The second session lasted approximately 45 minutes with the purpose of: (a) verifying the accuracy of the transcribed interview; and (b) comparing and refining the researcher’s interpretation of the data.

Three of the six participants also attended a 60-minute group discussion in a group room at Dodd hall to discuss the interpretation of
the data across the sample. All participants were asked to attend the
group discussion and filled out a schedule of convenient times at the end of their second interview. They were later notified by phone of the date and time set so that all could attend. One of the three who did not attend phoned later that week apologizing for having missed the meeting.

The group interview included a discussion of authenticity criteria that related to outcome, product, and negotiation (Guba & Lincoln, 1989). These criteria ensure that the participants’ rights have been honored and that their "constructions have been collected and faithfully represented" (Lincoln & Gubba, 1989, p. 245). Authenticity criteria are divided into the following five components: (a) fairness-degree to which different constructions and values are solicited and honored; (b) ontological authenticity—degree to which personal constructions are expanded and elaborated; (c) educative authenticity—degree of participants' awareness and understanding of other's constructions; (d) catalytic authenticity—degree to which participants are stimulated into action; and (e) tactical authenticity—degree to which participants are empowered to act.

In the group interview, participants signed a consent for confidentiality form (see Appendix E) and were given a worksheet to be used as a guide for the discussion (see Appendix F). The topics on the worksheet related to concepts heavily focused on by participants during their interviews. For example, for one topic participants were asked to choose which of these fit for them better: “socialize with others” or “feel isolated.” Then they had to further elaborate according to the
following questions: "How did you come to this?"; "How does it affect you?"; and "What can you do to change it?". The investigator asked participants to refer back to the worksheet for the next topic or when the discussion strayed off topic (e.g., eating before going supermarket shopping in order to spend less). As the seven topics were discussed, each participant had the opportunity to elaborate. After all seven topics were discussed, the investigator summarized the discussion and asked participants for insights. The investigator then asked the participants how they experienced the group discussion. Then the investigator thanked the individuals for participating in the study and sharing their experiences. She suggested that they create support networks to help others with chronic pain through brainstorming possibilities for support systems.

Data Collection

Participants were informed that the interviews would be audiotaped and transcribed, with direct quotes used as the primary raw data. Two tape recorders (a micro-cassette recorder and a radio-cassette recorder) were used in all first interviews and four of the second interviews to minimize loss of data. To maximize available time, demographic information was obtained from participants filling out an information sheet at the beginning of the first interview (see Appendix G).

The interview with the first participant served as the trial run and was used to improve the initial interview in terms of appropriateness of questions, time management, and equipment. The data obtained from this participant was included in the data analysis. The
interview procedure continued to be refined with each interview based on
the interviewer's and interviewee's experiences as noted in field notes.

Field Notes

To increase methodological rigor, the researcher's expectations,
reactions, and observations were recorded. The researcher's personal
beliefs were "bracketed"/recorded before the study began. For example,
the researcher expected that chronic pain patients began experiencing
pain during a time they were unhappy in their life, and that they have
difficulties in their relationships (see Appendix L). These notes were
included in personal notes. The four types of field notes recorded
before and after each interview were (Lincoln & Guba, 1985): (a)
observational notes; (b) methodological notes; (c) theoretical notes;
and (d) personal notes.

Observational notes. Observational notes captured the nonverbal
expressions of the co-participants and the situational variables
affecting the interview (see Appendix I). For example, observational
notes helped the investigator to capture the mood of the participants,
which may have influenced the interview. Jennifer appeared anxious at
the beginning of the interview, bouncing her knee and shaking her hands.
These behaviors ceased by the end of the interview as the participant
noted she was more comfortable. Observational notes also helped to keep
track of the type and number of disturbances (such as phone ringing,
knocks on door, and tape turning) and the times when they occurred.

Methodological notes. The second type of notes taken were
methodological notes, which involved the methodological process and any
improvements or modifications needed (see Appendix J).
Methodological notes helped in keeping track of the quality of recording under different circumstances. Transcriptions were made from the microcassette tapes using a Norelco microcassette dictation unit. After the fourth second-interview, the researcher realized that the distracting static on the microcassette, which resulted in minor loss of information, was coming from having the radio-cassette recorder on. The researcher, therefore, decided to discontinue use of the radio-cassette recorder. Fortunately, all interviews were properly recorded, and the rest of the interviews were easier to hear. The refinements related to time management and equipment that took place are listed as follows: (a) asking participants not to cover their mouths or to walk around the room while speaking; (b) asking central questions earlier in the interview; (c) asking the secretary to hold incoming phone calls; (d) interrupting and refocusing the participants who stayed too long on one topic; (d) being more explicit with time at the beginning of the interview; (e) not using the stereo as back up taping; and (f) bringing extra tapes in case the tape being used malfunctioned. One new question was added and three questions were refined. The new question asked about the effect of pain on sexual activity. The refinements related to making the questions either more specific or phrasing them in layman terms.

Theoretical notes. The third type of notes used were theoretical notes, which included the investigator's interpretations and hypotheses of potential categories and connections emerging from the data (see Appendix K). Theoretical notes helped to keep track of new concepts, such as living like a "robot". Several participants noted they felt "robot"-like in their everyday routines because (a) they were no longer
spontaneous; (b) routine chores were carefully planned and coordinated so as to decrease pain; and (c) they were not enjoying anything they did. They felt as thought they were just existing to do chores.

**Personal notes.** In order to minimize bias in interpretation, the investigator's beliefs and expectations were "bracketed"/recorded both before and during data collection and during data analysis through personal notes (Husserl, 1913) (see Appendix L). These notes helped keep track of the interviewers' expectations, their reactions to the interview content and process, and any modifications to their expectations. For example, personal notes recorded the interviewer's surprise reactions to unexpected issues. To illustrate, the investigator had expected chronic pain patients not to be in touch with their feelings. Conversely, most participants were in touch with them, but chose to hide their feelings of pain and loneliness from their loved ones in order to keep them happy and comfortable. In another incident, the interviewer became aware of not having given much thought to how pain affects the participants' sexual relationships. Perception of ability to fulfill their partners sexually reappeared throughout the interviews. These supplementary notes permitted the investigator to move back and forth between the data, generating strategies for collecting data, and emerging themes (Lincoln & Guba, 1985).

**Credibility of Data Interpretation**

Several techniques were included to improve the credibility of the data. Through triangulation, the congruency of independent measures (Lincoln & Guba, 1985), bias was reduced. The use of triangulation in qualitative research was borrowed from land surveying. In land
surveying, greater accuracy is obtained when the same object is measured through more than one perspective. In qualitative research, therefore, rigor is increased when concepts are verified by more than one method or person. Three forms of triangulation were used: (a) multiple interviewers; (b) multiple coders; and (c) multiple sources.

**Multiple interviewers.** The investigator conducted first and second interviews for five participants, and the group interview. A second interviewer, a 29-year-old female Caucasian doctoral student working in brain injury at Dodd Hall, conducted the first and second interviews for one participant. Another Caucasian female in her thirties, who is a doctoral psychology intern at Dodd Hall, compared interviews conducted by each of the interviewers for differences in content and questions. Her comments regarding her comparison of the interviews were: "similar enough," "got to basic ideas with slightly different questions," and "elicited same type of information."

The researcher would have preferred to utilize a third interviewer in order to increase rigor through triangulation. In fact, a third interviewer was scheduled. Unfortunately, due to a decline in participant responses, the third interviewer did not have a participant to interview.

**Multiple coders.** After the interviews were transcribed, two people in addition to the investigator coded the data. They were two Caucasian males, ages 25 and 26. These individuals were, respectively, involved in the fields of real estate and hotel management. Each was given copies of all first and second interviews and the code list. Each was then asked to code the highlighted units (multiple coding of a unit
was permitted). Codes with similar meanings were considered agreements. For example, "helpless no control" and "totally helpless" were considered to agree. The total number of agreements was then divided by the total number of codes (agreements and disagreements). Inter-rater reliability was 85%. Attaching the additional codes to the meaning units (multiple coding) resolved disagreements. For example, the researcher labeled a meaning unit with "helpless"; whereas, one of the other coders labeled it with both "helpless" and "guilty." Both labels were kept.

Multiple sources. Participants and experts were consulted about the accuracy of the data and development of grounded theory.

Through member-checking, participants were asked for their input on the accuracy and interpretation of the data and emerging theory. Participants were given a copy of their interview transcript at the beginning of the second interview. They were asked to read it over, to be on the lookout for any discrepancies, and to help with identifying words and expressions that were hard to hear on the tape recording. Participants were also given the opportunity to elaborate on anything they might have thought about since the first interview or anything that emerged from reading the transcript. One participant made typographical changes; two commented on the previous interview, and three noted that they had nothing to add. Tina and Jennifer commented on their previous interview. Tina said, "I see I don’t finish a lot of my sentences... that’s something I need to work on." Jennifer replied,

... the only thing that I think is important with chronic pain is that they get some sort of support form the doctor in charge somehow, the therapist, maybe a psychiatrist who knows about
medication. You really need someone to work with cause you can’t do it by yourself.

The rest of the second interview was utilized for follow-up questions and clarifications.

Six experts were utilized to reduce bias in the development of the grounded theory model. The following individuals read the first and second interviews for two participants and compared them to the general model: (a) A Caucasian female psychology intern, in her 30’s; (b) A 30-year-old Caucasian female psychology doctoral student, working in the brain injury unit; and (c) A Caucasian male rehabilitation psychologist in his 40’s. The chronic pain director, a Caucasian female rehabilitation psychologist in her 40’s, reviewed the grounded model for conceptual verification. She had seen this study’s participants in Dodd Hall waiting for their interviews and remembered them from when they participated in the chronic pain program in 1993 and 1994. She stated that the grounded theory model fit the sample, but that the sample was not representative of the chronic pain population, due to reasons such as willingness to change (see chapter 5). Also, the researcher’s doctoral adviser reviewed the model and offered further insights and reading material. She offered conceptual clarity and suggested readings by Yalom and Levine to aid in formulating the model (Refer to Chapter 5 for a discussion). The experts’ reactions to how the researcher interpreted the data are also reported in Chapter 5.

The characteristics of the investigator also strengthened credibility. Through graduate work in counseling psychology, the investigator acquired skills in interviewing. Through a six-month internship with chronic pain patients, the investigator became educated
in the field and familiar with this "culture." Knowledge of the "culture," as noted by Lincoln and Guba (1985), increases the credibility of the study.

Data Analysis

It was essential that the systematic analysis guiding this study was recorded accurately (Patton, 1990). Data analysis followed phenomenological and grounded theory procedures. The study was phenomenological in that the participants' personal experiences were sought; it followed grounded theory procedures in that theory was grounded in data (Glaser & Strauss, 1967). Data analysis included the following phases: (a) reading of transcripts; (b) coding and grouping of data; (c) identifying of themes; and (d) forming of the grounded theory model. Analysis cycled through these phases, which may occur simultaneously (e.g., identifying themes while coding the data.)

Reading of transcripts. Transcripts were read six times by the investigator. The interviews were read repetitiously to grasp the full essence of each participant's experience and to become aware of repeating themes.

Coding and grouping of data. Data collected from the audiotaped interviews were transcribed and then analyzed using HyperRESEARCH 1.57 for Microsoft Windows (Researchware, Inc., 1995). This software package eased handling and organizing the cumbersome transcript data.

The data were coded in meaning units of one to several sentence in length. For example, Brian said,

Oh, they're [goals and dreams] totally destroyed... my retirement program... that's another reason why my wife could have left me... that just really destroyed her personal life ... I just really
feel bad about that. She never complains. I want to do so much for her, but I can't.

This meaning unit was labeled with the code words "helpless" and "guilty." Meaning units were then compared to see if they referred to the same idea and could be grouped under a more abstract category. For example, "helpless" was subsumed under the more inclusive category "no control," and "guilty" was subsumed under the category "internalize negative." Data were categorized according to the study's research objectives: (a) to examine the unique subjective experience of living with chronic pain; (b) to identify similarities and differences among the participants' subjective experiences; (c) to identify and compare specific effects of chronic pain on their life events and roles; and (d) to identify and compare coping strategies for dealing with chronic pain.

The analysis resulted in a total of 331 meaning units, with 65 codes grouped into 11 categories. The process of coding and categorizing helped the researcher develop a more thorough understanding of the data. The data and its labeling were used for verification of emerging themes and theories. A list of codes, how they were grouped, and how many times they appeared for each participant follow:
<table>
<thead>
<tr>
<th>CATEGORIES AND CODES</th>
<th>FREQUENCY OF CATEGORY</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lost direction/Searching for direction</td>
<td></td>
</tr>
<tr>
<td>Need external expectations</td>
<td>Bonnie...0</td>
</tr>
<tr>
<td>Need others to function</td>
<td>Brian....3</td>
</tr>
<tr>
<td>Schedule gives control</td>
<td>Kelly....20</td>
</tr>
<tr>
<td>Lost focus</td>
<td>Tina.....2</td>
</tr>
<tr>
<td>Lost identity</td>
<td>Sam......0</td>
</tr>
<tr>
<td></td>
<td>Jennifer.10</td>
</tr>
<tr>
<td>No control</td>
<td></td>
</tr>
<tr>
<td>Close off (from others) forced</td>
<td>Bonnie...3</td>
</tr>
<tr>
<td>Homebound forced</td>
<td>Brian....19</td>
</tr>
<tr>
<td>Helpless no control</td>
<td>Kelly....4</td>
</tr>
<tr>
<td>No control over pay (deciding which activities will be worth the pain)</td>
<td>Tina.....5</td>
</tr>
<tr>
<td></td>
<td>Sam......1</td>
</tr>
<tr>
<td>Lost battle with pain</td>
<td>Jennier..5</td>
</tr>
<tr>
<td>Prisoner</td>
<td></td>
</tr>
<tr>
<td>Reason (fate dictated circumstances)</td>
<td></td>
</tr>
<tr>
<td>Totally helpless</td>
<td></td>
</tr>
<tr>
<td>Internalize Negative</td>
<td></td>
</tr>
<tr>
<td>Bitter internalize</td>
<td>Bonnie...3</td>
</tr>
<tr>
<td>Hide from self</td>
<td>Brian....16</td>
</tr>
<tr>
<td>Depressed</td>
<td>Kelly....7</td>
</tr>
<tr>
<td>Depressed-blind (blind to the cycle of depression)</td>
<td>Tina.....8</td>
</tr>
<tr>
<td>Discrimination -taken personally</td>
<td>Sam......2</td>
</tr>
<tr>
<td>Guilty</td>
<td>Jennifer.7</td>
</tr>
<tr>
<td>Guilty -can’t be all (that others expect you to be)</td>
<td></td>
</tr>
<tr>
<td>Guilty -financial (can’t provide)</td>
<td></td>
</tr>
<tr>
<td>Personality changed</td>
<td></td>
</tr>
<tr>
<td>Put down</td>
<td></td>
</tr>
<tr>
<td>Put down internalize</td>
<td></td>
</tr>
<tr>
<td>Put self down -hard time completing tasks</td>
<td></td>
</tr>
<tr>
<td>Choose to keep to themselves</td>
<td></td>
</tr>
<tr>
<td>Avoid having to defend yourself</td>
<td>Bonnie...3</td>
</tr>
<tr>
<td>Close off -own choice</td>
<td>Brian....12</td>
</tr>
<tr>
<td>Homebound</td>
<td>Kelly....14</td>
</tr>
<tr>
<td>Homebound -don’t feel like it</td>
<td>Tina.....6</td>
</tr>
<tr>
<td>Homebound -need a reason</td>
<td>Sam......1</td>
</tr>
<tr>
<td>Hide -embarrassed</td>
<td>Jennier..7</td>
</tr>
<tr>
<td>Hide -to spare</td>
<td></td>
</tr>
<tr>
<td>Robot out of habit</td>
<td></td>
</tr>
<tr>
<td>Sick of being bored</td>
<td></td>
</tr>
<tr>
<td>Taken forgranted -others’ time will be ruined</td>
<td></td>
</tr>
</tbody>
</table>

Table 3.2: Categories and codes used for analyzing data.
<table>
<thead>
<tr>
<th>Table 3.2 (continued)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Limited by Being Scared</strong></td>
</tr>
<tr>
<td>Scared of losing control</td>
</tr>
<tr>
<td>Scared of losing social security</td>
</tr>
<tr>
<td>Scared of people</td>
</tr>
<tr>
<td>Scared of real self</td>
</tr>
<tr>
<td>Scared of lack of control</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td><strong>Robot Life</strong></td>
</tr>
<tr>
<td>Act from fear</td>
</tr>
<tr>
<td>Robot because risk losing money</td>
</tr>
<tr>
<td>Act rationally</td>
</tr>
<tr>
<td>Robot because have to plan</td>
</tr>
<tr>
<td>Homebound fear</td>
</tr>
<tr>
<td>Robot necessity</td>
</tr>
<tr>
<td><strong>Have Control</strong></td>
</tr>
<tr>
<td>Act to reclaim</td>
</tr>
<tr>
<td>Hard time completing tasks - challenge self</td>
</tr>
<tr>
<td>Feel useful</td>
</tr>
<tr>
<td>Helpless -can fight to gain some control</td>
</tr>
<tr>
<td>Try to be self sufficient</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td><strong>Enlightened</strong></td>
</tr>
<tr>
<td>Deep awareness</td>
</tr>
<tr>
<td>Don’t have to be perfect</td>
</tr>
<tr>
<td>Examine self</td>
</tr>
<tr>
<td>Personality new</td>
</tr>
<tr>
<td>Right to feel bad</td>
</tr>
<tr>
<td>Thankful</td>
</tr>
<tr>
<td>Wants acceptance for real self.</td>
</tr>
<tr>
<td><strong>Externalize anger</strong></td>
</tr>
<tr>
<td>Bitter</td>
</tr>
<tr>
<td>Bitter externalize</td>
</tr>
<tr>
<td>Others discriminate</td>
</tr>
<tr>
<td>Examine illness</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td><strong>Focus on being understood</strong></td>
</tr>
<tr>
<td>Others don’t understand</td>
</tr>
<tr>
<td>No one cares to understand</td>
</tr>
<tr>
<td>Some try to understand</td>
</tr>
<tr>
<td></td>
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<tr>
<td></td>
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<tr>
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Identification of themes. Reading through the material many times, the researcher became aware of repeating themes. She then returned to the data for verification. The themes that the researcher became aware of and then analyzed were as follows: (a) control; (b) having needs that want to be met; (c) grieving the loss of identity; (d) reaction to life changes; and (e) reformulating a more developed self-concept. These will be discussed in Chapter 4.

Formation of model. The model was grounded in the data. As noted earlier, multiple sources were used to increase the rigor of the model. The model and supporting data will be provided in Chapter 4.

Concluding Remarks

This section has reviewed: (a) how participants were recruited and interviewed; (b) how rigor was increased through observational notes, methodological notes, theoretical notes, and personal notes; (c) how triangulation was demonstrated through multiple interviewers, coders, and sources; and (d) the non-linear analysis process of this study.

In the next section, you will be able to witness the private lives and thoughts of six individuals who have to live with chronic pain. "Thick description," direct quotations from the participants, will be used to support the model and to make the individuals come alive (Patton, 1990).
CHAPTER 4

RESULTS

This chapter presents the unique and common experiences of the six participants living with chronic pain. The nine sections of this chapter will cover the following: (a) individual profiles; (b) comparisons across individuals; (c) summary of the group interview; (d) follow-up with participants; (e) a grounded model; (f) negative case analysis; (g) feedback from experts; and (h) reformulation of the model. Thick description, the participants' direct quotations, will be used to support the grounded model. Quotations will be used sparingly and for clarification purposes in the individual profiles.

INDIVIDUAL PROFILES

For each participant, the following will be presented: (a) the interview context; (b) a biography; and (c) five themes. The themes were derived from the researcher reading the first and second interviews six times, coding and categorizing the data for a more thorough understanding (refer to Chapter 3) and then becoming aware of repeating themes. The themes are: (a) self-concept pre-injury; (b) self-regard post-injury; (c) control over one's life; (d) exploring the self-concept; and (e) the need to be accepted by others.
Brian

Interview Context

Brian’s two individual interviews were approximately seven weeks apart. His first interview had an easygoing pace. At times, though, I felt myself slipping into a counseling mode, which resulted in increased reframing of Brian’s verbalizations. This did not affect the content of the interview (refer to Chapter 4 for comments on multiple interviewers). Two interruptions occurred when I turned the tapes over. Brian was feeling down and seemed eager to open up. A knock on the door during this interview interrupted at one point.

Biography

Brian, a 66-year-old male, is currently married to his second wife and has nine children. After completing high school, Brian managed two large companies. He reported being happy with his income and described himself as a workaholic.

Brian injured his back six years ago lifting heavy boxes in the process of moving his two companies. While undergoing investigative surgery, cancer of the bladder was discovered. A year later, Brian suffered a stroke when he was building an addition to his house. The back injury, cancer, and stroke all led to Brian having to depend on social security. Other effects of his disability were his wife having to work, losing his retirement program, a drastic drop in income, and difficulty with sexual intimacy.

Brian went through the chronic pain program and a rehabilitation program for his stroke. At first, he hid his pain and loneliness from
his family. Later, he lost confidence in himself and became isolated and depressed. He blames himself for all that has happened.

**Self-Concept Pre-Injury**

Brian described himself as a "workaholic". Later in the interview, he noted having been a "joker," and "the life of the party." He said, "... I was always involved, people around, and I was the center of attention." He believed in mind over matter when it came to pain and was "belligerent." He was "... aggressive, confident, wasn't afraid of anything or anybody."

**Self-Regard Post-Injury**

When Brian came out of rehabilitation for his stroke, he said he was "still stubborn and fighting."

The third day, I had my wife strap me to my lawnmower. I don't rely on a walker, I don't rely on a wheelchair, I don't rely on a cane. I think my own personal fortitude is stubbornness. Slowly, he began to "regress." He started to blame himself: "It's pitiful what happened to me. So I can blame nobody else but myself," and to put himself down: "I just have become a pathetic, bitter, bitter person that's lost all respect for himself, dignity." He wanted to spare his family and friends from his disturbing feelings and so kept them all inside. He admitted, "I put myself, whether I am or not... into a good mood. It's a cover," and later added, "I get silly trying to hide it. But I don't let it completely get me down. Only if I'm by myself, then I give into the emotion." Brian has trouble hiding his feelings from himself and often puts himself down, "I am a partial man... I am... very, very disappointed in myself". He has lost self confidence and believes his wife backs this up, "I'm not useful. I've
caught my wife losing confidence in me, and it's rightfully so." He summarized his feelings by saying, "...I just have no self pride. I beat myself down so much. I don't have any. I really don't. I am quite disturbed, ashamed, disappointed."

**Control Over One's Life**

Brian spoke bitterly and sadly about giving into the pain and losing control over his life. Brian noted giving into the pain and "letting it take its course." "You don't live with the pain, the pain lives you." He offered a clear and vivid metaphor,

> How can you fight pain? I mean there's no results. It's a constant thing. When you go into a fight with a man, and he continues to beat the crap out of him time after time after time, you're going to quit going into there anymore. That's what I've done.

As a result, Brian felt he had a lack of control,

> I don't know why I get upset over what's happening all around. The evidence is you don't have any control over it, you know you don't have any control over it.

Brian was surprised at his realization during the interview of how much he wanted others to control his life and how he feared his own lack of control,

> And what it was the fact that while you're here [in the chronic pain program], every one of our steps was dictated. You do as your told. But when I go back home, I have to use my brain. When I want to do and what I want to do. And it was the fear of that... Fear of not being able to take care of yourself.

His fear of lacking control was also reflected in his dreams,

> I have some horrible nightmares. Horrible... and I'll wake up and try to shake them off and then go back to sleep and then go right back to my bad dream again. And it's always somebody getting hurt. But I can't do anything about it.

**Exploring the Self Concept**

Brian revisited his distressing thought, "How do I know what is me now?" Several times in the interview, He noted, "...what is reality?
I’ve been carrying this with me for so long, that it beat me to a pulp.”

He appeared desperate for an answer, yet scared at the same time,

I think in my mind that I’m more of a person than they’re willing to give me credit for. What would happen if I found out that I wasn’t? Then my world bubble would really burst.

The Need to Be Accepted by Others

Brian is aware of his desire to be accepted as he truly is now:

To be accepted as I really am... You get tired of putting out this comedy, foolishness in order to be included with people around you... if you really feel that you can make contact... a person would accept you as you really are.

Brian seeks acceptance, especially from his wife,

But... even when I do something and I do it right... every time I give myself praise, but I don’t get it from the outside even my wife. You try, and try, and try, and the one person your really want to please [his wife], you can’t.

Consequently, Brian is left with questions and feeling more lost,

“...why am I being shunned? Why am I being belittled?”

Sam

Interview Context

Sam’s two interviews were one week apart. The first interview was pleasant and extremely interesting. Sam was relaxed and in less pain than usual, and I was very alert and focused. The phone interrupted once during this interview. In the second interview, Sam was in a lot of pain and noted feeling uncomfortable in his chair. I, on the other hand, was eager to begin the session.

Biography

Sam is a 44-year-old divorced male who has one daughter he is currently helping to raise. He was an athlete in high school, hitchhiked across the United States to rock concerts at the age of 19, and became a Born Again Christian when he landed in California with his
friends. Sam enjoyed the physical nature of his work, which included construction and mining.

Sam was in a car accident at the age of 29 and spent 15 months in the hospital. Within a year, he lost both legs. For the next 15 years, he underwent 26 surgeries. His pain was concentrated in his back. A year after the accident, Sam got divorced and went back to school for two years. He was unable to return to physical labor and began a period of drinking, drugs, and isolation.

In the past five years, Sam has sought counseling and has been able to put himself back together. He is writing an autobiography, rebuilding race cars, doing art and photography, volunteering in a hospital, and participating in the Paraplegic Olympics (he has leg prosthetics). All these activities are helping him reclaim parts of himself. He enjoys helping raise his daughter and spent the entire summer with her. He noted being "self-actualized," being "happy," and "appreciating life." He claims that "spirituality" (the ability to examine oneself in a deep and meaningful way) has helped him be stronger than the pain and that his "near-death experience" has helped him see that his life is a bonus. In other words, he should have died and being alive is a reward.

Self-Concept Pre-Injury

Sam described how he used to be,

... I was always big and strong... I was able to do anything ... very physical person... I've always been an athlete and leaned on the physical side of my existence.

He also noted that he was always fascinated with religions. He enjoyed learning about different cultures and how they view reality.

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Self-Regard Post-Injury

After the accident, Sam noted that it was hard on his ego not to be working. He described becoming "more of a recluse" and not wanting to get close to others because he was still in a "transition" of coming back from the accident. With counseling, Sam started feeling more comfortable with himself and realizing that he was lucky to be alive: "I should have been dead, so it's all a bonus." He elaborated on this,

I would rather be this way than the way I was before cause I really had to confront myself... I had to look a little deeper into the bud. I think... I guess I always thought I should be dead... so everything was a real bonus. It's a pretty good life. I can do a lot of good things, I've seen a lot of good things. I'm pretty content. I feel pretty good about it.

He has found pride in the new opportunities that have come to him. These include physical activities: "In the disabled world now I'm talking; I'm a superman type guy cause I can get up and do so much stuff," and raising his daughter: "I help in raising her, and I love that."

Control Over One's Life

Sam feels that he can have control over himself and his life if he works hard at it. He speaks about having an "ongoing, wrestling bout" with pain and how he needs to be "stronger" than it. Spirituality helps him be stronger in this struggle. Sam is "fueled on passion" to reclaim those parts of himself that he lost and believes he has the power to change his life, even though it's tough.

I just don't think a lot of people know why they do what they do. Why outside forces are molding their lives and all that. They don't think they can change, but you can change. It's tough, but you can.

He also believes that we all have a "dark" side to our personality, but that we can "overrule" it.
Exploring the Self-Concept

Sam has been able to explore his self-concept through reading on philosophy and religion, therapy, and creative expression. First, Sam noted that "examining yourself" is actually spiritualism and that you need to become very spiritual to live. He defined being spiritual as being able to inspect his "habits" and "lifestyle." Second, Sam reported going to a psychiatrist to understand why he lived such a "reckless life" and that it helped him to be more comfortable with himself now. The following is an example of some of his creative self-explorations,

To tell your story is very therapeutic and even working on race cars is very therapeutic cause you’re putting something back together, I guess, you’re putting yourself back together.

The Need to Be Accepted By Others

Sam’s focus on being understood centered around the patients and staff of the Chronic Pain Program. He noted how no one can possibly understand chronic pain, unless they have lived with it, and was critical of the program for not "[going] very far to try to understand people and their experiences." He also made the point that the staff "should have went for the head more."

Jennifer

Interview Context

Jennifer’s interviews were two weeks apart and were given by the other psychology intern in her office at Dodd Hall. The interviewer noted that Jennifer was anxious (bouncing of the knee and shaking of her hands and voice) in the beginning of the first interview, but then Jennifer said she felt comfortable at the end of the interview. There
were two interruptions in the first interview due to a knock on the door and changing of the tape. Jennifer appeared more relaxed in the second interview.

**Biography**

Jennifer is a 42-year-old single female with two sons, with one son living at home. She has a ninth grade education and enjoyed working as a waitress/cook. She reports a history of bladder problems and "jumpy legs."

In 1979, Jennifer tripped over a rug at work and began having back problems. In 1983, her back injury was agitated when her sister fell on her from behind. Jennifer was told she had degenerative disc disease and neuropathy in her legs.

Jennifer, who was no longer able to work, went on social security disability. She went back to a technical school, but could not sit still for the final exam and failed it. She was angry that she could not work and that doctors would not help her with pain medications. Jennifer noted having to rely on "street drugs." Buying "street drugs" caused her guilt, and she was disapproved of by her church.

Jennifer reported having many tragedies occurring in the recent past. These include the death of several family members, being in two car accidents, and being "beaten up" twice. She has panic attacks when she is around people, which restricts her to her home much of the time. She also has a fear of moving (i.e., jumping, running) and is trying to combat her fear by jumping on a trampoline. Jennifer has placed her son in therapy hoping that he will understand her inconsistent behavior that is related to her pain and use of drugs.
Self Concept Pre-Injury

Jennifer described herself before her injury as a perfectionist with a “strong sense of doing the right thing.” She enjoyed “... being around people, serving them [through waitressing], and making them happy.” She also reported always having had strong religious beliefs.

Self-Regard Post-Injury

Jennifer no longer feels comfortable around people and has panic attacks when she has to leave her house. She noted, “I’m afraid that something’s gonna happen and there’s nobody to bail me out. It’s all me now.” She does not socialize or have fun anymore. She reported being a “compulsive overeater,” which is related to her “addictive personality,” although she no longer feels like she has to be a perfectionist.

Jennifer also reported feeling like a “robot,”

I have to do certain functions. They’re programmed. But there’s no... quality of life for me is spontaneous, doing things, enjoying life. And right now, I don’t enjoy life... I don’t feel like much of a person now.

Control Over One’s Life

Jennifer spoke about control in terms of controlling her pain and also in terms of controlling herself and her life. Statements about control in relation to pain to follow.

... when I start getting that little bit of relief from the pain [from street drugs], I don’t know where to stop. That’s why I really feel like I need to be in control... It’s kind of scary that maybe I have control over all this amount of pain I go through.

As the interview continued, Jennifer spoke about control in relation to herself,

... it’s like that 10% of people that are between a rock and a hard place and can’t get nowhere, but you can’t get out of the system, you know, to do something for yourself... I don’t feel I have control over making my body do what my mind tells me I have
to... I feel like I’m just existing right now just to do what I have to do... I feel like I don’t have control over me.

Exploring the Self Concept

Jennifer has started reading psychology books because they are “helpful.” She said,

Things [books] to really try to understand what it is that’s motivating me, is the problem that I have something that I create for myself, I’m creating... Can I change patterns that have been in my brain for so long.

Having passed her 40th birthday, she has been motivated to redefine herself,

It’s like all of a sudden who I am and what I am are changing again. I don’t want to be the person that just sits there, I want to go and do things again.

The Need To Be Accepted By Others

Jennifer focused on her younger son understanding what her pain is like. She explained how she ties a rubber band tightly around one of his fingers so he can actually feel what she feels. She also spoke about doctors not understanding or accepting her as a “whole” person.

It’s like she’s [her new doctor] not looking at the whole picture of who I am... You have doctors that don’t understand why you’re feeling what you’re feeling. You’re not supposed to be feeling that.

Kelly

Interview Context

Kelly’s interviews were two and one-half weeks apart. During the first interview, Kelly spoke almost continuously, and it was hard to interrupt her. Kelly had been in bed for three days before the second interview and felt as though she was “ready to blow up.” She noted she wanted a change in her life.
Biography

Kelly is a 53-year-old divorced female with one son. She lives alone with her two cats. After graduating from high school, she worked on an assembly line for a grocery store for 32 years. Kelly described herself as a "workaholic;" work was her entire social life.

In 1987, she fell at work, injuring her knees, back, and right hip. She was diagnosed with Fibromyalgia. Kelly continued to work intermittently for two years (work and bed rest) until work was no longer feasible. She went on social security and had her pension, which approximated her previous income.

Kelly now stays in bed for days unless she has an appointment that she has to go to. She feels like a "prisoner" in her home because she overrestricts her activities from fear that her social security will be cut off. She believes that "everything happens for a reason," including her injury. She is currently attending Fibromyalgia support groups and has begun individual counseling. Kelly is currently searching for another outlet as a replacement for work.

Self-Concept Pre-Injury

Kelly saw herself as a "workaholic" and felt "needed and useful" at her job. She prided herself on "earning her checks" and never having "any complaints out of the bosses." Her whole self concept centered around work: "It was just that to me work was everything." She saw herself as a "giver," always helping those older than she with errands and rides.
Self-Regard Post-Injury

When Kelly had to retire, she was “shocked.” She has trouble realizing that she’s not on welfare and feels as though she’s getting something she doesn’t deserve. The only way she feels needed now is by her cats who enjoy her company. Kelly has felt more “snappy” lately because she doesn’t feel understood. Everything has become more of a hassle, rather than a pleasure. She only gets out of the house for things she has to do. She is afraid to do things. “I find myself scared, more scared to do things.”

I get disgusted with myself because I can’t do the things I used to do. I can’t help take care of the people that I used to... I get disgusted with myself because I can’t do the things that I used to do.

Kelly feels lost and directionless, “I don’t know what to do. I’m at the point where I really don’t know right now.” At the same time, she feels the need to be active, “... I’m really getting tired of doing nothing.”

Control Over One’s Life

Kelly feels in control when she or her mom have to go to an appointment and, therefore, she is active and out of the house. She noted, “I really bounce back and forth... sometimes I feel I got a little bit of control and other times I don’t have any control.” She stays in bed, though, unless she has an appointment. Kelly noted that social security has taken control of her life.

... when I got industrial [disability compensation], industrial rules your life. They got control of you... they tell you where you can go and what you can do, and when you can do it.
Exploring the Self-Concept

Kelly appears to be evaluating her lifestyle. "So right now I’m trying to figure out what can I do. Because right now I feel like I’m a prisoner." She has begun to research her illness, and this activity is giving her a purpose, "... I’m trying to read up on it, and I have a whole big pile of paperwork, and trying to read up on it, and I associate myself with it." She is also beginning to explore the relation between cause and effect in her sedentary cycle,

So now I don’t know whether I fell out because I didn’t have nothing to do or I would have fell out anyway because I was hurting so much... Like I said, I think what gets me is a bad mood and then I get snappy. My own doing, that’s what I told the psychologist. I said I’m my own worst enemy cause I sit and fight with myself and then I get mad at them.

The Need To Be Accepted by Others

Kelly spent much of the interviews talking about how her mother and friends do not understand that because she is in pain, she cannot do what she was able to do before. Kelly feels guilty that she cannot help her mother and older friends by running errands like she used to, and, therefore, has a hard time feeling accepted by them. Kelly does feel accepted by her two cats, "... they know you, and they know when I don’t feel good and they give me extra attention...."

Bonnie

Interview Context

Bonnie had her interviews four days apart. Her interviews were shorter than those of the other participants due to her conversational style which was short and to the point. In the second interview, Bonnie tended to agree with my interpretations and did not offer many elaborations.
Biography

Bonnie is a 34-year-old married female, who lives with her husband. Bonnie graduated from high school and took some college courses. She has held various physical jobs, such as housekeeping and most recently outdoor landscaping. Bonnie sees herself as an outdoor person and enjoys outdoor activities.

In 1991, her jeep flipped over, and she was thrown out. Bonnie suffered many fractures, and she was left with chronic back pain. She was no longer able to continue with her landscaping position and eventually found an enjoyable job as a professional party decorator. Bonnie still tries to involve herself in outdoor activities, but in a non-painful manner. Bonnie feels lucky to have survived the accident and enjoys each day at a time. The pain, though, has caused some strain in her marriage. Bonnie often sleeps on the couch to avoid sexual intimacy, which increases her back pain.

Self-Concept Pre-Injury

Bonnie described herself as a happy, spontaneous person, "I’m just usually real happy and loud and cheery... I’d do handsprings for no reason." She also noted how she’s an "outdoor person" and enjoys outdoor physical activities.

Self-Regard Post-Injury

Bonnie spoke about how chronic pain has changed her lifestyle.

I go to parties and everybody plays volleyball... I feel like I’m on the outside. Which is a lot of the time because I can’t do the things that I used to do... I get tired real easy.

She feels incomplete now that she can’t be physically active to the degree that she used to be and that she can’t be physically spontaneous,
"... but there's one part of me that's not right, and it's like an imperfection." She hides behind others and creates a false facade for herself. "I act fine cause nobody wants to hear about me all the time." Fortunately, she noted that her family has become a lot closer since her accident, and she appreciates this closeness and lives for every moment.

Control Over One's Life

Bonnie said she moved from not feeling in control after her accident to later feeling in control most of the time.

I didn't have control for a while, but that wasn't the way I was gonna live... I just decided I wasn't gonna sit at home on my couch and do nothing, cause I'm not old yet, I'm not ready to rock.

Bonnie decided to be in control of her behavior, which meant being aware of her motivations, "I try to keep the upper hand. When I don't feel like doing something, I make sure it's just me and not just an excuse not to go."

Exploring the Self-Concept

As far as exploring herself, Bonnie focuses on how she deals with pain affecting her lifestyle. She tries to do what she wants while ignoring the pain,

It's just that I'm not letting it get me down. I know it's gonna be there. You have to have an attitude about how you're going to be about that being there all the time. It's gonna be there, so either ignore it or deal with it.

The Need To Be Accepted By Others

Bonnie felt listened to and accepted at the Chronic Pain Program.

Coming here, I felt like I had backup when I said this is what I'm dealing with and it's real. And other people feel the same way. It made me feel like I had the right to feel the pain, you know... It's like O.K., it wasn't my fault. But... nobody asks to have something happen to them like that. And I have the right to feel bad because I hurt myself really bad.
Tina

Interview Context

Tina had her interviews five weeks apart. During the first interview, she noted feeling uncomfortable sitting in the chair and tended to walk around the room at times. She reported having lower levels of pain than usual in both interviews.

Biography

Tina is a 53-year-old divorced female. She has three grown children and lives with her fiancee. Tina had some college education and then went to work as an estimator on jobs for food facilities. Her work involved traveling, and she enjoyed it.

Several years ago, she began having pain in her neck, head, and shoulders. This progressive pain developed at work. She was diagnosed with Spasmodic Torticollis (neck muscle contraction caused by spasms of the neck muscles). The spasms occur unilaterally and cause turning and tilting of the head. Tina had to hold her head up with one hand while working or walking, and this posture exhausted her. She discontinued work and went on social security disability. Tina stays at home most of the time now and does housework. She has recently begun a weekend home job coordinating a healthcare company. She feels that her dreams are ruined, and she feels helpless.

Self-Concept Pre-Injury

Tina responded to several questions, regarding describing herself before the injury, by referring to the dreams that were now ruined. She spoke about her dream future as one where she is doing crafts, traveling, and being active with her grandchildren.
Self-Regard Post-Injury

Tina stated that her dreams are now ruined, "I don’t really have things to look forward to. And I just live the days that go by ...." She no longer wants to be around people, "... I don’t want to go out and be with people. I don’t want to mingle with people or be with them and have to have relationships where I have to talk to people.” When asked to elaborate, Tina said that it’s too much of a hassle to deal with people. Tina noted that who she is inside has stayed the same, but "[f]acing reality is that my body can’t do what the person inside wants to."

Control Over One’s Life

Tina feels she has a lack of control. She believes that the system does not provide aid, because it wants her to be completely dependent on them or completely independent. She believes she could be more independent if the system were to help her a little. Tina also feels she has no control over how her pain progresses, and this lack of control is very “frustrating” for her.

Exploring the Self Concept

Tina’s exploration has focused on her illness. She claims to have researched Spasmodic Torticollis as much as she could. Tina noted that no medical cure exists for what she has.

The Need To Be Accepted By Others

Tina wants her fiancee to understand what she is going through, but notes that he does not give her support. She said she turns off the TV in order for them to talk, but he tells her everything will be “all right” and then turns the TV back on.
Comparisons Across Participants

In this section, for each theme, similarities and differences between participants will be discussed.

Self Concept Pre-Injury

In comparing how the participants saw themselves before the onset of their pain, it is important to keep in mind that their thoughts are post-injury and may be biased. In other words, they may now describe their former self-concepts in a more desirable manner. For five of the six participants, their pre-injury self-concept centered around what they were good at, where they felt most needed, and what they enjoyed doing. Brian and Kelly saw themselves as workaholics. They both noted being good at their jobs, feeling needed there, and feeling content when working. Jennifer did not describe herself as a workaholic, but did see herself really being good at waitressing and knowing how to make patrons happy. Making others happy, in turn, made her feel good. Both Sam and Bonnie saw themselves as physically active individuals who enjoyed the outdoors and were spontaneous in nature. The last participant, Tina, differed from the others in that she described her dream future self that she could have had instead of reminiscing about who she was.

Self-Regard Post-Injury

All of the participants, except Sam, described how they currently see themselves in negative terms. Brian, Jennifer, and Tina noted no longer feeling comfortable around people. For example, Jennifer has panic attacks due to fearing that other people will hurt her, and Tina no longer wants to talk with other people. Brian and Bonnie are no longer comfortable with themselves and hide their real selves from
others, often with the aid of a false happy facade. Brian, Jennifer, and Tina see themselves as living each day in a mechanical fashion. They don't perceive enjoyment in their activities and have nothing to look forward to. Sam, on the other hand, feels enlightened and fortunate to be alive. He feels more in touch with himself than ever and with a higher level of awareness.

Control Over One's Life

Despite the fact that control can be spoken about in relation to one's life, finances, pain, habits, and thoughts, these participants appeared to differentiate themselves between feeling that they have control, they lack control, or have temporary control. Sam and Bonnie feel that they have control. Sam noted that one can have control by working hard at it, while Bonnie noted that she tries to "keep the upper hand." Brian, Jennifer, and Tina all feel that they lack control. Brian feels that he lost the battle with pain and gave into it; Jennifer feels she has no control over herself, and Tina feels she has no control of either her life or the progress of her pain. Kelly feels she has control of her life when she has an activity she must go to, such as a doctor's appointment. When she tells herself that others are expecting her to go, she then goes and feels empowered that she is out there and "rubbing elbows."

Exploring the Self Concept

As the participants tried to understand themselves in their world, some of them focused on exploring (a) themselves at a deeper level; their illness; or (c) both themselves and their illness. Brian, Sam, Jennifer, Kelly, and Bonnie explored themselves (e.g., who they are and
why they do the things they do.) Brian is struggling with the question "What is me now?", whereas Sam, after much work, has already answered the same question. Kelly and Bonnie are both investigating themselves to understand the cause/effect cycle of pain and their reactions to it. Tina has only explored her illness and has not begun to research herself at a deeper level, while Kelly is investigating both her illness and herself. It appears that focusing externally (e.g., researching their illness) may be a first step toward understanding and accepting and that focusing internally (on the self) is much riskier and for some is the next step.

The Need To Be Accepted By Others

All the participants spoke about being understood or accepted by others. Brian, Jennifer, Kelly, and Tina wanted the family member they’re closest to to understand and accept them for who they are now. Brian wanted to be accepted by his wife; Jennifer wanted her son to understand what pain is like; Kelly wanted her mother to understand what she is going through, and Bonnie focused on her husband understanding her. Sam, having redefined himself, did not appear to have the need to be understood and simply noted that the chronic pain experience can only be understood by those who live it. Bonnie noted she felt accepted by others in the pain program and did not say much about her needs from her husband.

Jennifer, Brian, and Kelly attended the group interview and had the opportunity to share their thoughts and feelings with the other participants.
Summary of the Group Interview

Jennifer, Brian, and Kelly participated in the group interview. Degree of participation by each individual was approximately the same. The main points supported in the discussion were: (a) staying at home most of the time due to lack of transportation and pain; (b) staying at home makes them feel depressed; (c) purposely creating a robot-like existence to cover their "inadequacies", and to eliminate embarrassments and frustrations; (d) avoiding social situations to avoid being judged by others; (e) hiding their pain because they believe that nobody wants to hear it; and (f) being left alone is their ideal. The interviewer offered the group ideas on creating a chronic pain peer support group/network and tried to brainstorm with them. Unfortunately, due to minimal interest, no support systems were created. Jennifer was interested in helping others with chronic pain; Brian, though, noted having enough burdens and wanted to be left alone, and Kelly noted she was currently participating in a Fibromyalgia support group and also wanted to be left alone. As the participants left the group interview, Jennifer offered a ride to Kelly, but her offer was rejected.

Follow-Up With Participants

Participants were followed-up through a telephone call several months after the interviews. All participants other than Bonnie were reached. A short summary of the telephone call with each participant follows.

Brian sounded really down on the phone. Some of the comments he made were, "I can't argue - I don't know what is right or wrong," and "I feel like more of a burden on my family." When asked about whether he
had sought psychological counseling or support groups, he responded, "I don’t care... counseling wouldn’t help." Unfortunately, not much seems to have changed for him from the time of the interviews.

Tina said, "the Spasmodic Torticollis is about the same, but I’ve developed signs of Lupus and I’m depressed about that. I’m very tired and hurt all over." When counseling was offered to her, she responded with, "counseling can’t do anything... I need help to do things... I need a homemaker," and then she giggled.

Jennifer reported having had surgery for her herniated disc and said that it has decreased her pain. She is getting counseling, but still stays at home most of the time due to her panic attacks. She added that she is still searching for doctors who will work with her on medications.

Kelly was very happy to update the researcher. She told about how her mother had been in the hospital for several weeks and that this gave her (Kelly) somewhere to go and feel needed. Recently, her mother had a "miracle" - she recovered and returned home. Kelly then noted falling apart and not feeling needed. She said, "I don’t have a routine now." When asked about counseling, she said that she had to discontinue due to insurance coverage, but that she will start again in April.

Sam was pleased to share his progress and asked to be sent a copy of the study. Sam reported that he was doing "quite well." He noted having had a steroid shot in his back and that this, like a "miracle," drastically decreased his back pain. He then was able to get a part time job in a cooking store and is thinking about going back to school
to study photography. He also added that he sent out another draft of his autobiography to a publisher.

A Grounded Model

A theoretical model was created based on the personal experiences of the participants in this study. This section will focus on the developmental process of this model; the next section will introduce, explain, and support the model using thick description.

Development of the Model

The researcher read the interviews six times, and became aware of repeating themes. The themes that were investigated and that are elaborated on here are: (a) control; (b) having needs that want to be met; (c) grieving the loss of identity; (d) reaction to life changes; and (e) reformulating a more developed self-concept.

Control appeared to be a repeating theme and was followed up in the second interviews. Participants were given the three categories of "have control," "no control," and "control struggle" and asked where they see themselves now and if they see a pattern for themselves. Participants answered these questions, but then went on to other topics. They had a difficult time understanding what I meant by "control."

Reading the interviews and analyzing the data, the researcher began to ponder some of the ideas found in Maslow’s hierarchy of motives (1971). According to Maslow, our basic needs (i.e., food and shelter) must be satisfied before our higher needs can be (i.e., aesthetic needs and self actualization). The researcher took a different angle on Maslow’s theory. Maslow stated that needs are met in a hierarchical order; the researcher hypothesized that the more needs that are met, the
more "actualized" the person can be. Three needs that appeared central were "purpose" (i.e., a career or hobby), "close relationships" (i.e., a spouse or best friend), and "creativity" (i.e., painting or photography). An individual cycles through these needs, meeting each of these to differing degrees. For example, at one time, people can feel pleased with their hobby of needlework, happy in their career, but unfulfilled in a romantic relationship. This theory was supported by the data, but it was too broad. In other words, this theory seemed to fit all populations, but did not add explanatory power to specifically understanding the chronic pain population.

Through analyzing the data, the researcher noticed that the participants seemed to have lost their self-identity and were grieving this loss as though it were the death of a loved one. Thus, the grieving stages of Kubler-Ross (1969) were explored. She proposed that people go through five stages when they hear that they will soon die: (a) denial; (b) anger; (c) bargaining; (d) depression; and (e) acceptance. These stages did not capture the essence of the participants' processes, but rather oversimplified them. Although Kubler-Ross’s theory did not seem to fit the data, the idea of having a period of mourning over the lost self-concept continued to be researched.

The researcher went back to the chronic pain literature. The idea that participants were reacting to life changes caused by their chronic pain (Keefe et al., 1992), instead of just reacting directly to the chronic pain, seemed to fit the data and was investigated further.
According to Keefe et al. (1992), in most chronic pain patients, loss of income, confinement, and marital discord are present.

It is difficult for people to make sense of so many significant life changes and, therefore, it becomes nearly impossible for them to maintain their former identities. People have difficulty accepting their own experiences. Help in accepting life changes can aid those who have lost their former identities create more insightful and developed ones. Carl Rogers' theories on the actualizing tendency (Rogers, 1957) aided in the organization of these ideas and will be explained in the following section.

The researcher revisited each of these themes several times with deeper insights. Several of these themes were assimilated into the resulting model.

Presentation of the Model

In this study, six people were interviewed in depth in order to understand their personal experiences of living with chronic pain. As Carl Rogers stated,

It [a science of man] will be based upon understanding the phenomenological world of man, as well as his external behavior and reactions... we do not push the individual into some contrived situation to investigate some hypothesis we have imposed on him. We are instead opening our minds and our whole selves to learning from him (1980, p.239)

Rich insight has been obtained from being open to learning from the participants in this study.

Carl Rogers' actualizing tendency theory (1957) helped organize the data. The actualizing tendency theory supports that people move in the direction of becoming "more complex and complete" (1980, p.118). This tendency can be "warped," but not destroyed. If "warped," a genuine,
accepting, and caring relationship can help people utilize their natural resources of self-understanding and change (1980, p.118).

According to Rogers, people strive to perceive themselves as whole, which occurs when their experiences are congruent with their self-concept. Realistically, people have both congruent and incongruent experiences. These experiences either maintain and enhance their self-concept, or maintain and enhance experiences not assimilated in their self-concept. When experiences are not congruent with the self-concept, anxiety is experienced. In order to reduce anxiety, people selectively acknowledge and distort experiences so that they will remain congruent with the self-concept. Through the use of selective denial and distortion, people are able to maintain an identity. As a hypothetical example, Tom has chronic back pain and has been able to maintain his former identity. He is invited to his friend’s party, but declines due to back pain. He then rationalizes with himself that the reason he didn’t go is because he just didn’t like the people that were going to be there. In Tom’s eyes, he is still the “life of the party” and his friend’s party wasn’t worth his time. The following quotations represent how the participants described their identities before their chronic pain began:

I was a workaholic... fifty, sixty hours a week was nothing... I used to be a jovial person... a lot of life, a lot of fun... I have always been a people’s person... generally I’m a very considerate person... I was always involved, people around, and I was the center of attention... I was one of those people that was belligerent - ‘it’s mind over matter’ and that bullshit... (Brian)

I used to be an athlete... I was always big and strong... I was able to do anything... a very physical person... I’ve had spiritualism my whole life. (Sam)

I have a very strong sense of doing the right thing... I liked being around people... I like serving people and making them
happy... I'm an addictive personality... I've always felt like I've been very independent and able to do things on my own. (Jennifer)

I was a workaholic... I loved my job, I felt needed and felt useful... I never had any complaints out of the bosses, I earned my money. (Kelly)

I'm an outdoor person... I like to do outdoor things... I'm just usually real happy and loud and cheery... I used to be springing around, I'd do handsprings for no reason. (Bonnie)

Although identities appear to remain whole, individuals have to work at making their experiences be congruent with their self-concept. This process can be represented by Figure 4.1.

![Figure 4.1: Process of making experiences congruent with self-concept.](image)

People with chronic pain experience rapid and drastic changes in their lives due to their constant pain. Therefore, these individuals are reacting to chronic pain indirectly. They are reacting to these
life changes (e.g., loss of work and income, decreased sexual intimacy, divorce, decreased physical activity, etc.). These experiences are usually incongruent with their self-concept. These individuals use distortion and denial, at first, to feel whole again. Unfortunately it becomes extremely difficult, if not impossible, to distort or deny the fact that one’s income has decreased to 1/4 or that camping in the outdoors is only a memory. These individuals may find themselves having lost a sense of who they are, or having lost their former self-concept. They may feel a lack of control and may feel as though they are just existing. Their lives appear to be composed of daily routines, thus lacking spontaneity. Individuals need to grieve this loss as though they were mourning the death of a loved one. The participants’ statements capture the essence of this loss and grief:

Living hell... It really is... I’ve become quite a bitter person... the kids don’t like being around me anymore... I can sense it, I can feel it... I miss the fun in life... I miss not worrying about if I’ll hurt the next day if I go to the store, just do what I want to do... I can’t do it in my life, I’m very restricted... I’m quite very, very disappointed in myself... because of the financial burdens that we are in now and I thought had it completely controlled... but when you lose your job that pays you 70 to 80 thousand dollars a year, and then you’re forced on social security, it’s quite a cut-back, and I personally take the blame for it... I have become quite a bitter person, when you’re in pain 24 hours a day, and you try to hide it so that your family around you can be comfortable... I know I get crossed, edgy... I’ve developed this philosophy of ‘hey, I don’t give a damn anymore’... I think the majority of it just gnaws away at the inside, it comes out in dreams, I have some horrible nightmares- and it’s always somebody getting hurt, but I can’t do anything about it... I’m not useful, I’ve caught my wife losing confidence in me and it’s rightfully so... I eat out of habit... it’s a routine life... I don’t have an attractive life, I really don’t... now I find a corner, cause I don’t know how to communicate anymore... you take your time and do just about every little dumb trick you can do and it’s still obvious, and then you give into it.... I just let it take its course, if I have to hide I’ll hide... How can you fight the pain? I mean there’s no results. It’s a constant thing. When you go into a fight with a man, and he continues to beat the crap out of him time after time after time, you’re going to quit going into there anymore. That’s what I’ve done... the biggest loss is not being sexually
active, it destroys your ego and takes away all your manhood... I just try to hide... there's no living with the pain... you don't live with the pain, the pain lives you... fear of not being able to take care of yourself... lack of confidence spoils the rest of your life... I'm not defeated, but I'm down... I continue to feel being down... I don't have the right to upset their day, I get silly trying to hide it... I put myself into a good mood, it's a cover... I just have no self pride, I beat myself down so much... I am quite disturbed, ashamed, disappointed... you never get a clear picture of everything around you... what is reality?... I'm quite confused. (Brian)

I tried to be more sedentary in my life... but I lost one leg, then years later I lost the other leg... I've had to come back to work several times but in less physical capacity... my situation keeps deteriorating so I have to keep trying something else... sometimes I'd have to lay off and relax for a couple of days because my back would hurt... it's very tough not to do anything... you live in a nightmare getting back from those surgeries... that means your life stops, you have to lay in bed for a year maybe... the pain just kind of sucks the life out of your life... it's tough to have a normal existence or what people perceive to be a normal existence... I may be forever in a transition... you can't really have a social life like that, you know... (Sam)

It makes me feel very angry that I cannot go out and work... I cannot stand being in the house all the time... I don't feel like I achieve anything... I just... I'm trapped... four walls and that's it... so, it's like that 10% of people that are between a rock and a hard place and can't get nowhere, but you can't get out of the system, you know, to do something for yourself... I'm taking the final test, and I got stressed up about being timed and all that and I had spasms in my legs, I couldn't even sit still and I failed the class... what I've been experiencing is my leg locking and this is my driving leg, this drives my gas pedal and when it locks, it locks straight out and I can't move it... when I get severe back pain, I do buy street drugs... for 12 years that he's grown up [her son], he's grown up with me with chronic pain... he's been deprived of so many things because I can't do it... on top of pain, when you got depression, you get into a cycle... when you're depressed, you don't really want to do anything... and when you have pain, it makes it harder to do things... it's a very vicious cycle and when you get caught in it, it's like you're going round, and round and you don't know where the doors are... you can't find the right doors... I smoke marijuana on a daily basis because of spasms in my legs... the majority of the time, I feel very fatigued, very tired, really depleted of energy... I don't feel comfortable around people... the pain has caused me to just put myself in the house and do what I have to, but there's no fun in my life... I'm not meeting the needs that I need to go out and socialize, to do things... it's hard to sit through a movie, it's hard to go bowling, it's hard to play pool... I cannot fight the panic before getting out of the house... it's hard to get intimate with somebody, and you're never sure when the spasm is gonna hit... I don't do anything fun... I feel like I'm like a robot... I have to do certain
functions... they’re programmed... right now, I don’t enjoy life... I don’t feel I have control over making my body do what my mind tells me I have to... I feel like I’m just existing right now just to do what I have to do... I don’t feel like much of a person now... I don’t feel self-supporting... it’s just no fun anymore when you have to think about doing something before you actually do it... you learn to hide away how you feel about things and you don’t complain about it... I feel that something has been taken away from me and that’s my right to earn my way... you lose who you are because you’re not the same anymore... you change who you are... all of a sudden you become Jennifer with the pain instead of just Jennifer... (Jennifer)

... from 92 to 94, I only worked for five, six weeks... I couldn’t do it... I’d go in and I’d work a week or so and I’d be out six months... I’d go back in I’d work two, three, four weeks, I’d be out six months again... I found myself having to start to get up, you know, three thirty in the morning to get ready to go to work by six... I found out I couldn’t do that anymore... I would go home, I don’t know how many times I cried up the freeway, I hurt so bad... when I got industrial [disability compensation], industrial rules your life... they got control of you... they tell you where you can go and what you can do, and when you can do it... what am I supposed to do? I find out that I’m too snappy with people... I feel like they don’t understand me... my social life was my job... I’m getting too comfortable in the house... so right now I’m trying to figure out what can I do... because right now I feel like I’m a prisoner... if I do something to keep myself going, then I can’t do the next day... I don’t sleep very much anymore, I eat more... I find myself scared, more scared to do things... I get disgusted with myself because I can’t do the things I used to do... I can’t help take care of the people that I used to... the last few days I laid on the couch all day, I haven’t done a thing for three days... I don’t know what to do... I’m afraid of losing my money, cause I can’t make it without it... I really don’t know what I’m allowed to do... I’ve got to check into something, I’m going stir crazy sitting around the house... (Kelly)

... it [pain] has destroyed my life... it’s just destroyed it financially... I worked until the point where when I was coming home at night I had to crawl up my steps to get into my house cause I was just so exhausted... just from living with the pain and putting up with the inconvenience of holding my head and trying to do my job... some of the medicine that I took gave me such terrible side effects... I’d be going down the freeway and not know where I was or why I was there or if I was going in the right direction... I know that I can’t work... I don’t have very good concentration... with the medicines you also have a lot of memory loss... it has caused severe depression... I sat for two years in my chair doing absolutely nothing, except just looking into space... I don’t want to go out and be with people... just being with people is a responsibility... all relationships have responsibility, and I just don’t want the responsibility of a relationship... I don’t really have things to look forward to... I just live the days that go by... facing reality is that my body can’t do what the person inside wants to... I was going to fight it, and I was going to overcome it, and it wasn’t going to affect
my life... gradually, I began to accept that there were some limitations and then with that comes a lot of depression... so it's like they keep you down [social security] because if you make anymore over a certain amount, then you lose your benefits and you don't always feel like doing some things so maybe one month you're feeling great and you can do it, but you cannot keep up the pace... you can't keep up the pace for two weeks in a row... I also live with the fear that tomorrow I could be just like I was a few years ago... (Tina)

... it's just hard... I can't play volleyball, I can't water-ski anymore... I act fine cause nobody wants to hear about me all the time... he'll say [her husband] 'come and help me mow the grass' and I'm like no - I'm not fine... I felt like I couldn't do the things I wanted to... for almost a year... I just sat around like 'I can't do anything, I don't want to do anything, I don't feel like doing anything'... it's not that I don't have energy, it's that my body gets tired.... self-medicating with alcohol cause I couldn't sleep... sexual activity, sometimes it's just painful for my back, and when it's painful - it's not fun... so I'm not always as responsive as he'd like me to be... it changed all at once... one day I'm just happy happy all about, and then the next I can't even brush my own hair!... and it's so quick... it's like Monday I was this, and the next day I can't do any of those things anymore... there's one part of me that's not right, and it's like an imperfection... in the flower, one petal gives me that... like an imperfect flower you hide behind the other flowers so you wouldn't be able to tell... I'm not connected all together... it's like the physical and what I really want to do are separate... a lot of people they want to do something, they just do it... I have to think about how it will physically affect me... it won't go away, it's just something you constantly have to live with... (Bonnie)

Figure 4.2 on the following page displays what this stage may look like.
According to Carl Rogers (1957), people naturally tend toward becoming whole. People who live with chronic pain may feel anxious and lost, since they are not able to make their experiences congruent with their self-concept. They are looking for a way out of their routine days for a more fulfilled identity and life. Being involved in a relationship where the other individual is genuine, accepting, and empathic can help reformulate a more fulfilling identity. Whether a therapist or a close friend, this relationship can be used as a sounding board in order to share one’s incongruent experiences and than accept them as part of oneself. The more accepting the second party is, the more accepting the challenged individual can be to himself/herself. Through this manner, a new self-concept is reformulated which includes all of one’s experiences. This new self-concept is more complex, complete, and developed. It includes much higher levels of awareness, insight, and acceptance. Not all chronic pain patients ever reformulate
their self-concept. Some remain lost and helpless. Others begin to
search for acceptance in others (e.g., spouse, child, close friend), but
may not find it. For example, Brian looks for acceptance from his wife,
but does not receive it. Consequently, he puts himself down and feels
worthless. Others (Sam) are currently in therapy and "reclaiming" parts
of themselves. For example, Sam is consciously picking up the pieces of
his former self and assimilating them into his new identity. The
following passages will illustrate where each of the participants are in
this process:

... even when I do something and I do it right... every time I
give myself praise, but I don’t get it from the outside, even my
wife... it seems that if I ever make any gain, with a matter of a
few words it’s destroyed... looking for a little self praise to
bolster your pride and it’s not there regardless... to be accepted
as I really am... if you really feel that you make contact, really
a person would accept you as you are... I think in my mind that
I’m more of a person than they’re willing to give me credit for...
what would happen if I found out that I wasn’t? Then my world
bubble would really burst... I’d love to [see a counselor], but
there’s no way I can cover the expenses... in group therapy,
everybody says I’m a hog... I don’t want to give anymore, I
think I’ve given too much... I’m totally now turning the other
cheek. (Brian)

I had to confront my own demons because of my physical limitation,
I had to seek therapy... I went to a good psychiatrist and tried
to understand why I did what I did... why I lived the life that I
did, the reckless life... so, in that respect, I did a lot of good
for myself. But, it has helped me. I made the statement that if
I had to go back and be the way I was, I’d rather be the way I am
right now. At least my head is a lot clearer. My body has gone
to hell on me. My heart and spirit, that sort of thing, is much
better off after the accident... I’m more comfortable with
myself... more like a religious experience. It’s more
introspective, you know, to look at yourself objectively... I
think it’s good therapy to write about your life. Tell your whole
story and that kind of thing. I did a lot of pop psychology. To
tell your story is very therapeutic and even working on race cars
is very therapeutic, cause you’re putting something back together,
I guess, you’re putting yourself back together... you have to just
deal with the fact that there’s certain things you’re not gonna
do. A lot of things you’re not gonna do, actually. But just
be content with yourself... you gotta be happy with yourself. I
guess I’ve accrued self-actualization. The spiritualism... I do a
lot of volunteer work for the hospital with people that have just
lost their limbs and stuff, I counsel... you have to make up your
mind to live... just try to put it behind you as much as you can... I'm confronting my chronic pain... in 92, I tried to qualify for the Para Olympics... in the disabled world now I'm talking, I'm a superman type guy cause I can get up and do so much stuff... you can live and have a good life. I like life, I love life actually. I've had my daughter since the accident... that's a great thing for me... I help in raising her and I love that... cause we're all on a spiritual journey whether we know it or not. I just became much more aware of mine... I guess it's the way you look for deeper meaning in spiritualism... people need that mythology in their life... there's something greater than yourself... you need symbolism in life, I guess... since I went to a psychiatrist, I understood why I was drinking so much... I haven't been drunk for years. I don't want to; I'm not trying to get away from anything... I'm kind of fueled on passion to do something. And it's something that I used to do, like I'm reclaiming part of something I lost... To really live... to understand it, introspectively... that's actually spiritualism, too... examining yourself... Something greater than you, that is essence. You have to become very spiritual to live... I just don't think a lot of people know why they do what they do... they don't think they can change, but you can change. It's tough, but you can... we are animals, we have to control the animalistic side of us, there's a dark side to us, ying and yang, opposing forces, jockel and hyde. Everybody has a dark side... mean you gotta have that shadowy part of your personality. You just gotta know it's there and deal with it. You have a thought that may not be the purest thing in the world, whatever it is, the dark side of yourself, you overrule... I think in any religion, you inspect your habits, your lifestyle, why you do what you do... Negative thinking can permeate your entire being. You gotta really fight... you gotta be spiritual to push that back... I also said I would rather be this way than the way I was before cause I really had to confront myself... I had to look a little deeper into the bud... I always thought I should be dead, so everything was a real bonus. It's a pretty good life. I can do a lot of good things, I've seen a lot of good things. I'm pretty content. I feel pretty good about it. (Sam)

I wish that she [her mother] would go with me sometime [to a fybromyalgia support group] so she could hear it because she don't believe that there is such a thing as fybromialgia. Which I didn't either, but I'm trying to read up on it and I have a whole big pile of paperwork and trying to read up on it and I associate myself with it... part of that is my own fault because I won't get out or get into something... And that's what my psychologist tells me 'you won't try, you won't give it a chance'... So now I don't know whether I fell out because I didn't have nothing to do or I would have fell out anyway because I was hurting so much... when we had to stop, when we didn't have appointments, I sat back and I thought - whew, I don't think I could have made it if we had one today. Now, I don't know whether it was in my head or whether it really was... I keep thinking I got to get out and do something... I'm really getting tired of doing nothing... Just like that group therapy... I don't have to go there, but I make myself go there every third Tuesday. (Kelly)
I myself have done as much research on it as I could, and so I found out that there is no cure for what I have. They don’t know what causes it either... I guess I’d like to know that he really understands what I’m going through, and have some sympathy, a bit of sympathy, but he doesn’t... He just didn’t want to hear. I think he cares... but he ignores it... I’ve had to accept that there are things that are never going to happen... I have a big file at home on Spasmodic Torticollis... My experience with Spasmodic Torticollis is that my neck could be hurting so bad, but during sex I don’t notice it... I just had to learn that there were certain things I could not fight. I could try, but it wasn’t doing me much good... I’m the kind that digs and researches and does detective work. I’m medically inclined anyway... I want to do more, and I have started a weekend job which I do from home. It’s an answering service. I’m on call for a company and do coordination for a health care company. I can do that from home... I have been consciously and devotedly trying to find, trying to do something every day and, that’s meaningful, and starting to do some things that I used to do a long time ago... I also live with the fear that tomorrow I could be just like I was a few years ago... Something that I did just learn, and I think I’m going to take advantage of it is that there are massage therapy schools in Columbus whose students will work on you for a lot less than you would have to pay a massage therapist. (Tina)

Tanning is my way of giving myself 20 minutes away from looking at dishes, looking at laundry, looking at my kids. This is my time, this is something I do strictly for me... I myself feel like right now I’m doing what I need to do for me. I’m not worried about anybody else right now, I have to take care of me. I feel grateful that I’m walking... sometimes I feel more blessed because I don’t see myself as physically impaired as some people that I’ve seen... It’s like she’s [her doctor] not looking at the whole picture of who I am... It’s good to have people who understand where you’re at so they can help out and to have people who can take your children and do things that you can’t... I just finished reading Take Control of Your Life... according to his theory, a lot of this I bring on myself. It’s my body’s way of saying stop something and let’s do it the right way. It’s kind of scary that maybe I have control over all this amount of pain I go through... I didn’t have the support of the people that were in the program with me, nobody was there to push... it felt like I had to do it for me, but I also had to do it to show everybody that I could do it. At home, I do it... I don’t really feel like I have to do it for me. I’m working on that in therapy... The problem is that at home there’s nobody there to push you... If you watch a half hour soap opera or whatever, treadmill the whole time you’re doing it. I feel like I really push myself, plus I broke up with an old boyfriend, I want to make him turn around and look twice... I need to concentrate on me, on my relaxation, tanning- that’s top priority on my list right now... I’ve tried to set up a routine... I have myself scheduled pretty good... you need to have a routine... [interviewer - what would have helped make the transition easier from the program?] Probably a little more contact and support maybe from people in the group... maybe call, but I know it’s hard, because a lot of people live far away.
But maybe from the program itself to see how things are going... I think what a person with chronic pain needs the most is that you can’t do it by yourself. (Jennifer)

I really like working there [a balloon shop]... since I went to the clinic, I got it all talked out pretty much, you know, with people who understand... I always wanted to build a greenhouse and all that, but that’s not real. Now I’m at this job. And me and my boss are both going to take a test to become qualified balloon professionals. I didn’t really know the things that you can do with balloons... We’re [her family] a lot closer; we don’t pick at each other, and yell at each other... you realize, you know, to be thankful for the family we do have. We have no parents anymore so we’re all real close... It’s like let’s live for the moment... Don’t get all groused out about stuff... I don’t worry as much about little things... I’m not gonna let that ruin my day. No matter what I do, I’m going to have fun and nobody’s gonna ruin my good time... I think the best part about it [the chronic pain program] was talking to other people that deal with it everyday too... somebody actually does know what you’re saying, and understands. It makes a lot of difference that you can relate to somebody about that... it does help to talk to somebody... coming here [Dodd hall], I felt like I had backup when I said this is what I’m dealing with and it’s real. And other people feel the same way. It made me feel like I had the right to feel the pain... it wasn’t my fault... nobody asks to have something happen to them like that. And I have the right to feel bad because I hurt myself really bad... I used to think it [pain] controlled the way I do things. But, I try to keep the upper hand. When I don’t feel like doing something I make sure it’s just me and not just an excuse not to go... I think I deal with it [pain] pretty good. I think it’s because it’s been a few years, and I guess I had to accept it... Like a friend of mine said, I got my spark back when I got the new job doing something that I felt good at and something to do with my time... I try to involve myself [in outdoor activities] in non-painful ways... I didn’t have control for a while, but that wasn’t the way I was gonna live... that’s [the pain] a part of me I don’t necessarily care for, but it’s a part of me, and I have to deal with it... I’m not letting it [the pain] get me down. I know it’s gonna be there. You have to have an attitude about how you’re going to be about that being there all the time. It’s gonna be there, so either ignore it or deal with it. (Bonnie)

This process is shown in Figure 4.3.
In the following section, a case which did not fit the current model will be discussed.

**Negative Case Analysis**

Jennifer’s self-concept did not fit the current model. It appears that Jennifer’s self-concept includes many contradictions which, according to the model, would cause anxiety. This anxiety would be the impetus for change. On the other hand, Jennifer blames others for all her contradictions and does not take responsibility for her actions. The model did not include the dimension of responsibility. The following quotations from Jennifer’s personal experiences demonstrate these contradictions:

I have a very strong sense of doing the right thing, so I don’t feel comfortable working under the table, getting money like that. I even tried making extra money doing some things that weren’t so moral and found out that if you make dishonest money, for some
strange reason - bad things happen. You cannot live with yourself... When I get severe back pain, I do buy street drugs... I'd like to find a doctor that would work with me with them... I played around with a lot of drugs... I need a doctor to work with me, to get me away from what I buy off the streets and kind of keep an eye on what I'm doing. It's getting dangerous, I'm getting crazy (laughs)... The first head on collision was the other guy's fault... Then after that, my cousin's wife got drunk and decided that she just didn't like me... I opened the door and told them to leave, you know, and sober up. They wouldn't leave, and knocked on the door again. When I went to open it, so I could tell them to get out or I was gonna call the police, my cousin's wife pushed her way in and just started throwing me around and... tore my house apart, wrecked my doors... Then last year in July, she started trouble again - my cousin's wife... So I got very angry, and I had some jars in the car, and I took one, and I threw it up against the car that was out in the driveway and missed the car, hit the ground, and broke. Then I grabbed another jar, and I threw it. I missed everything. It just bounced on the ground and didn't even break (laughs). So finally, another brother of hers who owned the car said, 'That's my car, what are you doing?' I said, 'I'm just trying to get somebody to come out of the house, an adult to talk.' And I said I figured the best way to get somebody's attention was to throw something... I turned around and got attacked in the face with a set of keys... Well, I'm not a violent person, and I won't strike anybody or do anything... I just don't believe that violence against somebody else is gonna stop it... So I feel like she's [her doctor] pushing me to go against my morals because she doesn't supply, so then I have to buy them. When I buy them, sometimes I buy larger quantities to save money... I don't feel like I control a lot of the situation.

The current model, Figure 4.3, was reviewed by six experts (triangulation). Their comments and suggestions are found in the next section.

**Feedback from Experts**

The use of experts in the evaluation of the model (triangulation) increased rigor through multiple sources (refer to Chapter 3). Six individuals involved in rehabilitation (three rehabilitation psychologists, two psychology interns, and a psychological resident) working in Physical Medicine and Rehabilitation at Dodd Hall, contributed through their constructive criticisms of the model. Their comments have been organized around three topics: (a) responsibility; (b) stages of recovery; and (c) ideal versus realistic model. Some of
their suggestions will be incorporated into the model in the next section.

**Responsibility**

Comments in this area focused around patients taking responsibility for their life situation (e.g., actions, reactions, motivations, and circumstances). The psychology intern, who had conducted two interviews with one participant, noted that patients do better in therapy if they can take responsibility for themselves. In other words, if patients do not take responsibility, acceptance of denied experiences and growth will not take place. The psychology intern gave an example from Jennifer’s profile. Jennifer does not seem to take responsibility for her life situation, and therefore growth will not occur. For example, Jennifer blamed her car accidents and having been “beaten up” on others, and she blamed her doctors for her use of street drugs. One of the experts, a rehabilitation psychologist, stated, “The essence of dealing with chronic pain is self-management. It comes before self-love and the self-concept.” He explained that one must manage all of the self-related processes before a self-concept can exist. “The persistent effects of disability have to be managed,” he added. Those individuals with chronic pain need to be responsible for their actions and reactions, associated with the changes due to chronic pain, before they can perceive a stable identity. The model did not take responsibility into account, and adding this dimension would seem to increase explanatory capacity.
Stages of Recovery

The psychological resident agreed with the stages of the model. She made the connection between patients with chronic pain and patients with addictions (for example, alcohol) in that both populations move through stages. She referred to the book, Changing for Good, which explains the six stages of change to free oneself from bad habits (Prochaska, Norcross, & Diclemente, 1994). These six stages are precontemplation, contemplation, preparation, action, maintenance, and termination. As individuals proceed through these stages, different therapy approaches may be more beneficial than others. Research ideas relating to therapeutic approaches will be presented in chapter 5.

Ideal Versus Realistic Model

Two of the experts stated that the current model may be too idealistic. In other words, it may not be representative of the prototypical person with chronic pain. For example, the psychology intern noted that the model assumes a stable pre-injury self-concept; whereas, most individuals do not seem to have a high degree of clarity about who they are. She also noted that stages in the model may be skipped. For example, an individual may skip grieving for the loss of their identity and begin looking for acceptance. The director of the Chronic Pain Program stated that some individuals with chronic pain may not be capable of self-actualizing, and for some this may not be in their best interest. She also noted that the patient’s willingness to change is crucial. If patients are content in their situation, no amount of therapy will help them to reclaim experiences and to grow.
Reformulation of Model

To increase rigor, several suggestions made by the experts were incorporated into the model. First, the model's assumption that the patient's pre-injury self-concept is stable and unified was stated; and second, the model included the conditions for growth to occur: patients must (a) take responsibility for their lives; (b) be willing to change; and (c) be capable of self-actualizing.

![Diagram showing the reformulated model]

Figure 4.4: Reformulated model.
Looking back at Jennifer’s case, it appears that she does not take responsibility for her life. Lack of responsibility could keep her from growing and creating a new self-concept.

In the next chapter, the current findings will be integrated into the existing literature. Implications for the field, limitations of the study, and ideas for future research will also be presented.
CHAPTER 5

DISCUSSION

A notable poet and philosopher, Kahlil Gibran (1991) said, “You talk when you cease to be at peace with your thoughts” (p. 60). Many people with chronic pain are not at peace with their thoughts, and this research was a vehicle for them to “talk” and be heard. The participants’ willingness to volunteer for this study opened the doors of exploration. This chapter will relate the current findings to the existing literature. Implications for the field, limitations of the study, and ideas for future research will also be presented.

The findings of this study coincide with Beecher’s assertions (1959) that pain is not directly determined by the wound, but by indirect factors such as the significance of the wound to the person (p. 165). For example, Sam had lost both of his legs in the car accident, but realized he was lucky to still be alive. He was happy to have been given a “second chance.” Sam views the loss of his legs as a challenge to overcome. Brian had back pain and reported that it destroyed his life. He reported the disastrous impact the back pain has had on his career, relationships, and self-esteem. Sam was comparing losing his legs to losing his life in the car accident; while Brian was comparing his pre-injury situation (e.g., economically stable and with a
retirement plan) to his post-injury situation (e.g., unemployed and having lost his retirement plan).

The current findings from all six participants support the literature which asserts that cognitive strategies (e.g., mental distraction, focusing attention on physical aspects of the environment) can alter the appraisal of the pain (Genest & Turk, 1979; Turk et al., 1983). For example, Jennifer uses tanning to distract herself from focusing on the pain, and Kelly noted not thinking about the pain while she was working at the bakery factory line.

This study found that, as a result of chronic pain, many significant and incongruent life events occur (e.g., loss of career, loss of income, and marital discord). People react to these life changes by trying to assimilate them into their self-concept. Unfortunately, these life changes may not be assimilated due to their sheer significance and number. Therefore, people will not be able to maintain their prior identity and will, consequently, feel lost, robot-like, and depressed. For example, Brian feels ashamed and lost due to no longer being the breadwinner of his family, losing his retirement, and his children no longer asking him to participate in activities due to his pain. These findings support existing literature. Gamsa (1990) suggested that emotional disturbance is more likely a consequence than a cause of chronic pain. Kelly felt depressed due to losing her job, not before. Schramm (1995) noted that chronic pain is a syndrome and that some of its associated disabilities include inactivity, insomnia, narcotic dependence, spousal discord, and unemployment (p. 45). Jennifer stays home most of the time and buys drugs from the street to
relieve her pain. Davis (1989) stated that the effects of chronic pain on the individual are physiological (e.g., Sam's loss of his limbs), emotional (e.g., Brian's depression and guilt), social (e.g., Bonnie asked less to participate in sporting events), and economic (e.g., Jennifer's loss of income).

This study researched behavior in context. Through exploring the personal meaning of former chronic pain patients' life events and reactions, the participants' behaviors were not generic. Sam noted that working on race cars was symbolic for putting himself back together, and painting was a way of experiencing and understanding his pain. People can attach different meanings to the same behavior. For example, Brian hides his pain so as to keep his family comfortable; whereas, Kelly hides her pain because her brothers and sisters later use it against her to keep her from doing things. Nielsen (1990) said that the meaning attached to behaviors is the focus of inquiry, rather than the behaviors themselves. Human behavior cannot be understood without referring to its meanings.

Several chronic pain studies have assumed the context of the behaviors and, therefore, assumed the meaning attached to the behaviors. Fordyce et al. (1973) focused on eliminating maladaptive behaviors through the operant approach. That is, pain behaviors (e.g., moaning, grimacing, and reclining) were ignored and non-pain behaviors (e.g., activity) were reinforced. Generic lists of pain and non-pain behaviors disregard the context of the behaviors. Along the same lines, the Multidimensional Pain Inventory (MPI) (Kerns et al., 1985) operationalizes chronic pain-related behaviors. Through the patients'
acknowledgments of the behaviors they display, the MPI fits the individual into one of the three prototypes (dysfunctional, interpersonally distressed, and adaptive copers). Again, the MPI does not take into account the meaning attached to the behaviors. In other words, the personal experience of living with chronic pain is not fully explored.

The current results do not support Levine's assertions. According to Levine's *Healing into Life and Death*, 1987, all people experience grief. Grief can take the form of fear, guilt, anger, and blame; and can be related to not getting what we want, not having control, and losing face (p. 106). According to Levine, people become aware of the grief they have held all their life when they experience a significant loss. They then experience the accumulated grief "in all [its] painful reality" (p. 109). Individuals experiencing chronic pain undergo many life changes, which can result in grieving the loss of oneself. The participants of this study grieved for the loss of themselves, but did not appear to grieve for all the fear, helplessness, and anger they had experienced before their injury. In fact, they all described their pre-injury lives as positive ones. For example, Brian described himself as the life of the party and as always confident, and Bonnie described herself as spontaneous and always in a good mood.

The current findings seem to support Rogers' (1961) tenet that people need to experience their incongruent experiences in a trusting relationship in order to become their "potential self" (p. 76). Rogers recommended to clients to first experience all of their sensations without "... an attempt to relate these experiences to the self" (p. 80),
and then clients will discover that they can be their experiences with all their contradictions. Both Kelly and Sam have experienced a trusting relationship through psychological counseling and regarded it as a positive experience. Kelly decided to go on a long-awaited roadtrip after exploring her fears with her psychologist. Sam was able to explore his past drinking habit and understand the purpose it had served him. Now, he chooses not to drink and does not deny he had this period of continuous intoxication.

Yalom (1985) stated that experiencing is necessary, but not sufficient for growth to occur. Reflecting on the experience is necessary as well. Yalom, in The Theory and Practice of Group Psychotherapy, focuses on these two necessary components with specific reference to group therapy. Yalom said that we must experience the "... emotional and corrective experience" strongly, but that we also need to understand its implications (p. 28). Therefore, if individuals with chronic pain are able to experience their grief for the loss of their former identity, they then need to be able to place this experience in a cognitive framework. Sam was the only participant able to experience feelings associated with his "reckless" lifestyle in therapy and then to write about his life in his autobiography. Although Sam noted that being "spiritual" helped him to reflect on his experiences, Yalom does not include a spiritual element as a necessary component for reflection to occur. For Sam, spirituality helped him find personal meaning in his experiences. It is the personal meaning given to one's experiences that enables carry over. Yalom noted that if reflection does not occur after the experience, there will not be any carry over. Yalom labeled the
process of experiencing and then reflecting back on one’s experience the “self-reflective loop”. Figure 5.1 demonstrates how Yalom conceptualized it (p. 136).

Figure 5.1. Self-reflective loop.

Implications for the Field

This study conducted systematic qualitative research on the personal chronic pain experience. The findings of this study have several implications for the field.

First, chronic pain patients appear to experience an identity crisis. That is, significant life changes, due to chronic pain, make it harder for patients to maintain their former identity. The patients have not yet reformulated their identity; therefore, they are left midstream. Professionals need to be aware of the needs of this population: (a) to feel heard and accepted (Brian, Sam, Bonnie, Kelly,
and Jennifer wanted this); (b) to receive help in exploring the self
(Sam had received it, and Brian is looking for it); and (c) to receive
help in exploring possible activities (Kelly and Tina have asked for
help with this).

Second, some people with chronic pain may not benefit from a
therapeutic relationship if they do not meet the necessary conditions
(willingness to change, takes responsibility, capable of self-
actualizing). These barriers need to be addressed and alternate
approaches, such as confrontation and realistic goal setting (Strenbach,
1974), utilized.

Third, people with chronic pain differ in their recovery/growth
process. The three weekly counseling sessions received by patients in
some chronic pain programs should be used wisely. Instead of focusing
on adjustment issues, time would be better spent exploring patients’
identity status and recovery process. Results of this exploration can
be used as a referral for extended outpatient counseling after discharge
from the program.

Limitations of the Study

This study explored the "chronic pain experience." This goal was
carried out with a sample of the chronic pain population. The final
sample consisted of individuals who: (a) were between the ages of 34 to
66; (b) were Caucasian; (c) participated in and finished a chronic pain
program; and (d) were willing to drive to Dodd Hall two or three times
to participate in this study. Several questions arise as to how the
data would have differed for other samples of this population.
First, in considering different ages, adolescents are still trying to find/create an identity; whereas, older adults spend more time with their memories and in reviewing their life. How would the self-concept model hold up with these samples? Would the adolescents be "losing" their self-concept when they're still trying to create it?

Second, how would the model fit other ethnicities? For example, how would the model fit Hispanics? Being Hispanic myself, I am aware that one of the cultural norms is that emotional issues are assessed medically rather than psychologically. In other words, Hispanic individuals may turn to medications when they begin to experience life changes due to chronic pain, rather than seek a therapeutic relationship.

Third, many people with chronic pain are not referred to a chronic pain program by their doctors; or if referred, they are not accepted. How does this group differ from those who do participate in such a program and graduate from it? Are personality traits such as motivation and responsibility involved?

Fourth, only six out of 50 individuals who fit the criteria for the study participated. These two groups may have differed in respect to their support system (e.g., feeling heard by a spouse and, therefore, not feeling the need to talk to a therapist), income (e.g., transportation is costly), severity of injury (e.g., being mobile), coping ability (e.g., coping with pain the morning of the interview) and other factors.

As noted in Chapter 3, this study explored in depth a small sample. Due to budget constraints (resulting in a limited mailing
list), the sample was not as diverse as would have been liked. The chronic pain population is heterogeneous, and many chronic pain patients may have dissimilar experiences from this sample.

**Ideas for Future Research**

Ideas for future research studies include research on: (a) therapeutic approaches; (b) diversification of the sample characteristics; (c) the use of diverse methodology; (d) structuring psychotherapy into the system; (e) comparing the effects of chronic pain on self-concept as opposed to the effects of other disabilities; (f) possible effects of post-traumatic stress disorder; (g) hardiness as related to adjustment; and (h) the self-concept as a function of four variables.

First, different therapy approaches may be more beneficial than others, as individuals proceed through the stages of reformulating their self-concept. To help clients develop a better self-concept, the researcher proposes using existing instruments measuring the self-concept as part of the counseling process. For example, the California Psychological Inventory (CPI) (Gough, 1987) focuses on the assessment of personality characteristics important for social living and social interaction. Twenty scales (i.e., self-acceptance, responsibility, well-being, and tolerance), based on 462 true-false questions, are used to derive standard scores. This instrument could be completed by the client during the counseling session for the purpose of exploring the process of defining oneself. For example, does the client seem to struggle with questions relating to responsibility? What is this struggle about? The CPI could also be scored and this score could be
used to help the researcher decide which therapeutic approach would be most valuable. For example, if the client is not accepting responsibility for his/her actions, a more confrontational therapeutic approach would be called for.

Second, the limitations due to the characteristics of the current sample of chronic pain patients could be addressed through conducting similar studies: (a) in diverse locations; (b) with patients of different ages; (c) and through different interview formats (e.g., phone - to include those participants that may not be motivated to come to an interview or do not have transportation).

Third, participants' accounts of their experiences with chronic pain were retrospective and, therefore, may have been unintentionally distorted. By asking patients in a chronic pain program to keep a diary of their daily accounts, more accurate data could be obtained. This data could be analyzed using grounded theory. Data from their diaries could also be analyzed longitudinally. Through a longitudinal examination, the process of maintaining, losing, and reformulating one's self-concept may be explored more fully. For example, how does an individual experience no longer being able to maintain one's self-concept? Does this daily account differ from a post-hoc account months or years later?

Fourth, many people with chronic pain do not ever receive psychotherapy due to financial issues, lack of information, or lack of interest. It would appear that beginning psychotherapy soon after the pain becomes chronic would make it easier for clients to undergo life changes related to chronic pain, and to incorporate these experiences
into their changing identity. For this to occur, psychotherapy would need to be incorporated into the Bureau of Workers' Compensation. For example, people receiving workers' compensation would be required to meet with a psychotherapist weekly in order to receive their checks. Psychotherapists would be reimbursed through workers' compensation and termination would be determined jointly by the client and the psychotherapist. Research on the correlation between participating in psychotherapy and the rate of return to work would be beneficial in reducing the cost of disability on our economy.

Fifth, people with chronic pain appear to face similar life changes as do people with other disabilities (i.e., spinal chord, stroke, and muscular dystrophy). For example, loss of job and marital discord do occur with the onset of other disabilities. Therefore, losing one's identity may be an issue for individuals undergoing any form of illness or injury. An interesting distinction to take into account is whether the injury can be seen or not. For example, individuals with chronic back pain or a brain injury often have to convince others, and sometimes themselves, that they in fact have a real injury. On the other hand, individuals with a spinal chord injury or a severe stroke do not have to convince anyone. Research on the effects that the visibility of the injury has on the identity of the injured would be interesting. Is it easier on the individual if the injury is observable or hidden from view?

Sixth, some people with chronic pain have more difficulty adjusting to and accepting life changes and, therefore, cannot reformulate their self-concept. Could these individuals be suffering
from post-traumatic stress disorder (PTSD)? This mental disorder can develop when the individual’s coping abilities are overloaded when exposed to traumatic events (Boudewyns, 1996). Symptoms can include reliving of the event in nightmares or while awake, constricted ability to feel emotions, inability to experience enjoyable interpersonal relationships, difficulties with concentration, and impulsive behaviors such as sudden changes in lifestyle. Some of these symptoms overlap symptoms associated with chronic pain. For example, loss of concentration and a decrease in gratifying relationships were commonly reported by participants in this study. Maybe individuals whose injury was traumatic to the degree that their coping abilities were overloaded, are suffering from PTSD. Research in the utility of using treatments for PTSD with the chronic pain population is prudent.

Seventh, individuals’ coping abilities may be influenced by their personality styles. In response to stressful situations, how do individuals cope? “Hardiness” (Kobasa, Maddi, & Kahn, 1985) is a personality style characterized by a sense of commitment, control, and a perception of problems as challenges. Kobasa et al. investigated hardiness, exercise, and social support in a group of executives and found that when all three were present, the level of illness dropped dramatically. Research on the relationship between hardiness and chronic pain would be useful. Possibly, those individuals that have hardiness better adjust to chronic pain and its correlates. It would be interesting to explore whether hardiness skills can be taught (i.e., to see problems as challenges).
Lastly, the self-concept can be described as being a function of (a) activity level; (b) social support; (c) emotional adjustment; and (d) environment. In other words, self-concept = f(activity level x social support x emotional adjustment x environment). In order to understand how a person conceptualized themselves before the injury and after, each of the variables need to be understood. These variables will be described briefly: (a) activity level - extent of work, play, and exercise; (b) social support - extent of social network created by family, friends, and colleagues; (c) emotional adjustment - ability to cope with change and stress, optimism/pessimism, and time needed to adjust emotionally; and (d) environment - financial situation, living arrangement, and lifestyle. It may appear that increasing each of these variables would strengthen the self-concept (i.e., and increase in activity level or a larger social network). These variables, though, need to be viewed from the persons' perspective. For example, if individuals enjoyed a sedentary routine of computer games, reading, and needlework, increasing the activity level to biking and hiking may be too much of a change. It is important to help these individual return to their pre-injury level on each of these variables. Therefore, the more of a change there is on each variable, the more they are going to feel lost. The closer these persons are on each variable to their former level (i.e., very active in football and now very active in golf), the stronger their self-concept will be. Further exploration on how therapists and significant others can help people with chronic pain return to the same levels of activity, social support, emotional adjustment, and environmental arrangements would be useful.
Concluding Thoughts

The following excerpt from Kahlil Gibran’s book, The Prophet (1991), reflects people’s need to be heard, and to be heard unconditionally.

And a man said, Speak to us of Self-Knowledge.
And he answered, saying:
Your hearts know in silence the secrets of the days and the nights.
But your ears thirst for the sound of your heart’s knowledge.
You would know in words that which you have always known in thought.
You would touch with your fingers the naked body of your dreams.

And it is well you should.
The hidden well-spring of your soul must needs rise and run murmuring to the sea;
And the treasure of your infinite depths would be revealed to your eyes.
But let there be no scales to weigh your unknown treasure;
And seek not the depths of your knowledge with staff or sounding line.
For self is a sea boundless and measureless.

Say not, “I have found the truth,” but rather, “I have found a truth.”
Say not, “I have found the path of the soul.” Say rather, “I have met the soul walking upon my path.”
For the soul walks upon all paths.
The soul walks not upon a line, neither does it grow like a reed.
The soul unfolds itself, like a lotus of countless petals. (p.54-55)

Participants of this study now know “in words” some of what they have always known “in thought.” Due to this study, professionals, family, and friends now also know the perspective of some patients.
Through this qualitative exploration, I am honored to have found “one truth”: Living with chronic pain involves much more than feeling uncomfortable and taking pain medications; it involves the overwhelming task of reorganizing one’s identity.
LIST OF REFERENCES


Appendix A

Letter of Consent
June 26, 1996

Dear friend:

This letter is a request for your participation in a research study. The study is being conducted by Tael Frank, who is a doctoral student in counseling psychology at The Ohio State University. Currently, she is working on her dissertation under the supervision of Professor Pamela Sighlen.

Ms. Frank will explore the personal experience of living with chronic pain. To do that, Ms. Frank or a trained interviewer will meet with you twice individually and once in a group format. Sessions will be audiotaped and transcribed. The first interview session will last sixty minutes and will involve structured questions and open discussion. The second interview will last forty-five minutes and will involve your review and confirmation of your initial responses and further elaboration. The third meeting, to involve all participants in the study, will include an open discussion of common patterns in the chronic pain experience and your proposals on how this information can be further used. Interview times will be scheduled at your convenience.

Ms. Frank would appreciate if you would participate in this study. Identifying information will remain confidential. You are free to discontinue participation from the study at any time without penalty. Whether or not you agree to participate, please complete the response card indicating your decision and return it to Ms. Frank within the next couple of days. Only if you wish to participate, will she then contact the Chronic Pain Management Program to obtain your name and phone number. She will call you in order to answer any questions you may have and to set up the interview date at your convenience. Thank you for your time and consideration.

Yours truly,

Wanda McIntyre, Ph.D.
Program Director
Chronic Pain Management Program
614-293-3430

Pamela Sighlen, Ph.D.
Associate Professor of Psychology
Tobin Hall, 614-292-5204

Tael Frank, M.A.
Doctoral Student, Counseling Psychology
614-293-3430
Appendix B

Response Card
RESPONSE CARD

Code number: ________

__ I am interested in participating in Yael Frank's study. She may call me to further explain the study and the interview times.

__ I am not interested in participating in Yael Frank's study.
PHONE SCRIPT

I am Yael Frank and I am calling in response to your willingness to participate in my research study. Thank you for agreeing to participate. This study is designed to explore the personal experiences of living with chronic pain in individuals who have participated and completed the Chronic Pain Management Program at Dodd Hall in The Ohio State University. This exploration is important in that it will help therapists, family members, and friends better understand what a person with chronic pain experiences. Therapeutic benefits can then be maximized.

As indicated in the letter, you will be meeting with me twice individually and once with other participants like yourself. The first meeting will take approximately 60 minutes, the second meeting will take approximately 45 minutes, and the third meeting will take approximately 60 minutes and will take place in Dodd Hall. The three meetings will be scheduled approximately one month apart and will be audiotaped. Do you have any questions before we schedule the interview time and place?

I want you to know that your decision to participate or complete this study will in no way affect any future therapies at Dodd Hall.

Again your involvement and any information obtained will be kept confidential.

What times and sites for the first two interviews are convenient for you?
Appendix D

Semi-Structured Interview
SEMI STRUCTURED INTERVIEW

Code # ___________

Background
- What is your occupation/s if you are working? What are your feelings about the work you do? What are your feelings about no longer being able to work?
- What is your daily routine like?
- Have your beliefs/religion influenced your lifestyle?
- Describe your social life.
- How would you describe your overall quality of life now and before the pain?

Chronic Pain Experience
- When did your pain begin?
- Where is your pain?
- How did your injury occur?
- Did your injury occur on the job? Are you receiving financial compensation?
- When did you realize your pain was chronic? What was your initial reaction?
- How do you define chronic pain?
- Did the chronic pain program change your experience of chronic pain? How?
- Has chronic pain affected your life?
- Has it affected your relationships?
- Has it affected sexual activity?
- Has it affected your work?
- Has it affected your dreams?
- Would your life have differed if you did not have to live with chronic pain?
- What do you do to cope with everyday problems? Give me a specific example of a strategy you used. Was it successful?
- Do those close to you understand what your experience with chronic pain is like?
- How does your experience of living with chronic pain compare to those of others living with chronic pain?

Depression Correlates
- Has the chronic pain affected your mood?
- Has it affected your appetite?
- Has it affected your sleep?
- How do you feel about yourself?
- Has it affected your level of energy?
- Has it affected your ability to concentrate?

Conclusion
- Is there anything you would like to add that might help me understand your experience with chronic pain?
- Do you have any suggestions to improve the interview process?
Appendix E

Group Consent for Confidentiality Form
CONSENT FOR CONFIDENTIALITY

By signing, I agree that the group discussion on September 16, 1996 will be kept confidential. I will not release the names of any of the participants of the study nor any identifying information. I understand that the topics to be covered in the group discussion are personal and private. Therefore, I will honor the rights of my fellow participants and expect my rights to be honored as well. If I wish to speak about the group discussion with others, I will speak in general terms and will not divulge any identifying information.

X____________
Appendix F

Discussion Guide
June 28, 1996

Dear friend:

This letter is a request for your participation in a research study. The study is being conducted by Ms. Frank, who is a doctoral student in counseling psychology at The Ohio State University. Currently, she is working on her dissertation under the supervision of Professor Pamela Highlen.

Ms. Frank will explore the personal experience of living with chronic pain. To do that, Ms. Frank or a trained interviewer will meet with you twice individually and once in a group format. Sessions will be audiotaped and transcribed. The first interview session will last sixty minutes and will involve structured questions and open discussion. The second interview will last forty-five minutes and will involve your review and confirmation of your initial responses and further elaboration. The third meeting, to involve all participants in the study, will include an open discussion of common patterns in the chronic pain experience and your proposals on how this information can be further used. Interview times will be scheduled at your convenience.

Ms. Frank would appreciate if you would participate in this study. Identifying information will remain confidential. You are free to discontinue participation from the study at any time without penalty. Whether or not you agree to participate, please complete the response card indicating your decision and return it to Ms. Frank within the next couple of days. Only if you wish to participate, will she then contact the Chronic Pain Management Program to obtain your name and phone number. She will call you in order to answer any questions you may have and to set up the interview date at your convenience. Thank you for your time and consideration.

Yours truly,

Wanda McIntyre, Ph.D.
Program Director
Chronic Pain Management Program
614-293-3430

Pamela Highlen, Ph.D.
Associate Professor of Psychology
Townsend Hall, 614-292-5308

Tael Frank, K.A.
Doctoral Student, Counseling Psychology
614-293-3430
Appendix B

Response Card
I am interested in participating in Yael Frank's study. She may call me to further explain the study and the interview times.

I am not interested in participating in Yael Frank's study.
PLEASE NOTE

Page(s) not included with original material and unavailable from author or university. Filmed as received.
PHONE SCRIPT

I am Yael Frank and I am calling in response to your willingness to participate in my research study. Thank you for agreeing to participate. This study is designed to explore the personal experiences of living with chronic pain in individuals who have participated and completed the Chronic Pain Management Program at Dodd Hall in The Ohio State University. This exploration is important in that it will help therapists, family members, and friends better understand what a person with chronic pain experiences. Therapeutic benefits can then be maximized.

As indicated in the letter, you will be meeting with me twice individually and once with other participants like yourself. The first meeting will take approximately 60 minutes, the second meeting will take approximately 45 minutes, and the third meeting will take approximately 60 minutes and will take place in Dodd Hall. The three meetings will be scheduled approximately one month apart and will be audiotaped. Do you have any questions before we schedule the interview time and place?

I want you to know that your decision to participate or complete this study will in no way affect any future therapies at Dodd Hall.

Again your involvement and any information obtained will be kept confidential.

What times and sites for the first two interviews are convenient for you?
Appendix D

Semi-Structured Interview
SEMI STRUCTURED INTERVIEW

Code # ____________

Background
-What is your occupation/s if you are working? What are your feelings about the work you do? What are your feelings about no longer being able to work?
-What is your daily routine like?
-Have your beliefs/religion influenced your lifestyle?
-Describe your social life.
-How would you describe your overall quality of life now and before the pain?

Chronic Pain Experience
-When did your pain begin?
-Where is your pain?
-How did your injury occur?
-Did your injury occur on the job? Are you receiving financial compensation?
-When did you realize your pain was chronic? What was your initial reaction?
-How do you define chronic pain?
-Did the chronic pain program change your experience of chronic pain? How?
-Has chronic pain affected your life?
-Has it affected your relationships?
-Has it affected sexual activity?
-Has it affected your work?
-Has it affected your goals?
-Has it affected your dreams?
-Would your life have differed if you did not have to live with chronic pain?
-What do you do to cope with everyday problems? Give me a specific example of a strategy you used. Was it successful?
-Do those close to you understand what your experience with chronic pain is like?
-How does your experience of living with chronic pain compare to those of others living with chronic pain?

Depression Correlates
-Has the chronic pain affected your mood?
-Has it affected your appetite?
-Has it affected your sleep?
-How do you feel about yourself?
-Has it affected your level of energy?
-Has it affected your ability to concentrate?

Conclusion
-Is there anything you would like to add that might help me understand your experience with chronic pain?
-Do you have any suggestions to improve the interview process?
CONSENT FOR CONFIDENTIALITY

By signing, I agree that the group discussion on September 16, 1996 will be kept confidential. I will not release the names of any of the participants of the study nor any identifying information. I understand that the topics to be covered in the group discussion are personal and private. Therefore, I will honor the rights of my fellow participants and expect my rights to be honored as well. If I wish to speak about the group discussion with others, I will speak in general terms and will not divulge any identifying information.

X_________________
Appendix F

Discussion Guide
DISCUSSION GUIDE

Choose one: | How did you come to this? | How does it Affect you? | What can you do to Change it?
---|---|---|---
1) physically active ____ at home most of time ____
2) spontaneous ____ feel like a robot ____
3) socialize with others ____ feel isolated ____
4) can share feelings of pain ____ hide the pain ____
5) feel validated/understood ____ don’t feel validated ____
6) have a genuine relationship ____ relationships are fake/shallow ____
7) have an enjoyable routine ____ no routine/routine is for existing ____
Appendix G

Information Sheet
INFORMATION SHEET

Code # ___________________

Gender __________________

Age ___________________

Relationship status __________

# of children ____________________________

Living arrangement ____________________________

Ethnic/cultural background ____________________________

Spiritual/Religious preference ____________________________

Occupation ____________________________

Estimated yearly income ____________________________

Educational background ____________________________

__________________________

Community involvement ____________________________

__________________________

Interests/hobbies ____________________________

__________________________
Appendix H

Field Notes Key (for appendices I-L)
FIELD NOTES KEY

Br  Brian
S  Sam
Bo  Bonnie
K  Kelly
J  Jennifer
T  Tina

1  first interview
2  second interview
PLEASE NOTE

Page(s) not included with original material and unavailable from author or university. Filmed as received.
OBSERVATIONAL NOTES

Code # __________________
Date of Interview _______ Date of Notation _______

Length of Interview _______ 
Setting __________________________

Environmental Distractions:

   Br-1 Having to turn both tapes over at different times.
   Br-2 Knock on door.
   S-1 Phone rang.
   S-2 Participant said chair was uncomfortable.
   Bo-1 None.
   Bo-2 None.
   K-1 Changing tapes, uncomfortable chairs.
   K-2 None.
   J-1 Interruption of interview by someone knocking on door. 
      Interruption to change tape.
   T-1 Turning tapes over; participant noted she needed a pill
      lean head on.

Environmental Facilitators:

   Br-1 Easygoing pace.
   S-1 Comfortable rapport.
   S-2 Participant felt comfortable with me.
   Bo-1 Interview was quicker.
   K-2 She knew me now.
   T-1 Relaxed environment.

Interviewer Variables:

   Br-1 It was my first interview.
   Br-2 Confused (crazy day).
   S-1 Awake and motivated.
K-1 Maybe drawing or using imagery.

K-2 Giving social security a greater control over your life. She was at the point of "blowing up" - she wanted a change in her life - to start doing more.

T-1 Responsibility for pain and its effects. Victim role. How past trauma affects current coping strategies. Does comparing to others with chronic pain make you less special or less of a victim?
Appendix J

Methodological Notes
METHODOLOGICAL NOTES

Code # ____________
Date of Interview _________ Date of Notation _________

Concerns about the quality of recording:

Br-1 So far, sounds good. Second half is muddled because participant put hand in front of his mouth.

Br-2 Second half hard to hear.

S-1 None.

Bo-1 Tape was messed up, so borrowed a tape and a tape recorder five minutes before.

Bo-2 No.

K-1 None. Patient was very loud.

T-1 Participant stood up and walked around the room. Concerned about recording being too low.

Possible improvements:

Br-2 Don't use stereo as a backup.

Bo-1 Better tapes and have tape back-ups.

K-1 I need to have interrupted more quickly.

T-1 Ask participant whether they will need to stand up and walk around.

Which questions did the co-investigator focus on?

Br-1 Sexual activity, daily routine, social situation.

Br-2 No longer being spontaneous.

S-1 Spirituality; quality of life.

S-2 Spirituality and the author Campbell

Bo-1 How pain affected relationships.

Bo-2 None, really. She just responded, didn't elaborate.

K-1 Work and being spied on.

K-2 How she decides to do something. She thought it depended on her mood - but it seems to be the other way around.
Depression, frustration, diagnosis, and prognosis.

Which questions did the co-investigator struggle with?

Br-1 How would life have been without pain. Impact of religion on his life. How does your experience compare to others living with chronic pain? How have your dreams changed because of chronic pain?

S-1 Compare himself to others; sexual activity.

S-2 At what point did ying and yang alternate? Pain was controlled by his positive side.

Bo-1 How life would have been without chronic pain, and how her experience compares with others.

K-1 Relationships. Quality of life. Thoughts about herself.

K-2 That she wants to do something.

T-1 Comparing to other participants in the program.

What information was not obtained in this interview? Why?

B-1 None.

B-2 Drawing himself.

What sorts of information should be sought with the next participants?

Br-1 Self-concept. Responsibility for one’s life experiences.

S-1 Meaning of life. Reinforcements.

S-2 Is pain outside of you or part of you, or do you see it a different way? What image do you have of pain?

Bo-1 Effect of age, if any.

Bo-2 Image of pain.

K-1 Being spied on.

K-2 The effect activity has on them.

T-1 Role they’re in → victim, at fault, responsibility.

Suggestions from participant:

Br-1 “Just continue to let participant gabble.”
S-1 May give more structure to those who have a harder time talking about themselves.

Bo-1 None.

K-1 None. Enjoys being heard and looking forward to hearing others.

T-1 Just let person keep on talking. Maybe can get tokens for parking.

Possible refinement of interview questions:

Br-1 Ask about chronic pain experiences before asking about background.

S-1 Ask about meaning of life.

K-1 Be more explicit on the time factor.
Appendix K

Theoretical Notes
THEORETICAL NOTES

What were the main themes or issues presented?

Br-1 Being bitter and feeling at fault. Loss of sexual function. Boredom and depression.

Br-2 Needing a way out; a way to connect genuinely.

S-1 Spiritual growth and awareness. Having found answers.

S-2 Ying-yang, spirituality, the therapeutic effects of photography and art.

Bo-1 She loves the outdoors and outdoor activities, and now she’s restricted.

Bo-2 Deciding whether or not to do activities; control.

K-1 How she loved the job that she lost. Lawyers, bosses, and those watching over her to see if she’s doing what she’s not supposed to do. Feeling like a "prisoner."

J-1 Loss of control, depression, self esteem issues, rationalization, and blaming of others.

T-1 Depression, frustration, and feeling misunderstood.

What new concepts or hypothesis were suggested by the participants?

Br-1 Role of sexual function; self-concept; living life out of habit; drives are flattened.

Br-2 Losing past identity because trying to hide pain and being someone you’re not.

S-1 Most people with pain are blue-collar workers and they look for quick rewards and are not in touch with their feelings. He noted seeing a "vacant" look in their faces after they lose their job. They’re lost.

S-2 Pain as a part of yourself. Accept it and then try to overcome it. Awareness of ying and yang helps you have control over your behavior.

Bo-1 Age related to expectations. Treasuring life.

Bo-2 Using "ignore" instead of "control". Can change how activity is done instead of whether it’s done or not.
K-1 Having social security control your life. You’re always watching over your shoulder. “Extra attention” received from pets.

K-2 If I have to, I will → feel good;
Nothing to do, or don’t have to - stay in bed → feel down

T-1 Feeling misunderstood, a traumatic past before the pain began. Participant sounds like feels in a “victim” role that no one understands or can help. “Not my fault.”

Similarities in themes shared by other co-investigators:

Br-1 This was the first interview.

Br-2 Not being able to be spontaneous – always having to worry about consequences. “I’m by myself too much.”

S-1 No one understands me. Mine is a different experience. Clump everyone else into one group. Social isolation, depression, pain is always there. Effects.

Bo-1 Experience not understood, hiding pain.

Bo-2 Pain is always there. Pain is a part of me.

K-1 Losing work is a loss of identity. Religion not a big part of life. Sedentary life at home. Feeling guilty for not doing for others.

K-2 Activity does good.

T-1 Depression; helplessness; in touch with feelings; hard time comparing to others with chronic pain; shared information easily; appeared comfortable.

Differences in themes shared by other co-investigators:

Br-1 This was the first interview

S-1 Spiritual growth, happy with life, life makes sense, writing a book about experience, didn’t complain, helping others with same injury.

S-2 Very different. This participant has something much larger to carry him through.

Bo-1 Didn’t complain of unfairness or perseverate on the past.
Didn’t turn to cleaning house.

Bo-2 Can’t grow or be full self.

K-2 How social security is involved.
T-1 In how one decides to share pain experience. In support from family. Sexual activity only sometimes affected by pain.

Thoughts about the meaning of what co-investigators disclosed:

Br-1 There must be other positions for participant to still be able to be sexually active. Counseling may give control back to participant.

Br-2 I felt as though I was counseling him. He disclosed deep thoughts, some for the first time.

S-1 Very interesting. Gave me lots of insight.

Bo-1 She's in control and trying to make the most of it.

Bo-2 I wanted more information.

K-1 "There must be a reason for this, but I don't know what it is yet."

K-2 She blamed much more on the system.

T-1 I wonder the impact of loss of sexual function on self-esteem. Roles of being "at fault" or a "victim" (not at fault). Meaning of work to female and male; and meaning of losing that role. Could it be more negative for males? Interesting the loss of faith in G-d (other participant also noted religion has no bearing on his life).
Appendix L

Personal Notes
(prior to study, and
before and after each interview)
PERSONAL NOTES

Date of Notation _____________

Researcher's beliefs, expectations, and hypothesis prior to study:

Chronic pain patients:

- are socially isolated
- have a lower income
- began experiencing pain during a time they were unhappy in their life
- have difficulties in their relationships
- romanticize what their life would have been life without chronic pain
- feel increased self-esteem if they use active coping strategies (i.e., walking around the block when in pain)
- feel depressed if they use passive coping strategies (i.e., lie in bed)
- feel misunderstood
- lost their identities because they are no longer able to work
PERSONAL NOTES

Code # _______________ Date of Notation _____________
Date of Interview _______________

Interviewer's beliefs, expectations, and hypothesis prior to interview:

S-1 Participant feels guilt/responsibility; lost role of provider; may have issues of control.

S-2 Participant gained control over his pain during his near-death experience.

Bo-1 Control seems to be central. Age could play a part. Participant may think it’s unfair because she’s younger than other people with chronic pain. Did she feel like an outsider in the program?

Bo-2 She has control over the pain most of the time. She has trouble with not succeeding, so would rather avoid certain activities. Does not deal well with pain. Avoids pain, but tries to stay active.

K-2 Social security is controlling her life and she needs to be exposed to other activities.

J-1 Dealing with chronic pain causes changes in the way a person views themselves and the world around them. It effects self esteem and changes ideas for patients and families.

J-2 The changes in a person’s lifestyle as well as the financial, social and pain stressors would be overwhelming adjustment issues.

T-1 Her head pains would have a different effect compared to back pain.

T-2 Bounces between no control and control struggle. Easier to believe she has no control. Feels guilty when sees things are up to her. Doesn’t want the control- scares her.

Interviewer's reactions to information disclosed in the interview:

Br-1 I was struck with how low his self-esteem was and with the large amount of information participant shared with me. I was also struck by how participant’s sex life is gone.

Br-2 He needed to feel accepted and didn’t feel accepted by his family (especially his wife). The false facade he put to hide pain disconnected him from his true self.

S-1 Participant spoke easily. I was surprised as to how the accident was for him - a “spiritual awakening” and how much he appreciates life. I was surprised by my stereotype.
S-2 Pain is part of him and he struggles to "overrule it" everyday. Surprised at his reaction to talking about his photograph that looks like pain (looked scared).

Bo-1 Participant had control in her life. She seems to have it all together. Gave herself the right to be in pain. Liked program because validated her pain experience.

Bo-2 She said she deals well with pain. I hadn’t thought of changing how an activity is done. Another participant said that, too.

K-1 The participant, a female, was very strong spoken. The pain took away work (which was her being). She doesn’t know what she "should do” now.

K-2 I was happy and surprised that she was able to be aware of her thinking process and what works for her.

J-1 I both felt for this person in having to deal with her life-changing medical condition, and also felt that she engaged in rationalization and attention seeking behaviors at times.

J-2 This person seemed to indicate not only that her life had changed as a result of the pain, but that she had changed as a person, that her definition of self was forced to begin to change, and that she was struggling with this. I felt saddened by the idea of a person forced to make changes not only in their lifestyle, but in their self concept - what a huge and overwhelming adjustment that would be if one was in good health.

T-1 Participant felt misunderstood by everyone (fiancée and program). Participant looked a lot into the future and grieved for what she couldn’t do. She said she had a “troubled” past. This participant was depressed before the pain.

Changes in interviewer’s beliefs, expectations, and hypothesis:

Br-1 Negative effect of a change in income due to disability. Participants may be in touch with their feelings, but try to hide them not to bring anyone else down. Loss of sexual activity has a big impact on self-esteem and desire to live.

Br-2 Surprised at how he lost himself through hiding his pain.

S-1 It’s how one interprets the pain. This man lost both legs and is happier with life now than before.

S-2 Spirituality helps him overrule pain - something bigger than himself. Couldn’t draw images because the paper and pencil felt restricting.
Bo-1 Maybe age is related to expectations. This participant differed because she went back to work at a less physical job and she's happy. She's happy with life and lives each moment. Has improved family relationships, because more quality time and treasure them. Has somewhat impacted relationship with husband. No religion.

Bo-2 Control struggle occurs in social situations. Why?

K-1 Work was very important to this female, so not just more important for males.

K-2 Losing financial support is a payment as well.

J-1 Interviewing this subject gave me a greater understanding of how her life has changed in every way and in how it has effected her self image and lifestyle.

T-1 Interesting how she said she's still the same inside, but her outside has changed. So far, both participants used interview as a time to vent, cry, and cathart.
Appendix M

Brian’s First Interview
Brian’s First interview

- I’m gonna start by asking you a little bit about your background and then we’ll go more into your pain experience and so forth. And if at any time you have anything to add or any questions, just let me know. OK?
- ok.
- You said that you were in sales.
- Well, actually I was in business management of sales.
- Business management of sales...OK.
- I ran a wholesale distribution of interior building products.
- OK
- And I had like at one time six salesmen (muffled).
- And until when you doing that?
- Until I had my stroke in 88.
- In 88? Is that when you stopped working and you retired?
- Yeah, medically retired or I’d probably still be working if I hadn’t been.
- What was your feelings about the work that you were doing?
- Oh, I was in it for about forty somewhat years. I liked it. It’s a little different cut then the business world, but I was actually running two companies at one time.
- Oh really? ok. Which were the two companies?
- The first one was xxxxxxxx nicknamed xxxxxx and the second was xxxxxxxx. One was interior building products and the other one XXXXX was windows, doors, and so forth, called xxxx.
- What’s it like for you right now not to be working?
- It’s a living hell.
- Is it?
- Yeah. The only thing I got to sway the inward motion or emotions is my pain. Constant 24 hours a day.
- O.K., so it’s not...you don’t have a distraction right now like you did with your work?
- The only think as far as getting away from not having, not doing work is - I cut grass, I have flower gardens, I have my woodshop in the basement. But I have to be extra careful with the woodshop because coordination danger machines.
- So you miss working the way that you used to before you retired?
- Oh yeah. I was a workaholic. Fifty, sixty hours a week was nothing. Bet my wife appreciates that I’m home now.
- Yeah, I bet (laugh).
- But my mind seemed more occupied. Now my mind is basically idle.
- You’re trying to find things to occupy your time?
- I do a lot of reading and like I said even my number one escape when I was working was cutting the lawn and I could just relax into my own world. But now when I cut grass, I suffer for a couple of days afterwards I guess from pounding up and down. See I got an acre and a half and it’s all grass.
- Wow. What’s your daily routine like now?
- Oh, I get up when the wife gets up. I have coffee with her. We’re talking five o’clock in the morning. And then generally I’ll read the newspaper and I’ll let the dogs out, feed the dogs, do some housework. Ahh...that’s basically it. I don’t watch TV in the daytime.
- ok
- I don’t like to get trapped in anything like that.
- In anything inside the house?
- Watch t.v.. Yeah, that’s it. I watch t.v. in the evening because I feel that’s a relaxation in itself. I don’t want to get trapped in these stupid serials.
- But in the daytime you like to keep yourself busy...
Keep myself busy till about two o’clock. Then I lay down take a nap - that was part of my treatment and I have coffee ready for the wife when she comes home.

What does your wife do?
She works for University hospitals-mammography.
O.K., so she’s working during the daytime?
Uh hum.
What’s that like for you?
Boring. I sometimes find myself climbing the walls. It’s pitiful what happened to me. So I can blame nobody else but myself. (cough). In 88, I had a stroke. I was putting an addition on the house and I was up in the rafters putting insulation and dry wall and it was just about this time of year and the heat in the house was horrible. As soon as I woke up, I was in the hospital. The reason I was let... I was let or fired or whatever from work. back pain was horrible due to...

The back pain started with your stroke?
No. The stroke was a result of the back pain.
Oh, ok.

While they were doing investigative surgery and so forth, they discovered I had cancer of the bladder. And that along with losing my job, finding out that I really wasn’t half the man that I was or thought I was, and plus working in the heat, and so forth, I think that’s what led to my stroke. I completely lost all motor skills on the left side. I had to learn how to write again. Actually that’s why my handwriting is so sloppy. I learned to walk, speech, etc. I was in Dodd Hall for that for about five weeks.

O.K. The rehab here?
Uh hum. That’s when I got... I don’t think I was really hooked, I was dependent on pain pills.
This is your stroke, was in 88?
88 or 89.
O.K. And you said also that you have low back pain?
I have a horrible back pain.
When did your pain start?
About... How my back was injured was I was still working, being in the process of moving the two companies I was running into one warehouse. So I was pulled or instructed or whatever to help them move the material and I got into something that my body wasn’t designed for and there was a lot of physical work and I done something stupid and hurt my back and I got me into the hospital and I had a ruptured disc, a third and fourth disc vertebrae. Now I’ve got degenerating spine. Now while they were going through this, that’s when they discovered the cancer.
When did your injury happen at work?
In 88, mid... like about this time of year.
So it was a little bit before your stroke?
It was before... about a year before.
A year before the stroke?
Since then, I’ve been a survivor for about six years now. ah eight years. Five or six years I’ve been a survivor of cancer and my bladder’s clean. I go for checks every three months. They run a test on me. But then I developed prostrate problems.
What’s it like for you?
Living hell. It really is. I’ve become quite a bitter person. I used to be a jovial person. A lot of life, a lot of fun. The kids don’t like being around me anymore. I can sense it, I can feel it.
You feel angry all the time or irritated?
I don’t think it’s angry, I don’t think I’m feeling sorry for myself, I’m bitter. I think that’s a better explanation. But when you’re in pain 24 hours a day and you don’t... completely away from drugs, which I really appreciate.
You’re not on any drugs right now?
Not at all. The strongest thing I’ll take is a Tylenol. I used to be a heavy smoker. I quit smoking. I used to be a heavy drinker, I quit drinking. Sex is...or... The back pain completely eliminated sex in my life just because of the motion of the back. Which I think it’s interfered a little... I don’t know...it’s just my mind, we’re gonna work it out.

How have you dealt with that with your wife?

Oh, we talk quite a bit. I’ve got a very, very wonderful and understanding wife. And she tells me it’s not necessary, not to worry about it, but still there’s that drive that everybody has.

Uh hum. Definitely.

I don’t... I miss it. And I’m sure she does too. But it’s just a way of showing love for each other.

Is that what you were referring to when you said before you felt like half a man?

Yeah. And I miss the fun in life. I miss not worrying about if I’ll hurt the next day if I go to the store, just do what you want to do. I can’t do it in my life, I’m very restricted.

How do you feel in terms of before your pain started, before this phase of your life? Do you see a change in terms of how you see yourself, uh..

Oh, I’m quite... and I mean this seriously...I’m quite very, very disappointed in myself. Because of the financial burdens that we are in now and I thought I had it completely controlled. I was working, but there are certain things of habit. But when you lose your job that pays you 70 to 80 thousand dollars a year, and then you’re forced on social security, it’s quite a cut-back and I personally take the blame for it.

You feel like it’s your fault?

Oh, definitely.

What would it have been like if you didn’t have to live with this pain and the cancer?

I can’t even imagine it now. I’ve even thought of suicide several times.

Have you attempted suicide?

No, no. It’s against my religion.

How has your religion...Catholicism....

I’m not active in my church at all. You see, my marriage is not recognized by the church.

So you’re wife is of a different faith?

Yes. Actually, it’s my second wife. See now, a divorce is against the religion. Well...

How have your beliefs? How have your beliefs in Catholicism, how has that affected your life?

Has no bearing now. It has no bearing.

No, O.K.. It’s not a big part of your life?

Not at all anymore. In the back of my mind, I still have a lot of respect for the Lord and so forth and I try to live by the golden rule. The religion, since I was born and raised in it and was active in it, still a big part of me whether I recognize it or not.

O.K.

I don’t observe religion in my house of the Lord. I’m meaning I don’t go to church. Gee, I talk a lot. This is one of the side effects of the stroke. I’ll lose my voice. So on occasion, I may have to go out and get a drink of water.

O.K., no problem. Just let me know.

But I have become quite a bitter person. Very bitter.

What’s that bitterness about?

Everything. When you’re in pain 24 hours a day and you try to hide it so that your family around you can be comfortable...

You keep the pain all to yourself?

Oh yeah...It doesn’t fall on anybody else.

Does your family know what it’s like for you to live with this pain?

Oh, I... we don’t discuss it openly. I’m sure my wife does with the kids. We’ve got 8 girls and one boy, but that’s children by two marriages. I married a woman that had six kids. But they’re all just like my kids. ‘Cause their father died... I think... let’s see... either the second or third year that Mary and I was married.
So your wife may have spoken to your kids?

Oh, I think she has...in making excuses for my actions and so forth and going to bat for me. ‘Cause I... I... (caugh) I know I get crossed, edgy, and generally I’m a very considerate person. But I’ve developed this philosophy of ‘hey, I don’t give a damn anymore’. I really don’t. I’ve tried to get involved with this... you see, we have a boxer rescue where we place stray dogs and so forth. My wife, two other ladies, and myself placed 135 boxers last year.

Wow.

Some of them were pitiful dogs and we had to nurse them back to health. I used that as a diversion. I find (chuckled)... I find myself taking it out on the dogs. That’s not right!

You’re taking out some of your anger and bitterness on them?

Yeah. Dogs will be dogs and pets will be pets and you can’t expect them to do what you do.

So where is your bitterness and anger going right now? Is it directed outward or does it stay inside?

I think the majority of it just naws away at the inside. It comes out in dreams, I have some horrible nightmares. Horrible...

What are they about?

...and I’ll wake up and try to shake them off and then go back to sleep and then go right back to my bad dream again. And it’s always somebody getting hurt. But I can’t do anything about it.

Kind of feeling helpless?

Yeah, totally helpless.

Is that how you’re feeling...

I feel I don’t get involved in life enough. I’m not useful. I’ve caught my wife losing confidence in me and it’s rightfully so. As much as she tries to cover it up, and at times it’s obvious. The challenge to your manhood... The pain is constant. There’s... well, take our... we’ve got kids living in the state of Virginia, the state of Washington, Florida, Mississippi. We’ll take nice long drives sometimes to visit and there’s times when we drive to far I can’t even get out of the car, ’cause everything just locks up on me.

So things happen unexpectedly...

Yeah, a lot of times. The pain is just so severe, it’ll just knock my legs out (caugh).

What are some coping strategies that you’ve used in the past to help get through the pain?

Well, I try to dismiss it from my mind.

To block it out?

Yeah, to block it out.

And how do you do that?

Well, I get interested in something and get my mind off of my own problems. I took working in the flower garden. Really not much of anything helps because just like now. I think anybody else that has this pain I bet right now they’d be crying. There’s nothing they can do about it. They won’t guarantee the surgery plus I’m on Cumadin blood thinner. They’d have to take me off of Cumadin and I could stroke while they’re operating on me. So it’s really...

Sounds like a no win situation...

Yeah, that’s the way I feel, it’s a... Oh, I catch myself crying every once in a while, but...

Have you had, since your pain started, have you noticed changes in maybe your sleep? In your ability to go to sleep or stay asleep?

Yeah, I don’t sleep a solid 6, 7, 8 hours. I sleep an hour and then I’m awake.

And you used to be able to sleep through the night before?

Oh yeah.

Have you noticed any changes in your appetite, your hunger?

Ahh... I don’t think I ever get hungry. I eat out of habit.

So you don’t feel, kind of, that hunger or that appetite?

I drink an awful lot of water because of my throat, but I don’t think I ever get hungry. I just... it’s a routine of life. Eat something at breakfast, eat something at lunch, eat dinner.

Have you felt depressed or down?
• Oh, I think I get down, I very easily get depressed.
• Easily get depressed? What’s it like for you when you get depressed? What happens?
• Oh, I pull within myself. I get... get edgy...I don’t have an attractive life, I really don’t. I just... I try to dismiss it from my mind, but I’ve tagged my pain ‘the monkey on my back’. That monkey just kicks into high gear and boom, chain of thoughts change right back to where you are.
• So it feels like the pain has control over you?
• I think it does. I think I let it take control of me.
• You let it take control? What happens to the control that you have. Is that still there if you want to use it?
• No, I don’t think I’m too successful at it, to be honest with you. I don’t know if I have been. Like I try to divert my thinking, chain of thought, whatever, and ah working in the ....working in the woodshop, reading a book or something like that. All I gotta do is press a little bit and boom. There’s that reminder... there’s that old monkey back kicking around again.
• It’s very hard to push aside for too long because it comes back...When you were in the program here, and maybe at other times, you met other people with chronic pain.
• Ah ha.
• How are your experiences...your experiences with chronic pain, how are they similar and different, would you say, from the other people that you met?
• I really can’t answer that. I know they were in the room with me. xxxx, I think that was his last name, I think that was his last name, I think he was older than I. I’m 66, and I was 58, at that time he was 65, so he’s about 70 years old now. When he came into the pain clinic, the minute you walk in, you’re off of drugs. And I suffered quite a bit. Then as I do now. But I watched that man beg, cry, plead... I even went to bat for him. I think the only reason... I think the only difference was I think I had a stronger constitution.
• You can hold out longer?
• Yeah. I don’t think his degree of pain was any worse than mine.
• How were you before your pain started, how were you in handling pain before?
• I never paid any attention to it. I was one of these people that always cracked on somebody that... a pill popper. I became probably the leader of the pill popper pack.
• O.K. (chuckle) So if you had a headache, you’d pop a pill and it’d be gone...or ...
• No, I never took....before my stroke and my back injury, I was one of those people that was belligerent - ‘It’s mind over matter’ and that bullshit. Now I think what it was like and I think I’m paying for the boldness of the past.
• You feel as though it’s not mind over matter anymore?
• I was almost professional at that - mind over matter. But the mind can’t do it. You can’t control it like with inner telepathy or whatever. I just have become a pathetic, bitter, bitter person that’s lost all respect for himself, dignity. I used to be... I was always involved, people around, and I was the center of attention. But now I find a corner, ‘cause I don’t know how to communicate anymore.
• What’s it like for you to communicate now?
• Oh, since my stroke, see I’ve still got a lot of brain damage. It’s taken a lot out of me too. I’m able to talk... I’ve lost a lot of my vocabulary. I have problems with speech. If I’m not careful, I can get into feeling sorry for myself, which I still have that much pride left.
• And you’re trying to control that so you won’t get there?
• Yeah.
• Are you able to share with your wife feelings that you have about the pain and how it’s affected you?
• Yeah, she just took a profession. She should have been in the medical world because she has a natural touch for it and if it wasn’t for that lady hand-picking my doctors and so forth, I would have been dead. So I (muffled) for my wife, not only do I love her, I like her. I’m fortunate in that respect.
• I want to turn the tape over for a little...not to interrupt you.
• Let me ask you some questions about this...When did you happen to realize that the pain that you had was chronic? That it was going to last for a while? That it was something that you were going to learn to live with?
• Oh, I can give you miles and miles and miles of examples. Exploratory surgery... you don't have to get hit by a sledge hammer to notice. I mean there's a point where there's nothing else you can do. You get a prescription for Percocet or...
• You already became... you had become aware at that time that it was chronic a little bit at a time.
• I used to be able to brush things off.... A lot of it was ego, pride, and stubbornness. You take your time and do just about every little dumb trick you can do and it's still obvious. And then you give into it. I guess it's just human nature. Even being a stubborn old fool, as I am..
• It feels as though you've given up?
• I think I have.
• You've given up fighting the pain?
• I think I have. I just let it take its course. If I have to hide, I'll hide.
• But you're not fighting it?
• How can you fight pain? I mean there's no results. It's a constant thing. When you go into a fight with a man, and he continues to beat the crap out of him time after time after time, you're going to quit going into there anymore. That's what I've done. Right now I'm thinking about standing up just for the change of body position. You do things whether they do any good or not, but at least...... well, you're so obvious the pain... and then I almost cry or beat my fist against the wall or.... I'm by myself too much, I know that.
• What's your social life like now?
• Next to nothing. I used to dance.... I pay for it if I dance now. I used to take long walks, I used to ride a bicycle. The biggest loss is not being sexually active...Oh well...
• What's it like for you to have lost that part of your life? That part of your person?
• Oh, I think it takes... it destroys your ego and takes away all your manhood. You don't... you discover the kids quit inviting you or going to a concert or anything. And you know why... 'cause you'd end up destroying their evening. They're so concerned about you. You try to cover it up and they know every expression you got.
• What are some ways that you cover it up or some things that you do or ...
• I get very quiet, I pull away from the circle, or I just try to hide. Just stick myself in a corner somewhere or find a book or something to read... something to do... something to occupy your mind with. It's not a nice life. Yeah, I'm sure I'll get fat and I'll get a bulge. And it's another thing, you can't exercise. So you watch your intake.
• Is that what you've been doing? You've been watching what you eat?
• Oh, I cut out a lot of the sugars and a lot of the fats. Eat small meals.... I was always... I was always on the thin side. That's a result of breaking up a dog fight (points to stitches on fore arm).
• Oh.... How has your pain affected your goals and your dreams?
• Oh, they're totally destroyed. I... there's... my retirement program.... that's another reason why my wife could have left me... that just really destroyed her personal life... I just really feel bad about that. She never complains. I want to do so much for her, but I can't (tears, and I pass the tissue box). One thing I was blessed with was a good woman.
• Do you feel helpless?
• Huh?
• Do you feel helpless?
• Well, it depends on the day...
• Do you ever feel as though you have no hope?
• Well, I think it goes with the isolated times I've thought about suicide.
• What was the situation, what was going on for you when you were thinking about suicide?
• Oh, it's a combination of pains... see, there's degrees of pain... sometimes... right now I'm on a low level... I'm still in pain...but still.... sometimes I can't think, I can't lay down, I can't walk, I can't stand up. That's when you start driving your fist through the wall. That's when you try to hide so you won't hurt or insult anybody. You have a lack of control. It's very... I just came back from Washington D.C.... We were walking around seeing all these historical sights. I was at the
Washington monument and I looked out ... black man and a white woman making out. Hell, what’s happened to the respect in this country? I’ve always been quite a patriot. I can... we go to all the Ohio State football games and I belch out the national anthem and I get half way through and I start crying... that’s part of the stroke. I’ll tear up every once in a while, but I get feeling sorry for myself. Oh, all of this is inner emotion trying to get out.

- You feel like you have a lot of emotions and feeling in you that want to get out?
- Yeah, but to what effect? What good will it do me? I don’t know why I get upset over what’s happening all around. The evidence is you don’t have any control over it, you know you don’t have any control over it. I see the new generation and what the’ve done to themselves... I think that’s a diversion on my part. I worry over those kinds of things to get my mind off of my problems... How’s the interview doing?
- Oh, it’s... you gave me a lot of information... it will help me. How are you doing?
- Oh, I’m fine. That’s in the area that irritates Mary. People will come up and say ‘hi, how are you?’. I’ll say I’m doing great.
- How are you really feeling... what’s going on inside of you right now?
- Well, you can carry the pity towel so far... You’re fooling yourself if you don’t try to do something to divert the pain. There’s no living with the pain... ‘cause when I went through that chronic pain clinic they teach you to live with your pain. They’re wrong! You don’t live with the pain, the pain lives you. Oh. I forget the psychiatrist’s name who was here at the time, but xxxx was here, but she was over the woman who was in charge of our crises. I can’t think of her name... Like I said, I lost my train of thought.
- You were here in 1993?
- Yes, I think it was , yes. We were in our twelfth week, which is our final week, and she asked what I thought of the program, that was part of the general questions... I says... ‘the program sucks....if you would have started the program the way you ended up the program, the program would have made a lot more sense’. The final session, that’s when I had the family and so forth, I forget who the guy was xxxx (a medical doctor)... what he tried to do is show why you have pain... how you control pain... your pain is controlled by your brain. Drugs doesn’t do anything for your pain, drugs interfere with your brain. And there was a few other things he said, there was a diagram on the blackboard and so forth... I just... I stood up...I said ‘why didn’t we start the whole twelve weeks with this instead of the critical thing at the very last show’. He couldn’t answer that question.
- How would that have been different for you if he would have done that in the beginning?
- Well, if we would have started out with the end result... if what really the chronic pain clinic was for - to get you off of drugs, to teach you to live with the pain, to teach you to walk, and work, and so forth, but .... If they would have started the program with ‘all that drugs do is affect your brain’, that would have been step one... then we could have gone from there. How do you keep from affecting your brain? You don’t take drugs. You go plan two, plan B, whatever. Exercise programs... they tried... I can’t exercise... all it does is irritate it. We went in the swimming pool everyday. While you’re in the pool it’s fine, but you can’t live in the pool! You got to come out take a shower and dry off. Then you take a couple steps, and there’s you’re pain back. But when your pain disguises itself and then all of a sudden it takes off its disguise, well - it’s worse.
- How did the program affect your pain or like your experience with chronic pain?
- Well, the only benefit, the only credit I give to the chronic pain clinic, they got me off drugs. Because the drugs... it could have been a problem... I might have committed suicide. But since I’m off drugs, I have a clearer brain.
- So before...
- They taught us all ... rearranging you coverts, your cabinets and so forth... the things you use the most you put in eye length... the things you don’t you put up higher. Little things like that. Those were beneficial. But a psychiatrist, I can’t think of her name, I said ‘there’s something...’, it was the final week, I said ‘there’s something that’s bothering me, but I don’t...’. I haven’t been able to put my thumb on it, about going home, and it took me about three weeks to realize what I was afraid of. And what it was was the fact that while you’re here, every one of your steps was dictated. You do as your
told. But when I go back home, I have to use my brain. When I want to do and what I want to do.
And it was the fear of that. That’s why ... that’s the reason I was asking about her to see if she was
still here. She says if you ever find out what it is, give me a call. Fear of not being able to take care
of yourself.

• So here you had someone else controlling...
• Oh, you were totally controlled. You were told what time to go to bed, what time to get up. At seven
  o’clock you had to be here, at eight o’clock you had to be there, eleven o’clock you had to eat your
lunch.... your whole day was lined up for you.
• Your worry was that when you would go home, your control would be back to you.
• Yeah, I wouldn’t have that regulation. I’d be back to controlling myself. How easy would it have
  been.... how easy could it have been to be back on drugs. You see. before you had an angel over... all
the doctors and so forth.... Especially when you’re by yourself eight, nine hours a day, it’s so easy to
get into the vices. I tried mental sex... as a bandaid approach. But the final result was that that part
of my life is over.

• That part of you is gone?
• Oh, yeah... That’s being a man... that’s part of manhood. It might be a false facade in some cases.
• Have you ever had a chance to grieve for that part of your life?
• Grieve? I feel I’m grieving now. Am I the first interview on this? (yes). You can go to school on me.
I’ll be as helpful as I can be for you.
• Is there anything else you would like to add about your experience... something that I haven’t asked...
that you’ve thought about.... that you think would help me more to understand what it’s like for you
to live with chronic pain?
• When I was in the hospital for therapy for the stroke, two doctors told me I’d be in a wheelchair the
rest of my life. I went out of here in a wheelchair. This is before the chronic pain clinic. I still had
some of my stubbornness, some of my ego. I was in a wheelchair one day. The third day, I had my
wife strap me to my lawnmower. I don’t rely on a walker, I don’t rely on a wheelchair. I don’t rely
on a cane. I think my own personal fortitude is stubborness. Now, after so many years of pain and
pain and pain, now I’m starting to regress.

• Regress in which way?
• Doing what I used to love to do. Like getting on a lawnmower and cutting the grass. Just let my
mind relax, stray, fantasize, whatever. That was my escape from reality... ha! I get on my
lawnmower now, and it’s getting to the point where I don’t want to cut the grass and I was probably
the most fussy person in the world about my lawn and my flowers. It’s not important anymore.
• You don’t care about that anymore?
• I cut grass now out of necessity.(turn other tape)
• There’s one dog I haven’t been able to find a home for, but she’s a fence jumper. She’s always
getting out of the yard. I have split rail fence all around my yard and I have wire on it to keep the
dogs from pulling out... because I’m a strong believer in you have pets, but your neighbors shouldn’t
have to worry about your pets. I attached that... I’m very proud of myself... I’m not much of an
electrician, but you got to wire it correctly and it works... perfectly. So I ran a test on it. I grabbed a
hold of the little things that hook up to his collar... it’s got two probes up against the neck... that’s
where they get the shock. I pushed my fingers against it... I walked into the wire (laughed)... I
jumped and when I did, I wretched my back. I went down on my knees and I didn’t think I was going
to be able to get up. My wife helped me to get up. But it’s stupid things like that that I kick myself in
the rear for. I know that I’ve got a chronic back, I know that there’s nothing they can do about it
now, but why purposely irritate it? Again, that’s the human element involved. Nobody’s perfect....
I’ll probably think of other things before the next meeting.

• Do you have any suggestions of how to improve this interview for future participants since you’re the
first person?
• No, I think you’re handling it correctly. Just let the patient ramp and rave. Pull at them here and
there... ask certain questions. Your tactic is good.
Well, I can schedule the next time that we meet or I can call you in a couple of weeks if that would be better for you, if you'd know your schedule more.

Oh, another thing has happened to me since... I've had to have two skin cancer operations. Right up here that's not real skin (points to top of head, where he's bald). It's artificial skin, believe it or not.

Really?

Right down to the freckles (chuckles).

How do they make artificial skin?

I don't know how they do it... but when they cut it out, being partially bald, my skin is stretched tight anyways. So when they cut all the diseased skin out, they couldn't stretch all the remaining skin back so they stitch it up... so they had to put a patch in there. They stitched it all the way around. There's no feeling to it, it feels raw. That was due to not wearing a hat... especially the way I work. Now I'm very religious about it.

Hindsight's twenty-twenty.

Yeah... Well, I have no other suggestions really.

Well, I want to thank you very much for sharing your personal experience with me. It is very helpful in terms of... to help everyone that's suffering from chronic pain.

What's really going to be interesting is when you get the group together. (talk about my sunburn)

It (the program) was quite helpful, I have to be realistic. There are advantages to it. What you gotta do is open your mind and accept it. That's probably... most people don't open their minds and accept what's good for them... (spoke about all the friendships he made in the program).
Appendix N
Brian Second Interview
Brian's Second Interview

- What we can do is while you're looking at that I can ask some questions that I wanted to ask you. One of the ones was in terms of how you see yourself, how you define your whole person, who you are...
- Well, I'm a 67 year old excuse for a man.
- How did you see yourself... how did you define yourself before the pain and everything?
- Well, aggressive, confident, wasn't afraid of anything or anybody.
- So how you see yourself... your identity has changed?
- Dramatically. Lack of confidence spoils the rest of your life. If you don't have self-confidence, you're like a shadow, shoved in the corner.
- Have you accepted how you see yourself now?
- No, I haven't and I don't think I ever will. I still have times I cry.
- So even though you may feel that way about your self-esteem, you haven't accepted...
- I don't think I ever will either. I am a partial man, I've got some health problems, I don't think they're ever going to go away.
- So, in terms... it seems that the identity that you had before... the identity that you have now, the change is that you lost something - self confidence and so forth? You lost a couple parts of yourself?
- Aha
- Have you gained any new parts?
- If I have, I haven't recognized it.
- So it feels like you lost...
- I don't know, I've got that old monkey on my back that keeps reminding. You remember the monkey, don't you? (Aha). You've got a nice smile. (thank you).
- What I wanted to do relating to the question that we just talked about is... in terms of how you see yourself now, your whole person.... can you somehow get that on paper? Either abstractly or with a picture?
- I wouldn't even attempt it.
- You wouldn't attempt it?
- Aa.
- Would it be too hard to get it down or ...
- What good would it do?
- Well, help me to understand more how you see yourself more concretely.
- I don't see where putting it down on paper, Dr., is gonna do any good. It is doctor?
- Almost, half a year.
- Great, congratulations.
- Thank you.
- My... this doctor in chronic pain.... I'm not defeated, but I am down... and I continue to feel being down.
- Is it a new struggle every day?
- Aha. Well, it's not a new struggle...
- The struggle is continuous...
- Yeah.
- It happens again and again every day.
- That's what you got to look forward to. No matter what you try, what you do, it's constant.
- In terms of deciding if you're going to do an activity or not, something in particular... including yourself and other participants... try to understand it this way and you can tell me if this fits you or if we need to change it. I have been kind of looking at the positive results from doing an activity such as feeling better, being able to accomplish something... and this is the payment, such as you can lose your financial support or you can pay with having pain for two weeks afterwards or not being able to do exactly what you want to do, doing something less. This result is again something positive that
you get out of doing it. What I've seen is that when the positive results are greater than the payment and you're willing to take the payment, that's when you do the activity. How does this fit for you and what parts of it don't fit for you? How do you go about deciding what you're going to do or not?

* Well, basically I know through practical experience no matter what I try, I suffer the consequences.
* Doesn't matter what you do, you're gonna pay for it? (yes) And how do you pay for it?
* Oh, degree of pain, more discomfort, nagging, lack of... the ability to know that you're going to try and do something... the reality of the pain is no longer with it. You got to push yourself, at least try, if you don't - you're gonna be a couch potato and become an old man. I'm a young old man.
* A young old man?
* Even with my family....
* Meaning that you still do things despite the pain?
* Aha. I have to.
* When does it happen that you don't do an activity?
* Oh, I don't think I've ever did an end to the fact that knowing that the back... that the pain is going to be there. Like I said, I'm not an idle person, I'm not. I do. Just like going to the football game Saturday. I mean it, by the time I got home, I was in severe pain. Because of the activity of jumping up and down. I get quite excited at games. Where we tailgate is a pretty good walk to the stadium. I know it will come back. But I get home, or half way home, it hurts, paranoia. So my battle from then on is not letting interfere with other people around me.
* Keeping it inside yourself?
* Aha. I don't have the right to upset their day.
* So you still try to go on doing what you want to do?
* Yeah, like I do just now, I get silly trying to hide it. But I don't let it completely get me down. Only if I'm by myself, then I give into the emotion.
* But when you're around other people, you're better able to hide it?
* There are times that they know, they could tell. I try not to be too critical about it.
* And when you're hiding it from them, do you find yourself hiding it from yourself too?
* No, I haven't been that fortunate. I'm sure they know when something's wrong with me cause I get too silly.
* So they may know what's going on?
* Pretty much.
* It must be hard to hide it too...
* Oh yeah, all I got to do is watch my walking, my nursing this or that...
* Um... do you see the pain, or the monkey on your back, do you see that as part of yourself or outside of yourself?
* Well, I've had it so long, yes it is.
* It's a part of you?
* I've accepted it as my own, a part of me, and a little... it's a shame. I wish there was a way I could push a button and say - hey, go away.
* Move over...
* The monkey's on my back.
* It's kind of like... did you have a period in the beginning where you did try to push it away?
* Oh, yeah. I went nine yards in both directions.
* And it didn't happen.
* Yep.
* So now it's become a part of you.
* All you gotta do is twist it the wrong way or sit the wrong way. step the wrong way and it's there. I got into a mirror one time to try to get rid of it.
* A what?
* A mirror.
* A mirror?
Look into a mirror, that's how you start your day. I look in the mirror, I say - I'm proud of myself, I'm mad at you, or whatever. I try to say I'm proud of you. Some days I say that, some days I'm not.

How has that affected... having the pain, how has that affected your spontaneity?

Well, you... you live with caution. There's a lot of things that spare of the moment comes up and you go somewhere and... then again, you know that you can't. After so long a time, you're just gonna add to your misery. And again, you have (?). So a lot of things I'll just back out on. Make up some excuse.

That's different from how you used to be before?

Oh, definitely. I used to be a suggestor.

For doing activities and stuff?

Aha. I was going out and playing putt-putt, or regular golf or bowling, or walking, whatever.

Now it's more trying to see if you can do what...

Now it's sometimes I'm a tag along. Sometimes.

In terms of when you do activities, when you're gonna do something, do you feel that doing helps you and helps how you feel about yourself?

Yeah, regardless of what the outcome is, it's the fact that you're doing it.

That you're doing something?

You're doing something. You're not totally pulling in within yourself, putting that wall up on you. That's the last thing I want to do is put a wall between me and life.

So by doing something maybe you're showing yourself that you haven't put up the wall?

Aha, a sense of communication. The fact of being here and rubbing elbows.

Would you say that you do when you're in a good mood or you get in a good mood when you do?

That's part of my silliness.

In which way?

I put myself, whether I am or not, I put myself into a good mood. It's a cover.

So you can appear as though you're in a good mood no matter what.

Well, yeah. That's... living with the pain so long, you create a sense of....

A facade?

Well, it's like a facade, but I'm trying to think of another word that provides description, but you can't. That's another part of my stroke damage. That's.... my neurologist works over here.... one of the problems I'm still having with the stroke is that when I get tired, I get slurred speech. I don't pronounce my words correctly or I go into spaciness, I sit and stare. I get blank, this is not working. Now, is that a built-in buffer.... I don't know? Is this something that I've created on my own.... I don't know. He didn't know. Besides the back pain, I've got some serious head problems, too. I got a lot of damage to the cerebellum. Can't really comprehend. I sit here, I can read a paragraph. Just look at it and scan, taking out the key words and so forth.

It's harder for you.

Hard to the point that everything runs together. So I gotta hone in on a set of words or whatever and concentrate. That's the way I had learn how to.... totally learn how to express myself.

To start over?

Yeah. I really.... teach myself how to use my hands, completely lost all motor skills on my left side, I still can't write too well. Good Lord put me to the test or something, I think he'll make me a saint (laughs).

When are there instances.... you say you can make yourself look happy and so forth....

A lot of it is a false facade, granted not all of it is with people around me. A lot of it is for me, to pick myself up.

Does that work?-(?)

When do you really feel happy?

Really happy? To be quite honest, it's so long I can't remember. Wishfully, I put myself in the position where again I'm getting silly and hope some of it rubs off on me.

When do you feel better about yourself?
Yeah, I just have no self pride. I beat myself down so much. I don’t have any. I really don’t. I am quite disturbed, ashamed, disappointed. A young man goes through life and lays out plans and so forth. Then his plans start developing and they start coming true, picks you up and makes you feel good. If it’s something you really want to do, you do it. I’m restrained. Regardless of what I try or what I do, it just doesn’t happen anymore. I used to be productive, active...

Do you ever feel productive now?

-(sighs) I want to say something that’s going to contradict something in here (pointing to transcript).

O.K.

But... even when I do something and I do it right.... everytime I give myself praise, but I don’t get it from the outside, even my wife. That’s another thing that really tears me down... the fact that all these plans that we made together are totally destroyed. And my wife blames me. It seems that if I ever make any gain, with a matter of a few words it’s destroyed (begins to tear). I don’t know.

So, when you do something that you feel good about...

I look and I ask...

Ask your wife what she thinks?

And as great a person as she is, it’s just not her. She has totally destroyed her future and the only thing she can do to save herself is to reach out and touch. (?). Look at me (gets tissue).

And it must be hard as well... it takes a lot more effort now to do an activity...

That’s the pitiful thing about it. You try, and try, and try, and the one person you really want to please, you can’t. I feel sorry for her cause I have made things rough for us. All my retirement effort down the drain. All my private time in life....(knock on door)

That’s the first time I ever said that. That’s reality

What’s it like to share that feeling?

-(sigh) I don’t... I don’t share it with anybody. I have expressed it to her and .... I really think she knows what’s she’s doing. It’s her true feelings coming out and comes out in a moment. And rightfully so, I probably deserve it. Again, I might be making excuses for myself.

And again it would be nice if...

Yeah, it would, but.... I tried the.... I totally gotten myself to the point that.... I’m looking for the word....intimidated.

You feel intimidated?

Aha.

By her?

Yep.

In which way?

-(sighs) Commitment, I guess. Doing something and looking for a little self praise to bolster your pride and it’s not there regardless.

And that’s something that’s important for you.

Yeah.

That you need.

Yep. The reason I don’t converse much is because there’s nobody I can talk to that it would be private, that it would stay right there. Unless it’s a person like you. I must be careless about what I say or my actions... I really don’t know, doc... I sit back, why am I being shonned? Why am I being belittled? Maybe I’m not the person I think I am.

At the same time, maybe you ... getting the respond back when you try hard to do something...

Maybe I try to do hard.

Too hard to please?

Too hard to please them. I guess somebody knows that they’re doing whatever they can do to get on you good side and they, on purpose, go the other way.

That must be frustrating after a while, too.

Especially when it’s you’re own family.

You probably tried as much as you can.
Yeah. I have a stepson. I got into an argument. I totally turned the other cheek just to keep from creating any more of a problem, meaning I took all his cuffs. (first side of tape ended)

You develop a way of (?). It gets harder to keep your spirits up. (?).

It seems from what you’re saying that a lot of what you have in your world right now is feelings of feeling false....false facade...

It might be the fact that you’re in pain constantly, you never really get a clear picture of everything around you.

Because you’re not putting a clear picture of yourself out?

Yeah.

And maybe what you’re getting back is muddy?

By the truision of your own making.

And what I hear you say is what you want is to be real.

To be accepted really as I am.

To be accepted for who you are, not for the false front that’s out there. At the same time, putting yourself out as you really are feels probably feels as thought that’s a risk.

You get tired of putting out this comedy, foolishness in order to be included with people around you. If you sit in the corner and you’re quiet, then the other reaction comes, "oh, what the hell is wrong with him today?". I don’t....

So maybe the cost making other people feel comfortable by keeping it inside... now what’s happening is that you’re not feeling real anymore and relationships are not feel real.

Oh yeah, that’s exactly it. And you wander all these years of doing it, if it’s coming back to haunt you?

And maybe you feel it’s time for something to be different because this is not what you want.

Or time to end it all...

What do you mean by end it all?

Suicide.

Is that something that you’ve been thinking about lately?

Well, yeah.

What’s stopping you from committing suicide?

Reality. Who are you hurting when you do that? My religion dictates against it. But I have thought about it, I really have. Before, I never thought about it. (?) You get shoved into a corner, you try to fight back. (?)

I think from what you’re saying it’s an important part from just being a person to have a genuine connection with other people.

Yeah, if you really feel that you make contact ....really a person would accept you as you are... I don’t have the luxury of continuing this false facade, I really don’t.

What would it be like to try to just be you?

How do I know what is me now?

You lost a sense of who you are?

Well, I don’t know how to explain it.... but, what is reality? I’ve been carrying this with me for so long, that it beat me to a pulp.(?) yourself. (?) carry it for a while. I’m tired.

How would it be if (?) that genuine connection could be you?

I don’t know if I have the ability to see if it’s genuine or not. Do you know what I mean?

Not knowing what’s the real you anymore?

Yeah. The family that( I lived with is )my wife’s family from a previous marriage. I got three girls (?). I told them a long time ago, you don’t accept my wife - you don’t accept me. (?)But, the cards are on the table, I believe that way and I basically still believe that way. Everybody makes their own bed and they have to sleep in it. (?)

It seems as though even though having, by putting this facade up, you’ve kind of lost touch with who you are...

With myself...
With yourself...and it seems that you got to a point where you want to get back in touch with yourself and not use that facade.

I don’t know how to do it.... I really don’t. I buried it for so long...

Yeah, time to rediscover. And even, I think the biggest worry is even if I could...

There would probably be a risk that would go along with that...

Anything that I do, I try to have a plan B. In this case, it could go one way or the other.

What would be the worst that could happen?

Find out I’m really not the person they think I am.

What’s that about?

Less than I really am or I think I am....I don’t know. I think in my mind that I’m more of a person than they’re willing to give me credit for. What would happen if I found out that I wasn’t? Then my world bubble would really burst.

If you found out that you were less than that?

Yep. I’m complex, aren’t I?

And at the same time, (?)

I would love to be fun and fancy free, not worrying about consequences.

And that’s something that you have to worry more about.

Yeah, yeah. How long do you keep up this false facade? What did you do to get this false facade across? Yesterday (?) Here I am pouring my heart out and it has nothing to do with pain (laughs).

Have you thought about, or I don’t know if maybe you had before, of going to see a counselor just to be able to...

I went through that. Dr.. I can’t think of her name...

At Dodd here?

Not at Dodd, at the... Dr. xxxxx. Fabulous young lady. We really dug down deep and dirty, but it got to the point where she was trying to pull everything out of me and we would get back to talking about my childhood. My parent, I know there’s a lot she’s correct on, but to dwell on it, on something that you can’t do anything about. What good does it do to look at what’s wrong with my childhood, what’s it got to do with reality?

You wanted to work on the present?

Yeah, and I finally told her that and that’s just her tactic. So we didn’t have a meeting of the minds, so we got it off and it was going into the second year.

Have you looked for anyone else to work with?

No, but there are times that xxxx did do me real good as far as being able to look at things at face value.

Is xxxx Dr. xxxx?

Yeah. I thought I was a black and white person, there was right and wrong. Then I realized, even though I thought I was that way, the giving that I put out is very personal. (?) Make excuses, in other words. Here we go again, picking my mind again... (laughs)

You’re doing it.

Yeah, I know. I’m sorry.

It seems as though you have, you seem to be clear on what it is you want and what you want to do. You’re next step is how to figure out....

I’m quite confused, I really am...

I’m wondering now if giving yourself another chance to work with a counselor that would be something you would giving yourself and that would be really good too.

I’d love to, but there’s no way that I can cover the expenses. (?)

I’m wandering in terms of... I haven’t tried this myself... in terms of working with .... have you ever looked into community mental health in downtown here?

Is it a charitable thing?

I think maybe...

I won’t consider that.
• You won’t consider that? In terms of...
• And I’ll be quite honest why. The caliber of people involved.
• What about, and this would be a less expensive option. I’m not sure if you would be interested, group therapy?
• No, again, in group therapy everybody says I’m a hog.
• You’re a hog?
• I’m the person that’s always going on and everybody sits back and crosses their legs.
• That would be a less expensive option.
• In the chronic pain program, I had group sessions, two three times a week. It was just like was it was me and the counselor.
• Well, you know what you want. You’re aggressive in getting it and that’s good. It’s a good thing. And it seems as though you’re at the point where you know what you want to focus on, you know what you’re confused about and what you want back.
• You don’t know how I try.
• Right, and now it’s how to figure out how you’re going to go about it and you’re stuck. You want someone to talk to where it’s not gonna go anywhere, but then you also have the financial issue of how you’re going to pay for it.
• Financial is a big worry. But separation, divorce, suicide.... three things. My world is my toy truck. (?) I fantasize, I daydream quite a bit. It’s something that I’ve let my mind do to cease the moment. I’m not a dumb man. I’m not. I have always been a people’s person. (?)
• I’m wandering if there are some alternative ways to be able for you to connect again.
• The fact that I would be asking of myself to do more. I don’t want to give anymore. I think I’ve given too much. I’m totally now turning the other cheek. I’m getting tired of being the person that says “oh yes, you’re right and I’m wrong”. Sometimes you don’t know who’s right and who’s wrong. Sometimes you’re right and they’re wrong! But you’re the person who cowards out.
• You’re feeling tired of having to give.
• To give and not receive. True definition of love is to give without asking to receive. You know who told me that? Dr. xxx, he was involved in the chronic pain clinic. I’ll always remember that. So where are you from?
• My family is from Florida.
• I realized before.
• I lived in Florida before I moved here.
• You’re a delight to know.
• Thank you.
• You really are. I tell you that honestly with no motive in mind.
• I’m going back to live in Florida for good.
• So when is the group thing coming up?
• The group is gonna be next Monday.
• Is my time up?
• Yes, but it’s O.K. (wrote time and place)
Appendix O

Sam's First Interview
Sam’s First Interview

• The first thing I would like to ask you is how your pain started, what was the situation, and where the pain is?
• I was in an automobile accident in 81 and it did pretty extensive damage and spent a total of about a year and a quarter in the hospital and 26 operations. And I lost my legs. bilateral amputee. Is this what you’re asking me, am I answering the questions? (yes) And I have vertebrae (muffled) from L3 to L1. I got two six inch rods and eight screws holding that together. That and I still got about ⅛ of my lotisemus dorsal and I also pulled my bicepedal tendon. I got a lot of problems with this arm. But outside of that, everything is O.K..
• When did the accident happen?
• 81.
• Where do you have pain right now?
• Pretty much everywhere. I think just the back thing is probably the tougher one to... you know, if you’re a bilateral amputee, it puts a lot of strain in your lumbar area because it doesn’t pick your legs up, it takes place in your ankles and the ball of your foot. It’s very tough for a bilateral to move a lot and not have back pain. The back just seems to be the center of everything. I had three back operations, they couldn’t get the vertebrae to stay together and those were very tough to come back from. I don’t know if it’s just my age. I’m sure it’s partly my age. It makes it tough to come back from the surgeries. It’s been three years since my last operation. I had three back operations and an (ulcer) operation in a two year span. It was very tough to come back from.
• So you had how many operations?
• 26. I’ve had over 50 hours of surgery.
• And how has that been like for you to have gone through all that?
• Probably what you would call pure hell. It’s more like you don’t recover, it’s more like crawling out of the cave again. It’s very tough. You spend a lot of time, you know, laying in the bed. Staring at the ceiling, you can’t move.
• You were working before the accident?
• Yeah...
• And what were you doing? What was your occupation?
• I worked for coal processing, I was a foreman for this man in West Virginia. I was a very physical person. A lot of heavy equipment and heavy equipment operation. Very physical worker.
• Did you enjoy your job?
• Yeah, I did. I was good at it. I have nothing to add to that, actually.
• You stopped working after the accident?
• Well, I kind of started and stopped. You know, I tried to be more sedentary in my life. But I lost one leg, then years later I lost the other leg. And I’ve had other operations. I’ve had to come back to work several times but in less physical capacity. My situation keeps deteriorating so I have to keep trying something else.
• And you’re not working right now?
• No, not now. But I’m trying... I’ve been writing a book for about the last three years... I’m on the fourth draft. But I had a real tough time... I had a real tough winter...it was real tough this year...a lot of pain this last winter. Winter is not good for me at all. It’s unbelievable. I can’t... I lost the ability to concentrate. If you write, you’re gonna get a stream of consciousness whenever you try to write. It’s kind of like you see artists or writers. They always portray them as crazy or alcoholics, but they got another reality. They stay in that stream of consciousness - it’s tough to do, especially when you’re in a lot of pain.
• What’s it like for you not to be working now?
• Not to be working? It’s hard on your ego and self-esteem.
• In which way? How does it affect it?
• It’s your self-worth...it’s self-worth and doing something, you know. That’s just the way this society is. It’s more of an industrial society. To be something, to feel good about yourself. It’s not really my
idea of self-actualization per se, but it's tough. It's tough not to do stuff. Not to do anything, not to be able to do anything. But I've done so much better in the last four months. I really had a tough time. Up until a ... well, maybe as far back as February. I started working on... That's kind of what I did, I worked on race cars. I built a race car and I got moving around again. It helped me out a lot, just getting up and moving around again.

And you've been concentrating on that for the last couple of months?

Well, yeah. I have ... I tell you just the idea of moving ... it's some pretty heavy stuff. Just getting up and moving and physically doing something and it's I can't begin to tell you how gratifying it is.

Had something changed for you that you had started to use your hands more in the past couple of months?

No, just getting up and just building my stamina back up a little bit. Just work a little bit. A couple of hours a day. Worked up to two or three hours a day, four hours a day, sometimes I work for a whole day. Sometimes I'd have to lay off and relax for a couple of days because my back would hurt. I overstressed, you know, I stressed my back out. I had to lay off for about a week or something. Then I'd start up again.

What's your daily routine like now?

Well, lately it's day. Like this morning, my daughter and I we walked around Antram lake. I try to walk a mile a day. I haven't done it for about three or four days, so it's good to get back to it today.

You usually exercise, walk in the morning?

I try to walk in the morning. I had my daughter. I got these new artificial legs and I'm running. I can run a little bit. I run as much as 40 yards at a time. I try that twice. 1.2 miles. That's how far it is around the lake. Then I try to spend time, you know I got my daughter all day so I try to stay up with her. We do things... go to movies a lot. And ah... just kind of putter around. Staying up all day is a big deal... sometimes I have to take a nap and rest. It's good if I can stay up all day.

Is your level of energy different than before the accident?

Oh yeah, I was ... I used to be an athlete and ah... I was always big and strong... I was able to do anything... very physical person.

Now you found you had less energy?

Oh yeah, it's very tough not to do anything. It's tough to limit yourself. I would imagine I'm the equivalent of a 75 or 80 year old man sometimes, for the most part. But the best change is the walking. It's been a couple of weeks now and I'm walking.

You're feeling real good now?

Yeah.

How has the pain affected your goals or your dreams?

Well, it depends on what time of the day you ask me that question. Right now... I spent a lot of time. I had to confront my own demons because of my physical limitation. I had to seek therapy. I went to a good psychiatrist and I tried to understand why I did what I did... why lived the life that I did. The reckless life. So, in that respect, I did a lot of good for myself. But, it has helped me. I made the statement that if I had to go back and be the way I was I'd rather be the way I am right now. At least my head is a lot clearer. My body has gone to hell on me. My heart and spirit, that sort of thing, is much better off after the accident.

How would you compare your self esteem from before and now?

Well, I'm more comfortable with myself, you now. I had to, you know, more like a religious experience. It's more introspective, you know, to you look at yourself objectively and anytime you do that, there's always... I think that's what separates the classes, I think. the ability to look at yourself. Am I answering your question?

So for you, having been in that accident, going through that, it was more of an awakening?

Sure, that's why I wrote... I don't know if I would have ever written the book.

Is the book about your experience?

Yeah, about my life. More or less about my life. Have you ever read Jack Carolak - On The Road? Have you ever read that book?

No.
Yeah, I guess that’s how I spent the 70’s I guess. I hitchhiked around the country a lot to rock festivals - California, Florida, Massachusetts. Yeah, I think it’s good therapy to write about your life. Tell you whole story and that kind of thing. I did a lot of pop psychology. To tell your story is very therapeutic and even working on race cars is very therapeutic cause you’re putting something back together, I guess, you’re putting yourself back together. That’s the biggest thing to overcome is .... I kept ...ah.... my physical situation kept deteriorating. I’d come back, I’d work for maybe a year... year and a half and have four operations or a convalescent for a year or so. More operations, more convalescing. It’s like a cycle, you know. It could be very devastating. Some people could go through a wreck and then come back. Something like that, just one big wreck and you’re over that. Mine just kept grinding. You know, just kept... You live in a nightmare getting back from those surgeries. That means your life stops. You have to lay in bed for a year maybe.

You kept putting your life on hold at different times?

Oh yeah. That’s pretty much been the pattern for fifteen years. Just try to get up and go again is tough... you’re getting old. The horizon (chuckles) is not as far as it once was. There’s a lot of things you think you would have wanted to do with your life, but obviously you’re not gonna do them.

And what’s it like to think that?

Well, I suppose a lot of people have to do that one way or the other eventually. You have to just deal with the fact that there’s certain things you’re not gonna do. A lot of things you’re not gonna do, actually. But just be content with yourself.... you gotta be happy with yourself. I guess I’ve accrued self-actualization. The spiritualism...

It’s interesting that that happened for you after a traumatic incident in your life.

Yeah, well, I had a near death experience. I...

In the accident?

Right... I even joined a near death experience group. A lot of people see angels and that sort of thing. A lot of really nice things happen, but for myself that was not the case. It was a bad situation. I saw myself in a black liquid and it was just the blackest black there is and I felt I was starting to swirl around and I felt myself going down like in a drain or something. And then I realized what this must be. This must be dying. I’m dying here. And I thought to myself - I had a choice here to live or die. If I wanted to die right now I think I could, and if I wanted to live I could. I think I want to live. I tried to come up out of the drain and I woke up in the hospital. So... That was quite an experience.

How has the pain affected your relationships in your life?

Well, it has not been good for them. Um... Chronic pain is kind of like a black cloud floating around you following you around in a lot of ways. Cause the pain just kind of sucks the life out of your life. I do a lot of volunteer work for the hospital with people that have just lost their limbs and stuff. I counsel. People have gone through a lot of operations and they say -it’s just sucking the life out of me. If I tell that to somebody, they’ll know exactly what I’m talking about. Cause it does suck the life out of you. You can be very short with people you know, you can get angry, you get tired, frustrated. When things go bad, you can just go...

It gets to you fast?

You can go right downhill fast. You got a headache or toothache or something. It’s like living with an eternal toothache, I guess. Like I don’t feel as bad as I did cause I exercised some today. I don’t feel good right now, but I can’t let that get to me. But it’s just always there, you know. It’s just always there. It’s your mind set. You have to make up your mind to live. Just try to put it behind you as much as you can. It just surfaces. It’s always there.

What would you say is your role in terms of your chronic pain experience... in terms of responsibility for what happens in your life... how do you see that for yourself?

The responsibility for what happens in my life?

In terms of your chronic pain experience. Do you feel active in that process?

If I try to deal with my chronic pain, am I confronting my chronic pain? Yeah, I’m confronting my chronic pain. I’m, like in 92. I tried to qualify for the pair Olympics. It’s for people with physical limitations. But my back was so bad, I had to go in for surgery 12 days after the time trials. My back was pretty bad at the time. But I was sixth fastest in the nation. I had laid off a month waiting to let
my back heal, so my lungs kind of went to hell then. Otherwise, I think I would have qualified. I was, as far as the people that built the orthopedic... my legs, they think ... in the disabled world now I'm talking. I'm a superman type guy cause I can get up and do so much stuff. They're pretty impressed with me. That's why I go to talk with so many people, just to act it, you know. I got so much wrong with me and I go in there and to see me, I don't have to hardly say anything. Just to see that you can get up and live. You can live and have a good life. I like life, I love life actually. I've had my daughter since the accident. You know, that's a great thing for me. I help in raising her and I love that. And I can't, right now I can't... I don't have the material wealth, but spiritually I think I'm in pretty good shape. It takes a spiritual experience. Cause we're all on a spiritual journey whether we know it or not. I just became much more aware of mine.

• Did you have the divorce before the accident or ....
• No, I had already lost the leg. I had lost it, it had been gone over a year or something, but I hadn't even begun to deal with it, you know. There was nobody to talk to, I didn't know what to do. I really had a tough time dealing with it, you know. I tried to... I went to school for two years. I tried to get back to the workforce, but I took up physical labor again... heavy physical labor and it began to wear my leg down. That was a mistake. I just.... it couldn't get through my mind to sit down and do sedentary work. I just couldn't do it cause I've always been an athlete and leaned on the physical side of my existence.
• How has pain affected... or has it affected your sexual activity or sexual interest?
• Uh... it pretty much killed it. I gained a lot of weight since the last operation. I gained 60 pounds. It just takes out so much of my time trying to get up everyday and do something. I've become more of a reclusive. I guess there's nothing you can do about that. I don't know. I guess I dated some other girls with disabilities, but for the most part, most people with disabilities are pretty bitter.
• Are you bitter?
• I don't know. That's a tough question. I don't think I am cause I'm sure they all don't think they are. I think I laid that down pretty much. But ... I've had a bad experience with it... people don't like to be reminded of their mortality, you know. People don't like that at all. And I'll tell you, I met a lot of women, but it's kind of tough to work it into the conversation - I have artificial legs and that just wheh- they evaporate. So it's tough, social life is tough. I have dated, you know. I haven't dated anybody for a while now. About three or four months. I was dating my ninth grade sweetheart. I've known this girl for like thirty-six years and I was dating her for a while. But I don't want to get anybody too close, cause I'm still in a transition I feel because physically trying to come back from this. You become very vulnerable, you know. Your emotions and all in this kind of situation.... It's tough to have a normal existence or what people perceive to be a normal existence. I don't know... I may be forever in a transition... I don't know. I don't know if I'm ready to accept that now.
• You still feel like you're in a process?
• Well, yeah. I tell you, that first year. 92 to 94 I had four operations from 94 to 95. I used a cane I was on a cane all the time. I could just barely get around. I put it down and started walking without the cane. Big big deal for me, you know. But I've gone through this so many times, you know. It's a cycle, it's just a cycle. It's just demoralizing, it's just demoralizing. You know, you can't really have a social life like that, you know. Once you meet somebody else that's going through the same thing... but that's crazy, that's a crazy experience. How can you... You have to be crazy to get through it. I think, after a while.

Do you feel as though people understand your experience and know what it's like for you?

• No, how can they? How can they conceptualize... it's just so far off the charts for most people. I'm sure you live in academia. People in this can't even conceptualize it, you know. I've dated people from the medical profession and they deal with people living and dying everyday, but they never do it personally. When they meet the patient personally, then they get attached to them and then they blow them away. I don't know if you've ever experienced that, maybe you have. It's tough for people to accept that. Most people's lives aren't like that, you know? The answer to the question would be no (chuckles).(turned tape)
In terms of when you were here in the chronic pain program... what was that experience like for you? What effect did it have on your chronic pain experience, if any?

I was critical of the program. I thought xxxx was well-intentioned... she meant well. But, I really don't think they really go very far to try to understand people and their experiences. Of course it could be more of a class thing. I think that... I don't know if you're familiar with Barbara Ikovich, she wrote a book Fear of Falling, it's like the abyss between the blue collar... white collar middle class. Most of the people in this program I would say are blue collar. They never really had a lot of money in their life. They can be pretty condescending to these people. I knew a guy that came in... They rule a lot of people out of here. There was a guy that came in... he had a bullet in his spine. He just wasn't used to moving around or exercising, you know what I mean? The whole idea was just pretty foreign to him. There was another older lady, she was about 45 or 50 and I didn't think she really experienced much physical exertion to deal with that pain. It will take your pain level up when you start exercising. Very painful. They were pretty intolerant. There were like 600 applications to get in here, and only like 5 or 6 people went through at a time. Doesn't that suggest anything to anybody, you know? They couldn't manage very many people. It's just, it was very strange. There were some very good people... there were some beautiful people in here... good souls. I couldn't help getting the feeling that that some people are just putting their time in, too. I guess that's in any profession.

How would you compare your chronic pain experience to the chronic pain experience with other participants or maybe other people outside the program that you know with chronic pain?

Well, I think one thing that helped me was that I was an athlete, I was a very physical person. And I don't think that they had... Just the statement 'it sucks the life out of you'... it's just so draining... 24 hours a day, 7 days a week. You know, it's just... that can just work on you and drain you, it's just so draining. I don't think a lot of those people did a very good job. I don't know what happened to those other folks, I never saw them again. I know a lot of people that had gone through here were pretty unhappy about the program.

Does that compare to how you feel?

Yeah, they didn't like the way they were treated. It's just... I don't know how much thought they put into it. Maybe they just need to rethink it. They weren't working on the psychology of it, or maybe working on it as much as I think they should. They meditated, they did talk to an extent. But I think maybe there's only so much they could do. I'm not sure how they would restructure it. I think it's just the way you think about it. They just thought it was one big physical bootcamp. Thinking about it does a lot more than just talking about it. But I think that, you know, it's the reason they just... you know, dealing with the poverty in this country, they should just take an army of psychiatrists and just start at one end and go to the other. These people, they can't articulate what they're feeling. These people didn't know what they're feeling or what I'm feeling. They could do more to identify that. That would have been far and away more beneficial than any physical program that they did.

Was the program beneficial to you?

Tough to say, tough to say. I was unhappy with it, I think. I mean there was some good to it, but I thought it could have been much better. I think they should have went for the head more. If these people would understand why... just the way they approach it. There's probably many psychiatrists that really know how to deal with chronic pain. Even this guy down the street, I think it's xxx. He's a good man, I think, but I'm not sure exactly where he's at on that. I didn't talk to him before, but I think that's what they need... they need to talk to people to get them to identify what they're feeling and why they're feeling.

To put you in touch?

I really don't think...They didn't seem... the people that are running this didn't seem like they know that much about chronic pain. I guess they knew what they were focusing on. ...the muscles, you know. They really didn't address the head, that should have been their goal.

You were saying that your accident was kind of like a spiritual experience for you, maybe a spiritual rebirth. In terms of your religion, in terms of Christianity.... how did Christianity affect that experience for you or how did that experience affect your beliefs in Christianity?
Well, Christianity is a toughie. It's a... Christianity is a good thing, I think it's just the people in it that are kind of messing it up, as any religion, I guess. I guess it's the way you look for deeper meaning in spiritualism. I heard once - you really can't interpret heavenly knowledge... heavenly wisdom with earthly knowledge. Did that make sense? But I guess it's more like Unitarians, then I meditated with the Buddhas. I did a lot more meditation. I didn't really endorse Buddhism. I did like the meditation. I guess it's an interesting religion... I knew more about it. I read about all religions. I don't know if you're familiar with Joseph Cambell. He wrote With a Thousand Faces... he wrote the book Anyway, George Lucas (muffled) wrote the Star Wars Trilogy. Joseph Cambell... he was the world's foremost authority I think on all ancient religions that's ever been in this world. He knew everything. And he just, you know, people need that mythology in their life. I guess I see spirituality as the the life force coming through you. Women would understand it more if they had a child, there's life within you. And it's just the life coming through you. That's G-d, the life force coming through, and it could be multi-faceted. There's something greater than yourself. But anyway, Cambell ... (muffled) he loses himself or dies, like Dantes descends into hell and they're born again or something. He realized that there's something greater in life than him. So they say that's the basic of all the stories that have ever been told in the world.

It looks like you're getting a greater picture of religion beyond your religion.

Yeah, yeah. Ancient religions of the world... they're all basically the same. And he interpreted the meanings of all the symbolisms of all the religions that have ever come and gone, you know. Fascinating man.

What was his name again?

Joseph Cambell. He led a charmed life. He was born at the turn of the century... he went to Yale, Harvard I mean,... he was on the track team. Track at the time was a premiere sport and he was on the 440 relay and he was one of the fastest men in the world. I'm not sure if he went to the Olympics or not, though. They were the fastest 440 relay in the world. Then he went to Paris for one reason or another and he met Salvador Dali and all these artists... but at the time they were all in the streets painting... they were nobodies. He met all these people in Paris in the 20's. He lived a charmed life. Then he meets this dancer from this Grand Dance Troupe, you know, this beautiful dancer. And he marries this beautiful dancer then he goes in these woods for five years and writes this book A Hero with a Thousand Faces. Then he became an instructor. He led a great life. If you wanted to pick out a life that you want to be like, this guy had a great life. He did a lot of great things. He was just so fascinating. I was just mesmerized by this guy. I have a friend up in Portland that actually attended his classes. I can't remember what college he was at. He loved this man, you know. He understood the whole reasons of life, you know. You need the symbolism in life, I guess. I'll have to look him up.

Oh yeah, there's tapes of him, videotapes in the library

How would you describe your social life now? I think you started talking a little bit about that...

Oh... it runs hot and cold. I don't know if it's any more chaotic than it used to be. I get involved in a lot of social... I was... one time I was on the board of directors for the xxxx Art League... and I was at one time, the President of xxxx Art League. Then I was in this other group - the xxxx Council for Arts and Disabilities. You know, so I shooed a lot with a lot with a lot of different people in all those committee meetings. You know, I did a lot of that and I ran around with that certain group of people. Then I did photography too. I have a lot of photography. I show down in the Short North area. A lot of real strange abstract photography. A couple of them made the dispatch. Pretty strange. There was one show I got blown out of... one show that accepted. I took it, went down to another show, they didn't accept it. took it to another show and it got on the Sunday Dispatch.

You just gotta keep trying.... it doesn't mean anything.

Yeah...

What coping strategies do you use now to deal with your pain?

Coping strategies...

What are some ways that you deal with your pain when your pain increases?
Well, I experiment with different things, you know. A lot of the time, I just lay down, but I don't always do it. You gotta be careful drinking cause you can get sucked into that.

Has that happened with you?

From time to time, you know. But I tell you, since I went to a psychiatrist. I understood why I was drinking so much, you know. And I haven't been drunk for years. The most I've ever drank in like a 14 hour period was five beers. And that's only happened like once or twice. I'll drink a beer maybe two. I just... I don't want to. I'm not trying to get away from anything. But I'll tell you this, it feels great because your body stops hurting. Oh boy, that is amazing, you know. A beer or two and your body stops hurting - it's wonderful. You can't just stay like that, you know, it's a bad thing. Too many other bad things happen. And then smoking pot. I smoke pot. It has the same effect. you know. That's good, I strongly endorse it myself. I personally don't pound a lot of it down. An example would be. I bought an ounce of pot in December. I still have some of it, you know. I take a couple puffs and I can still do something. I don't want to drive. As long as I'm staying home, you know. And my daughter's not around.

It helps relieve your pain?

Oh yeah. But that's a double-edged sword too. It's just like any other medication, except it's not prescribed. You can get sucked up into that. I think... I can kill a refrigerator when I smoke pot. That's the bad thing about it, so I try not to do it too much. I'm continually rethinking that, you know. But I tell you, it and any other drugs, there's no pain pills that help you because they're not designed for long-term.

And then you're back hurting again...

Yeah, even an anti-inflammatory. I used to take 2500 milligrams a day. So I now take prescription. You just can't take a lot of it cause you just get so immune to it, you know. Take that stuff for years. There is no pain drugs that can help you. in my opinion. Physical activity is the only thing that can really help you with your muscles and that.

Have you had any feelings of helplessness or hopelessness?

Well, sure, sure. I mean you go through a lot of heavy stuff. Your body is so fractured... there's so many doors that are closed to you socially, career wise, so many things I could have done to make a lot of money having a job, you know. I could have done a lot of things. That stuff... you always revisit that. How could you not... how could you not think about that?

Have you felt depressed would you say?

Oh, sure, sure. And there again I don't think I should be surprised. I mean your body is all mangled up and you're in a lot of pain 24 hours, anybody in my shoes should be depressed. That's almost a given, you would be crazy if you wouldn't. I don't know how anybody could not be depressed. If they say they're not they're lying. I know they're lying.

How would you compare your quality of life now in terms of before?

I appreciate it more. I should have been dead, so it's all a bonus. In my opinion, I should be dead. So it's all a bonus. That's a good thing, you know. I think if I finish this book and get it published... Oliver Stone makes a movie of it, it could justify a hell of a lot of stuff. (laugh)

You'll be up on the screen...(laugh)

That's right...

Let me just look... I think we went through pretty much... Let's see, is there anything else that you would like to add that would help me understand your experience that we haven't covered?

Well, I don't know. What do you think you're really basing... like can you summarize what you're trying to get at?

I'm trying to understand the chronic pain experience from the point of view of some of the people that have it. So far it seems, in terms of different literature that's been written and different research that's been done, there's a lot on chronic pain but not from the perspective of the people that have it. And so that's what I'm trying to get at. I'm trying to understand what it's really like to help people understand a little more about it.
Well, I think it’s gonna be more of a class thing. I know there’s a lot of studies on that, too. And I don’t know if they can articulate how they’re feeling. So you really have to dig with those people so they could tell you. That’s just with the people I saw come through this place.

They had a hard time articulating?

Yeah, they don’t know.... You know, I can talk for hours. We can talk about all kinds of stuff if you want to.

Do you have any comments or any advice in terms of the interview procedure with future participants? Any changes, any suggestions?

I guess how you’re going about getting the information.... you might give them, for instance, a situation. (switched other tape) Especially with people that don’t talk a lot, I guess. You might try to draw a clearer picture...

Maybe give more structure?

Yeah, but I don’t know if that would help or if they’d be really needing it. per se. I don’t know, I guess you would probably know because you could probably sense how much people talk. I mean how much they can talk about it. Another thing is... You might think to talk to them more, because I know myself that it’s hard for me to talk about it because it opens the floodgates (phone rings). One of my biggest problems is... I think maybe that’s why I talk for hours, it’s very hard to talk about it because I don’t like to think about it. It’s hard to just think about it. I guess the series of interviews that you have, I guess that’s a good thing. Maybe you can get into it more. That’s hard for me to talk about it because it makes you be more aware of the pain.

Have you been feeling more aware of the pain in here?

Probably so, yeah. I don’t know if there’s a better way of going about it. I guess it’s just the rapport you have. If you get a good rapport with somebody, maybe you can get them to open up. I tried to tell you as much as I can. I don’t know if I’ve done a good job or not.

Yeah, you’ve done a great job. It’s been really great to hear what it’s like for you... different from other people.

It’s different from most people?

Well, different in terms of yours seems to be an awakening in some respects.

Well, I’ve had spiritualism my whole life. When I was 19 I left here. They called the Midwest the rustbowl because all the factories had kind of gone to hell, you know. I went out to southern California. Became a born again Christian. We’d just be on the beaches of southern California in 1971. That’s about the year you were born right?

Actually it was, on the dot.

Well, man, I remember that. That was a spiritual experience in itself. Plus that whole California trip, I don’t know if you’ve ever been out there. Boy, it was strange in the 70’s (laughing). Yeah, O.K..
Appendix P

Sam's Second Interview
Sam’s Second Interview

- I have a copy of your interview for you to look at. I want you to browse through the interview and if there’s anything that you want to talk about further, let me know. I also have some questions I would like to ask you.
- Who or what do you think has control over your life right now?
- Who has control over my life... who or what? I guess this is going back to the spiritual question... is that what you’re saying... kind of going that way or...
- Whichever way you want to take it...
- That’s a very broad statement. I’m not exactly sure how you want me to answer it. That’s what I would say I guess... spiritual. It has control... it’s like life or God. or.... Control is whatever I think I guess. I don’t think that some social service or something has control over my life or I have control over my life or... there’s a lot of ways you can go...
- In relation, in terms of you having control over your life or what you do in terms of pain having control over your life...
- Oh, does pain have control over my life?
- Yeah, if you look at it that way. Which do you think has control or maybe more control, has it changed for you...
- Pain does control your life... in a lot of ways, yeah. It’s kind of an ongoing wrestling bout with that... sometimes you win and sometimes it wins. So you really got to get up and do something.
- If you’re going to do an activity, and you know that you’re gonna have pain afterwards, under what circumstances are you going to decide to still do that activity?
- That’s a big problem with me because I’m kind of fueled on passion to do something. And it’s something that I used to do, like I’m reclaiming part of something I lost. That happens to a lot of people that are disabled later in their life where they lived a normal life. They’re in their 30’s or 40’s or 20’s... they’re disabled so there’s a lot of things they can’t do, they regret. Where somebody’s been disabled all their life and they don’t... That’s a big thing. So my point is if I can do something that I used to do or when I was in one piece, younger, it’s special, I’ll risk really messing myself up. Something like that. If it’s worth it, you know what’s coming though, you know. Like I said. I have these new legs and I was walking about a mile a day with my daughter, then I started running a little bit about 40 yards at a time two or three times. The pounding is too much and my back...
- And you used to run before you had the accident so that’s part of what you’re reclaiming?
- Oh yeah, I haven’t run in 15 years. You know, I was an athlete in highschool. So I haven’t been running for 15 years like that. It was worth... I’m hurting right now. I can’t do anything for probably two or three weeks.
- If it’s an activity like running that you have a passion for and you’re reclaiming this part of your life, would you substitute walking instead of running, so that you don’t have to deal with that pain? Would you do a different activity, even though you have a passion for it not to deal with the pain?
- Shwoo... there’s a lot of things, yeah. I’ll pass up a lot of things. And I’ve gotten so much better. Like last summer, I was strong enough to for to three stock car races. Physically, I mean... I did got to the fair with my daughter and that lasted several hours... something like that is a big, big deal, you...
know. Like going to Kings Island, or Disney World, or Cedar Point, I never had to take my daughter to a place like that, but I know it’s hard for me to last that long. That’s a big deal, but... that’s a big space. Plus, also because of my back. I was afraid to go on the rides because of the centrifugal force. I would love to do that, but I know that it would kill me, so. But I’m working towards it. I just got to the point where I can use an electric cart sometimes. But that’s hard on the ego.

- In terms of the accident, how did that affect the control that you have on your life? In terms of the control that you have over your life before the accident and now?
- I was a very physical person. You know, that place is low in some areas of your life. I did physical things, construction, I worked for gold mines, big trucks, and stuff like that. I worked in big factories. And I did that, that’s when I was going to Houston. I was going to these big oil companies to put out the fire. That’s what I wanted to do. That was a big transition that a lot of people that become disabled at their prime have to deal with it. Especially when you were an athlete. Everything, your whole essence was... that’s a tough transition. It’s like these great athletes, great singers, or dancers, they can’t...
- And you were able to make that transition?
- Oh, you have to. What’s scary is the people... you see the people that don’t make it, a lot of people in this building they got tombstone eyes and they give up... just waiting to die. That’s scary. That scares the hell out of me. So you go another route. To really live...to understand it, introspectively.... That’s actually spiritualism, too -examining yourself. Something greater than you - that is essence. Spiritualism, you know. You have to become very spiritual to live.
- With having a connection to something greater than yourself, does that pull you to keep moving forward?
- Right. Like I said, women would probably know more because of the child that comes through them. Life comes through all of us. I was really fascinated by Joseph Cambell. He just mesmerized me. I had to really research all this and look to these other spiritual people... interesting people....
- Do you think if the program was more intellectually stimulating that it would have been more beneficial?
- No, no. Well, it would be like religion ought to be. Introspection - I think that’s what you’re talking about, why you do what you do. It’s just the behavior patterns that change their lives. Why... I just don’t think a lot of people know why they do what they do. Why outside forces are molding their lives and all that. They don’t think they can change, but you can change. It’s tough, but you can.
- Being introspective and understanding why you do things.... that...
- The biggest breakthrough for me was I took a painting class... and I could express myself... I kind of had it on my mind to be stoic in a way not being noble... but even talking about pain and all this that was happening to me, it made me crazy. And you start thinking about it.... I could be dead... I’m almost dead anyway. So you have to be careful talking about it, it opens up the damn birds sometimes. It is tough. It’s a tough way to live.
- It seems like some powerful things in your life are spiritualism, your pain, and yourself. Since you talked about art, would you be willing to see if you can get them down on paper?
- It’s tough to put on paper when there’s no color. I’m thinking color (laughs).
- I wish I had crayons, but...
- Crayons? That’s a double entendre. I don’t know what I could do... what are you trying to say... I read about this in... actually, I talked to artists that do this for a child psychiatrist. They have them draw something... they analyze colors, they analyze the size they make themselves, the relationship.
- I’m interested in what the relationship between those things are for you? When you put it down on paper it becomes more clear even for the person doing it.
- Well, since I told you I did that photography, I wish you would have asked me - I would have brought you a picture. You would have seen how... reflectively I know. Really, it’s a really far out photography...
- What’s the photograph of?
- It’s abstract. And it looks like different colored plastics with different lights, heat lamps, lens which makes it look very large. It’s just all colors and shapes. I tried to make it deep dimensions. It looks
like you could almost reach into the picture. The depth of field is what fascinates me. I really think you would like them. You ought work that out, you ought to see these. Maybe they would explain more. But I don’t know if I could paint... you see that’s why I don’t know if I could take this and draw something like...etch a sketch. I don’t know what you want.

- Are a lot of the photographs that you take relate to experiences of your life in terms of the pain and spiritualism and so forth?
- Right.
- They all deal with that?
- They do to me. There’s... do you listen to public radio? I got a lot of my work up there at the station. What’s the name of that radio station? (laughs). I gave them a bunch of pictures. I don’t know how much effort you want to put into this, but it’s on (address). I think it’s still hanging there. I do groups of 4, about 20 by 30, so it makes for a big 16 inches long... it’s a big deal.
- What does the largeness, how does it relate to you, or does it?
- Oh, yeah. It’s what sells it... it’s boom... it’s in your face. The size is the big deal. I put my stuff out on Octoberfest. Abstract art at a German Octoberfest. One time, they had modern art there. That was a couple years before. It had changed bigtime. It was all strictly German hand-crafted stuff, these little abstract pictures gold framed they looked terrible. You gotta make those bigger. When I started using paint, I started using these great big canvas, it was great. Take all these acrylcs and brushes... huge. That’s another thing, I can’t do it on a little piece of paper.
- This is restricting?
- Yeah, that’s... as strange as it may sound, but...
- Do you have an image of the pain? If you had to imagine what it would look like?
- I just took a picture. It’s a very scary picture, I don’t like it, I want to take it, actually I want to burn it. It looks like a quarter moon kind of like a crescent with the face - a real evil face- and I think that’s what you’re talking about. That’s what it is to me. That picture scares me. I guess that’s what it is. I don’t like to look at that picture at all.
- What does it make you think of when you’re looking at it?
- Just the darkness. The dark side of it. There’s a book Meeting Your Dark Side, and it’s like 20 or 30 psychologists, all the cast of characters, we are animals, we have to control the animalistic side of us. There’s a dark side to us, probably, ying and yang, opposing forces, jeckel and hyde. Everybody has a dark side. This book even says... these real fanatical Christians that try to rid themselves of every impure thought go crazy because you can’t do that. I mean you gotta have that shadowy part of your personality. You just gotta know it’s there and deal with it. You have a thought that may not be the purest thing in the world, whatever it is, the dark side of yourself, you overrule.
- That picture that you took is a part of you?
- Yeah, that represents something I guess... my psychic.
- So you have the ying and the yang, you have both parts, but the good part, let’s say, is overruling the bad part?
- Yeah, I think it’s not only for myself, but for every human being in the world.
- So the pain is a part of you...
- Right...
- but your strength right now is more powerful?
- Right...
- So the other part has the control.... the stronger part?
- Right...
- Has the stronger part always had that control in your life?
- Oh no.
- When did it start for you?
- Ah... it goes back to the introspection. I was always fascinated with religions. I was a born again Christian about after a week I turned 19. I grew pretty much in a secular home. My mother went to church, but she never talked about it. We just kind of went.... We didn’t talk much about it. But I
moved out to Southern California when I was 19. Back then, February 71, for a 19 year old in those
days, that was a spiritual experience in itself. Then my friend was a born again Christian and he was
already out there. It was a great experience.

• Is that when the strong part took control?
• Yeah, well. I didn’t have all that figured out back then. What I was doing, I think in any religion,
you inspect your habits, your lifestyle. Why you do what you do. You think about what you’re doing
and how.... It’s the California experience, you know. They’re the father of all that thinking. So at
that time it was pretty heavy, and I thought I was gonna go to Vietnam. Me and my friends we just
assumed, we were waiting around to come and get us, terrible.... Life was very explosive, I think.

• How have you seen yourself progress in terms of being of aware of that, of what had more power,
more control?
• I’m trying to understand what you’re talking about. Are you saying that... my better nature was taking
over.... is that what you’re saying?
• I guess what you want to call both sides of yourself?
• Ying and yang.
• You were saying that one part was stronger than the other part? Is that how it’s always been or has
it...
• Well, that was .... I guess there’s just always... it kind of ties in with your decision making, your
character, and why you do what you do and what you don’t do. The angels on this shoulder say to do
something good for the person and the dark side says the hell with it. It just takes a physical
presence, a much bigger presence. That’s kind of your negative thinking. It becomes a big part of
your negative thinking. Negative thinking can permeate your entire being. You gotta really fight...
you gotta be spiritual to push that back. In my opinion, it’s overcoming physical pain because it’s
tremendous... it’s tough to do. I’m very sore right now.

• Spirituality has given you the strength to fight back?
• Sure. I wouldn’t be here if I wasn’t a spiritual person.

• How did your near death experience, how did that affect that part of you?
• It was scary. That was a scary thing. That was a wake up call. This was years before I was a born
again Christian obviously, I wasn’t a born again Christian at the time. You can’t really understand
what’s happening to you. I still didn’t have the ability to introspect.... to know what was happening.
What forces are having this big impact on my life. I was very unhappy. I’ve gone through a divorce
and so as far as... alcohol and drugs just deaden pain, that’s their job. That could happen to anybody
easily. It’s not a very far distance to fall. It could suck you in. Something bad happens to you, your
determination evaporates. That’s tough.

• That’s what happened to you in the beginning?
• Oh, that happens all the time. Day in and day out. It’s more or less the same thing, just on a bigger
scale.

• Is it like a new struggle every day?
• Yeah. Pain has a real demonic presence in your life. It can be real heavy and real unrelying. There’s
no rules on that, you know. So if I break anything else, I’m in big trouble.

• You said that in your accident, you saw that you had a choice to live or die, and you decided to live.
Do you make that choice for yourself again and again or have you made that choice once?
• Well, ah... huh....I know I’ve been very close to death several times. It’s not that far away from us,
any of us. You want to let it into your life. People have a false sense of security about their life.
People downstairs and upstairs in these rooms. One drunk driver, one this, or one that, dove off into
a shallow pool. I know a lot of people that jumped in shallow water and broke their necks. A lot of
them. There was a nurse here that was walking in the street with her friends, some drunk drove on
the sidewalk, now she’s a quadriplegic. A girl was a homecoming queen at a high school, now she’s
got rods, halos coming out of her head. You can’t even imagine how that feels. When I first got in
my accident, they wouldn’t let me out of the bed for six weeks. They took about an hour to cut me out
of the truck, I guess. I was pretty mangled up.

• What was it like for you to accept that pain as part of you?
Huh... it was tough. It was overpowering. I was on two milligrams every two or three hours for six weeks. I went through a lot of surgeries.

It seems like after the accident, your pain was very powerful and then it slowly...

Oh, yeah. You almost... you can... I contemplated death. That and the biggest... there’s not much a person can take... unbelievable. My legs didn’t break, they crumbled, they exploded. It was like the x-rays came down there was blackness and a couple little white specks, then there was the ankle. One of them blew up. I was so locked in when I hit it. That was pretty painful. This leg swelled so bad that they opened it up and they laced it up... they plugged these things all the way down my leg... the leg was about that round. I guess what you’re getting at here is how much control pain has in my life.

Yeah, I guess the way I was thinking of it was the control that you have yourself and the control outside of you that pain has and you just put it in terms of pain being a part of you, maybe like having two forces within yourself and which one has more power over different times in your life. It was a different way of thinking to think of the pain outside of you.

Inside and outside... yeah... But I also said that I would rather be this way than the way I was before cause I really had to confront myself. After I lost my second leg, I knew I had to look... you really don’t like what you see. Oh well.

Do you think the two parts were always within you even before you were aware of them?

Oh, I’m sure they were. Are you familiar with The Prophet? I lived by that book, I did (I do too). The lotus blossom that reveals a petal to you. I had to find out more in a hurry, I guess. I had to look a little deeper into the bud. I think... I guess I always thought I should be dead... so everything was a real bonus. It’s a pretty good life. I can do a lot of good things. I’ve seen a lot of good things. I’m pretty content. I feel pretty good about it. When I finish this book, I’ll feel excellent. Then, I’ll feel wonderful. You know, if you’re gonna be an artist, you gotta accept the fact that you may be dead before it makes all the gold. But you gotta take that chance. People like to verbalize, I think I rather live it. I’ve gone all over the country, it’s a great experience. A lot of people... I think it’s becoming a more encapsulated society. They read about people, but they don’t actually do it. I would have loved to go all over the country, I’m envious of you. South America, Middle East, United States. You must have a great perspective... that’s incredible. I could speak about the United States like that, but not about the world.

Are there any other things we haven’t hit on? I think I asked you the things I wanted to.

I don’t know. I kind of ramble in and out of things. I really can’t stay on one subject. Because it’s emotional for me to talk about it. You can probably ask me the same questions and get completely different answers. (laughs)
Appendix Q

Jennifer's First Interview
Jennifer's First Interview

• Hi. I'm just gonna start... I have some questions listed here. I'm just gonna start with some of these.
  To start out with, xxxx, can you tell me a little bit about how the pain started for you and what happened?
• It's probably back in 1979. I took a fall over some rugs at the place where I work and dislocated the (?) or whatever and from then on, I just started getting worse and worse. I went away for a while cause I did go to a chiropractor and straightened things out. But, it was like after that, I started having back problems from then on. And then in 1983, it just really took over.
• What happened then? Did anything more happen?
• Yeah, my sister, we... my father had a heart attack, he was in the hospital and we'd gone up to visit him. When we get together, we get kind of gushy at times like that. She had to go to the bathroom and would not go in the hospital. We walked out and we were laughing and I went to unlock the door and she laughed and told me to hurry up, she had to pee. And I said, well - you're not gonna pee in my car. She laughed so hard she kind of fell on me and I was bent over and I don't know what she did (laughed). But it took me a long time to straighten back up. The combination of the two things, ever since then I get a little more things that happen, more and more. (knock on door, interruption)
• O.K. So your original injury occurred on the job then, but there were subsequent things that happened...
• Yeah, just little things after that would just aggravate the situation. Once it got out of place, then it was just hard to get it back in.
• How about right now, do you receive financial compensation from the original injury?
• No, I tried to fight that - the fall over the rugs. They came up with something... they said to me that in the x-rays, I had abnormalities in my back that anything would have caused it and they didn't think they should be medically responsible. That was a long time ago and I didn't know nothing about lawyers or anything like that, so I just settled for a little cash and that was it. You know, they did pay for my chiropractor for a while. But then, like after that, it was hard to get work. I was in Cleveland and I moved to Columbus and they were supposed to transfer me down and they didn't. They messed me up real bad because I had taken action against them and so (laughs)... it was just really hard to get work after that.
• What about now financially, are you....
• I'm on social security disability (muffled).
• How has that been for you? Has that affected how you feel about you?
• It makes me feel very angry that I cannot go out and work. I cannot stand being in the house all the time. I don’t feel like I achieve anything. I just... I’m trapped... four walls and that’s it. If I go out to work, I lose my medical card first thing if I get any kind of income, and with my medications, I don’t want to lose my medical card. So, it's like that 10% of people that are between a rock and a hard place and can't get nowhere, but you can’t get out of the system, you know, to do something for yourself. So hopefully they're gonna change things (laughs). I have a very strong sense of doing the right thing, so I don’t feel comfortable working under the table, getting money like that. I even tried making extra money doing some things that weren’t so moral and found out that if you make dishonest money, for some strange reason - bad things happen (laughs). You cannot live with yourself. I have myself right now in tremendous debt... credit cards up to the max, you know, basically because with not being able to work and trying to budget out. Right now I get $691 a month. It’s kind of hard to live on that when you got a kid that’s almost a teenager and he’s wanting hundred dollar shoes (laughs). It’s hard.
• Adds some stress.
• Aha. Stress on top of back pain and that’s no good because you’re not supposed to be stressed out (laughs).
• What kind of work were you doing when it happened?
Waitress, cook, back of the restaurant. When it happened, I was in charge of banquets. So I used to do large groups of people and carry very large trays outside (laughs). You know, I could carry nine meals on one hand and nine meals on the other. So I was pretty good at it and I'm pacing for it.

Is it something that you enjoyed?
Yes, very much. It was the kind of work that I really wanted to do. I liked being around people. I like serving people and making them happy (laughs).

What about... when did you come to realize you had chronic pain?
Um... probably around 83. I had joined up at the school for keypunch operator. I had been having trouble with my legs, too, and they couldn't figure out if they were connected to the back of the (?). Then they started saying I had tendonytis in my legs cause I was doing exercises and I was under this school. But I would start getting real bad cramps. Charley horses and spasms, and they would just hit you. The last part of the schooling, I'm taking the final test, and I got stressed up about being timed and all that and I had spasms in my legs, I couldn't even sit still. And I failed the class. In order to go back, you had to pay all the money again. So I just stopped that and started going to Dr. xxx, my neurologist to try to find out what's going on with my legs. Then I got pregnant in 84 (laughs). That didn't help (laughs). I had a very hard time with him because of my back. Then I became a diabetic while I was pregnant. It was just rough. He came out all healthy and I'm fine. I wish I could go back and do it over again, cause this 12 year old drives me crazy.

You just have one?
I have two. I have a son that's 23.

Do they live at home with you?
No, the 23 lives on his own.

Where is your pain now?
My legs. I have... they diagnosed me with having degenerative disc disease in my back and peripheral neuropathy in my legs. I say it's something hereditary. My mother had jumpy legs, my grandfather had jumpy legs. You know, I always remember everybody sitting around shaking their legs. I never understood what it was about. So I think the legs doesn't have anything to do with that. I don't know... they say when you have back pain, you end up with problems in your legs. I always had pain in my back, but I guess I kind of just gotten so used to it. It's rather hard to deal with your legs if they're jumping or .... like right now, what I've been experiencing is my leg locking and this is my driving leg. This drives my gas pedal and when it locks, it locks straight out and I can't move it. It scares me because when I do that it goes straight on the gas pedal (laughs). So it makes me wonder why it's doing that. I hate to go to doctors cause they just tell me over and over, it's nothing.

What kind of treatments are helpful to you now?
I'm not on anything at all for my back or my legs. I'm on no muscle relaxants, no antiinflammatories, no pain pills, no medications at all for that. I was on Naprosen, but I guess I had an allergic reaction to it. I break out in hives, but I don't think it has nothing to do with the Naprosen. I can be sitting there, and I just break out with weird hives everywhere. At first, everyone said it was the tanning bed, cause I do tanning everyday for relaxation, that's the only place I can get 20 minutes total relaxation. I do that and they thought it was a reaction to that. I tan all the time and I had never had a reaction like that before (laughs). So I'm off of Naprosen and so I'm not really on any kind of medications. When I get severe back pain, I do buy street drugs. Pain pills if I can find them, whatever I can find to get over the really bad part so I can function. I'd like to find a doctor that would work with me with them. I'm an addictive personality. I played around with a lot of drugs, they know this. In trying to avoid the pain, things like that. I need a doctor to work with me, to get me away from what I buy off the streets and kind of keep an eye on what I'm doing. It's getting dangerous, I'm getting crazy (laughs). When the pain gets so bad, like we had a really wet summer and we had a bad winter and it was terrible in moisture. There were days where my kid would come in and he would see that look on my face, and he'd know -just leave me alone. Because I'd be yelling, and screaming, and hollering. He's been around this all his life. For 12 years that he's grown up, he's grown up with me with chronic pain. It's been ... he's been deprived of so many things because I can't do it. There's no father in the house, so it's up to me, and there's just so much
I cannot do. I can’t go out and play ball with him like I used to. I did for a while. I played basketball and fell right on my face (laughs). But I try, and when I try I usually end up doing more damage to myself trying to please him and then I suffer for longer real bad.

- It sounds like it interrupts your ability to interact with your son.
- It ... the pain... O.K., I have a lot of depression too - I’ve lost my whole family. Within the past four years, I think everyone in my family has died, except for my sister. Just me and her left. And she’s a fruitcake and I’m a fruitcake and we just ... we’re in that place in our lives where we just... you know, where’s mom and dad to lean on again? It’s been a lot of depression. On top of pain, when you’ve got depression, you get into a cycle. You end up .... I don’t know...
- How has that cycle been for you?
- When you’re depressed, you don’t really want to do anything. And when you have pain, it makes it harder to do things. You’re more apt to sit there and convince yourself you can’t do this, you can’t do that. It causes you to feel more depressed, sitting there and thinking about the things you haven’t done. I have a 12 year old.... I have to wash his clothes, I have to wash dishes... But these are things that if they cannot get done, there’s just nowhere to go with it. I have a hard time with dishes because of my sink. There’s ways I learned through the pain management program putting my foot up. All the stuff I learned, I refocused. I’m on one now. Dr. xxx on how to accept the control of your life. So I continue with exercises, but it is so hard to push yourself everyday and deal with it. Sometimes there are days, I just want to lock myself in a room and blow my brains out (laughs). It’s hard.
- So, there have been times when you have felt suicidal?
  - Very.
  - Has that been recently or in the past?
  - It’s probably been on ongoing thing for a long time.
  - How do you get through those times?
  - My belief in God and my belief that life is precious and that nobody has the right to take a life. That keeps me going and the guilt that I’ll cause my children. Cause I know they’ll go through the anger and the questioning. I can’t do that stuff. It gets kind of hard.
  - How about your appetite? How does the pain affect your appetite or has it?
  - Yeah, I’ve had compulsive overeating when I get very depressed and very painful. If I don’t have anything to relieve it, I catch myself just snacking, binging on whatever is available. Since I’ve been through the pain program here, I have learned how to make more healthier choices. Sometimes I’m really not so concerned with my overeating cause it’ll be on fruits or salads. So I have learned to incorporate healthier parts into my overeating (laughs). It’s still... I battle with the weight problem. I know that the more weight I put on, the more problems I’m gonna have with my leg and my back. But sometimes it’s just hard to get yourself motivated to get on the treadmill and to do those things that you know you have to do. But just don’t have enough push to push you there. It’s a very vicious cycle and when you get caught in it, it’s like you’re going round and round and you don’t know where the doors are. You can’t find the right doors.
- How about sleeping, has it affected your sleep?
  - I have very restless nights. I smoke marijuana on a daily basis because of spasms in my legs. It controls them if I smoke a joint before I go to bed. I don’t get woke up with real severe Charley horses. But sometimes, [the pain] it can just like throw me right out of bed. If I don’t have marijuana, then I suffer (laughs). It can be agonizing if it’s rainy. You know, I tend to walk floors more than I tend to be in the bed. And then the next day, I feel worse because I haven’t had sleep. Sometimes I get good sleep, and sometimes I’m very grateful. It’s more times than not that it’s interfered with pain. It’s very hard to find a bed that’s comfortable and suitable because since the original back pain... In the past two years, I’ve been in two head-on car crashes and I’ve been attacked twice and beat up. So that’s added more on top of everything.
  - How have those things happened?
  - How have those things happened to me... (laughs). The first head on collision was the other guy’s fault. He was coming out of a sidestreet onto high street. The thing that upset me the most about it was ... the police officer was there... nobody got any tickets. I mean, he had backed himself back into
the street. He told the cops one version, which I thought if somebody pulled out from a side street, there should be no versions. You know, plain and simple. Well, I hit him. He didn’t judge it. I had to fight and prove that I did not have a car accident. You know, that it was not my fault. So, that added to aggravation. I had to go track him down, witnesses, you know - to see if anybody had seen him. Then after that, my cousin’s wife got drunk and decided that she just didn’t like me. So I wasn’t talking to my sister at the time. Her and my sister got together and they came to my house early in the morning and started banging on the door. I opened the door and told them to leave, you know, and sober up. They wouldn’t leave, and knocked on the door again. When I went to open it, so I could tell them to get out or I was gonna call the police, my cousin’s wife pushed her way in and just started throwing me around and... tore my house apart, wrecked my doors. Her brother ended up coming in, and my boyfriend ended up getting into it. One guy got his head gashed at with a shovel. I tried to take him to court (laughs). Nothing came of it, it was all dismissed. Then last year in July, she started trouble again - my cousin’s wife. My niece was dating a guy from the neighborhood and one of her relatives was in love with him. She starts going down and picking on my niece. So I started... now, I called to make sure that my cousin’s wife wasn’t gonna be there and I went over to talk to the other girl to say - look, he’ll choose who he wants to be with and there ain’t no sense in you causing a fight or her causing a fight. It’s his choice. So I went over there. Well, when I was standing there, all these kids in the house, and they’re yelling cokehead, whores, m.f. bitches. Little kids, three years old, five years old yelling these things and nobody would come out of the house. So I got very angry and I had some jars in the car and I took one and I threw it up against the car that was out in the driveway and missed the car, hit the ground, and broke. Then I grabbed another jar, and I threw it. I missed everything, it just bounced on the ground and didn’t even break (laughs). So finally, another brother of hers who owned the car said - that’s my car, what are you doing? I said I’m just trying to get somebody to come out of the house, an adult to talk. And I said I figured the best way to get somebody’s attention was to throw something (laughs). So he come out, and we started talking and everything was going really nice. We were having a nice conversation. Apparently, whoever was in the house had called my cousin’s wife. She come down. I didn’t even hear the van pull up. I turned around and got attacked in the face with a set of keys. I got poked in the eyes, she broke my glasses, she just literally jumped on me. Well, I’m not a violent person and I won’t strike anybody or do anything.... I just don’t believe that violence against somebody else is gonna stop it. So next thing you know, I don’t know what happened but the whole yard is full of kids and other people. I’m being beat in the head with a broom by somebody. Well, my only concern was my niece. I’m yelling - get in the car, get in the car! I finally got myself in the car. I pushed her back and I said -look, if you’re gonna fight, one on one, that’s fair. If you’re gonna have everybody out here bashing me around, what is this? I managed to get in the car, I got blood all over my face, probably insane. I don’t know. I go down the street, I get almost to the end and I’m thinking I can’t let my ex-boyfriend see me. He lives up the street, and I didn’t want him to see me with all this blood and everything. So I turn around. I back up and turn around. Meantime, she’s getting in her van and gonna come after us. Well, I start heading back towards her place. A broom comes in the back window - we hadn’t gotten any of the windows up, hadn’t gotten any of the seatbelts on. Last thing I remember doing was turning around grabbing the broom cause I heard the kid screaming. And I turned around and grabbed the broom, I looked up and plow, head on right into us. I don’t know whether she hit us or I hit her, you know, I ain’t exactly sure what happened, but I mean she totaled my car. But it still hurt (laughs).(turned tape)

- You were talking before about how the pain affects your appetite and your sleep. How about your energy level, how is your energy level?
- Some days it’s good, and some days it’s bad. Some days I feel like I could just get up and conquer the world with the energy, but my body denies it. It’s like -well, you got this energy, but we’re not gonna do anything for you. So sometimes I have and sometimes I don’t. The majority of the time, I feel very fatigued. Very tired, really depleted of energy. There’s not really much there. I’m working on that. I’m on an antidepressant and I’m also on (?) for bladder stabilizer. I have an unstable bladder.
It seems like the combination of the two kind of picks you up a little bit. Makes my mind think — gee, there's so much I can do. It really picks my mood up, but I can't do anything with it.

- Sometimes you feel like you've got the energy, you're ready to go, but...
- It's just how to get that push to get you going. Cause I know when I get started. I feel better about myself. But it's very hard to get started with anything. It's very hard to keep a routine schedule, very hard to do that.
- How about your self esteem? How has that affected how you feel about you?
- Pain has really affected me as far as ... because I don't feel comfortable around people. I don't feel I can do the things I used to be able to do. It's hard to talk to people because you're fidgeting or something and it makes people wonder. You know, I always have people — what's wrong with you?; are you paranoid?; I just.... I tend to stay away. I never like to ... I used to like to drive. But driving now is very hard, so I don't make a lot of trips anywhere. I don't do much of anything to get myself out and about like I used to. The pain has caused me to just put myself in the house and do what I have to, but there's no fun in my life. I'm not meeting the needs that I need to go out and socialize, to do things. It's hard... it's hard to sit through a movie, it's hard to go bowling, it's hard to play pool. The only time I can dance anymore is if I get drunk. A couple drinks in me and then I feel it [the pain], but I don't care (laughs). I don't like to drink. I'm not very much of a drinker, but I do like to dance. Everything makes it very hard.

- How about... you mentioned panic attacks. About having those now, how they keep you at home.... can you describe those for me and tell me a little bit more about them?
- Well, I've noticed... it's like going to the doctors... now I have a reputation since I decided to be honest with my therapist, my psychiatrist and my doctor, they know my drug history, what I do, and all of this. I don't feel like now they're treating me as a person, they're treating me as an addict. It causes me not to be around doctors. With the problem with my cousin's wife, the legal system.... I told my son over and over again that we're gonna do it the right way, we're gonna take through the legal system, and it will serve it's purpose- but it let us down (laughs). So it's different... it makes me not want to be... when I know I have to go some place, to a doctor's appointment, I have to get myself into it. The day before I'm so tense, my stomach is cramped. I usually have diarrhea. I just get myself so worked up and then I know I have to get dressed. Part of this is from a bladder problem too, which I discovered that I probably had since I was five. My parents just didn't think it was a problem that should be dealt with, it was hush-hush, keep it in the closet. Since I was five. I had dealt with a lot of problems and I had to hide that. Which is where low self-esteem, trying to grow up and be a teenager with a urinal problem, you know, you can't socialize there. I found that difficult. And as I've gotten older, it got worse, so I found help for it (laughs). All the things combined just made me where I cannot fight the panic before getting out of the house. And I catch myself checking. Check to make sure the animals are O.K., I check to make sure the stove is off. It seems like there's something that just don't want me to come out of the door. It's like I will do everything I can, make up every excuse I can not to go. It took me a long time with tanning. When I first started to go, I was very conscious about getting out. About people coming in and out. At the gym, I felt very uncomfortable. But when I got in there, all nice and warm and safe in that nice little room. I still have to sometimes fight with myself to go because I know it will make me feel good. It's such a struggle sometimes to do things that make you feel good.

- It sounds like tanning is one thing that you can break out of the house and ...
- I know that relaxation is a big part of pain... you have to learn to stop and relax and that's one thing I could never catch on to... even here in the pain program. I had a very hard time relaxing. My mind was just constantly racing. But I find that being in there, I feel very safe. I don't feel like anybody can come in there and attack me. I don't even feel safe in my house unless all my doors are locked. I have a knife under the cushion in the couch. I just don't really feel safe there either. Tanning is my way of giving myself 20 minutes away from looking at dishes, looking at laundry, looking at my kids. This is my time, this is something I do strictly for me.

- You said earlier that having that tension does affect your pain.
Yes, it does. Because you seem to be more in tune to the pain when you’re feeling anxious or stressed out about things. I become more aware...

...and focused on it?

Yeah, very focused on it. It becomes the center of my attention. They try to keep me from going out. So they work together. I don’t think the panic attacks would be so bad, if it wasn’t for the pain that follows it, you know, because I just blow that off. It’s gonna get worse and harder. I’m working on ways to break myself from that. When I go to the grocery store, I give myself a pat on the back. Cause I have to walk and be around people. I have to smile and socialize at times. So I’m working on it.

How about getting to a doctor’s appointment? How do you make yourself do those things?

Because I know it’s for my own good. Basically, I know I can’t miss therapy because I know I need that connection with somebody who’s sitting there and can listen to what I’m saying and they’re not criticizing me, they’re not being judgmental. I can’t talk to friends and family cause everybody is like– oh, you’re doing this wrong, you’re doing that wrong. I myself feel like right now I’m doing what I need to do for me. I’m not worried about anybody else right now. I have to take care of me.

Those are kind of things that work for you.

Yeah.

Let me make sure I get to a couple of specific questions. How about relationships, how has pain affected relationships with people of the same sex and people of the opposite sex?

No, I don’t have too many girlfriends (laughs). I’ve only been in Columbus for ten years in December. I’ve only been in one real relationship since I’ve been here and the pain really has interfered sometimes with the relationship. It’s hard to get intimate with somebody and you’re never sure when the spasm is gonna hit. You feel very conscious about things because you don’t feel you’re moving the way they want you to move. You just don’t have much control over what you do and you don’t feel comfortable…. I don’t feel comfortable with somebody being romantic and wanting to pick me up. That just totally obsesses me that I’m too big, I’m too heavy, that he’s gonna drop me, that I’m gonna hurt my back. It’s a lot of that… I don’t do anything fun. I think that’s a part of why I can’t keep a relationship. Because I don’t know how to get out of the house and have a good time. So it’s hard to get a relationship going. It’s hard to meet people.

How about the people that are close to you, do you feel that they understand chronic pain, do they understand what you’re going through?

Sometimes I do, but sometimes I don’t think they understand the depth that one goes through when you have to deal with it for such a long time. Most of all, I have two really close friends right now. And both of them have back problems. They’re young, he’s only 25 and she’s 19. They both have problems with their back and I try to stress to them, you know, how they should work things and what I learned through my management control so that they don’t end up like I am. I guess I get a little critical of them when they get on the phone and they’d be complaining because I say you don’t know what pain is yet. Wait till you have it for over 13 years (laughs). You know, so I try to get them out of the things that they do so that they don’t end up like me. I didn’t have anybody to tell me that…. nobody in the family talked about anything with pain. I remember something with stomach pains as a child. By the time I was ten, they took my appendix out. They didn’t know what it was. They did exploratory. So as far back as I can remember, I was never taught to deal with pain. Medicate it, medicate it. You should never in your life have to deal with pain was the message I more or less got. My father was a medical transcriber, so he was like - you shouldn’t have to deal with anything. It’s hard when you realize you can’t be medicated for all your life. Maybe you can, maybe you can’t. I don’t know. I think I function better on pain pills, but I don’t think I want to be on them for the rest of my life because I don’t think that’s what my body is made for me to do. I don’t think it should be drugged to perform.

How do you feel like your situation compares with other people who have chronic pain?

I feel grateful that I’m walking. I was told that I’d be in a wheelchair after five years. I still walk, I still got good legs to carry me around. They may hurt, but I feel…. sometimes I feel more blessed because I don’t see myself as physically impaired as some people that I’ve met. And then I get mad at

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myself because I think I’m such a baby and I whine about so many things. I should be grateful the way I am, and that I’m not as bad as I could be.

- What about your overall quality of life, how would you rate that?
- Sometimes when depression really sinks in, I don’t really think I have a quality of life. I feel like my quality of life, there is none to it. I feel like I’m like a robot. I have to do certain functions. They’re programmed. But there’s no... quality of life for me is spontaneous, doing things, enjoying life. And right now, I don’t enjoy life. That’s not too much that I do, that I enjoy.
- Are there somethings that you do... you mentioned tanning relaxes you?
- Yeah, I relax during tanning. I do like to play on the computer. I’m trying to get used to it. I know society is going computer. So I figured I might as well catch up a little bit and maybe that’ll help me. I get on and play the card game. It really... I can keep my mind focused on the cards, then I’m not so focused on the pain and depression. So that helps. I love to read, but most of what I read right now is helpful. Some psychology books. Things to really try to understand what it is that’s motivating me, is the problem that I have something that I create for myself. I’m creating.... Can I change patterns that have been in my brain for so long. Now that there’s no family left, I kind of feel a freedom because I don’t have to stand up to certain expectations and I kind of feel like I can go out and be anything I want, but I’ve got all this pain (laughs).
- How about quality of life before, how was that?
- Before all this happened, I had a good life. Besides the few problems like the bladder and everything, life was relatively normal and good.
- How about goals, how would you say pain has affected the goals you have for yourself?
- Pain has interfered with completing my tasks for school. So I kind of see any attempt that I try to do as not completed. It’s like I cannot complete anything. I don’t know if it’s just I’m afraid to complete it, I’m afraid what we’ll happen to me if I achieve something. I’m not really sure where all that comes from. I have a hard time.... I don’t know why I get myself worked up where it causes the pain to interfere. What’s going on, but I just have a hard time.
- What would you say your goals are, since you can’t achieve the ones you set for yourself before, do you have goals that you reach for now?
- I’m trying to be realistic in not setting too high a goal for myself. My religion interferes a lot because ... I changed religions. But I’m on this fellowship religion that I am. So I’m kind of like castrated. I can’t talk to nobody except to the big high up people. So I have no connection there. But yet I still have my strong beliefs. It’s kind of hard to have some goals, when I kind of feel like there’s no future (laughs). That’s kind of hard to get out of too because of the depression because my religion, I don’t believe in heaven or hell. So it could be very easy for me to commit suicide and all this. I know I wouldn’t know what was going on. With my death, would come no more memories, you know. I would just be out of it. That scares me because it would be easy on that. It’s hard to see a future when you do so much research and I sit here and I don’t see my future because I got thrown out because I do smoke marijuana, which is illegal. You know. I have to fight that issue everyday with me and my child. He knows I smoke, but he also knows it’s illegal. I smoke it for one reason. But even his cousins, some of his friends, some of my friends, they smoke it for different reasons. How do you explain to your son that - I’m not in it for the buzz (laughs).
- So the reason that you’re not involved in the same community...
- Because of the things that I do for the pain. Also we have to go door to door, and I couldn’t keep the pace.
- I got the impression in talking to you before, just in things that you said over the past several minutes... a sense that on one hand you use marijuana as well as other substances to deal with the pain; on the other hand, I get the sense that that doesn’t feel really good sometimes.
- Yeah, it feels really wrong to me. Like living double standards and I’m trying to raise a 12 year old in this society. And things are so changed from when I grew up. I have to reorganize and change my way of thinking so that I can work on him. But it’s hard. If I would have seen my parents doing marijuana, I would have questions. I was the one that introduced my parents to marijuana, you know. I don’t want him to get the wrong... I’m not saying he can’t use it, because he’s a kid. All the kids, I
feel, go through certain periods where they try to establish their control. Whether it'd be drugs, you know, what way they're gonna turn. I want him to know that I understand this, but that I'm not doing things for the same reason. With the way I am with pain pills, not being able to get them from the doctor. If I call up, and it's a really bad rainy day,... (turned other tape)

- For the first couple of years that I was here, I had this really good doctor who would give me Nicoden when he knew it was really bad. If the weather had been a really long period of rain, he would give me some relief. I knew I could call him up - I will call you in for five maybe ten of them. I felt I had control. I lost him because the medical card, and disability didn’t take the card no more. So when I found this new doctor, I’ve been through a drug program to try to get somebody to work with me, get me off, help me just get under control. So right away, she knew me as a drug addict. So her main goal was to give me no drugs! But I’m not only dealing with chronic pain that I had when I first went to her, I’m also dealing with depression from the loss of all my family, two more accidents, gotten beat up twice. It’s like she’s not looking at the whole picture of who I am. So I feel like she’s pushing me to go against my morals because she doesn’t supply. so then I have to buy them. When I buy them, sometimes I buy larger quantities to save money. I have all these pills and my son will see a person taking a bunch of them. And the next couple of days, he’ll see someone who’s very gorggy, you know, who’s kind of out of it and he don’t understand that. Because then I go beyond what they should have been used for. But when I start getting that little bit of relief from the pain, I don’t know where to stop. That’s why I really feel like I need to be in control. I don’t have the money to keep going to the streets and buying. I mean, drugs are seven bucks a pill on the street. These people are making money because I have a medical card. They’re making money off of me that they shouldn’t be making. I can’t fight the system. That’s nothing I can control. I just would like to have somebody work with me. It helps me with my morals as well as with what I’m trying to put out to my kid. I don’t want him to grow up with all these mixed signals, that’s why I put him in therapy.

- Let me go through a couple more things, and after that we talked for almost an hour, so... How about your daily routine, do you have any? I know you said it’s hard to have... do you have a certain amount of routine to your day?

- Well, it’s summertime right now and most of the time I baby-sit my son’s friend cause his mom works. It’s easier for me just to keep him so that my son has somebody to play with and doesn’t constantly agitate me all day. It’s kind of hard to plan a routine. I try... I usually get up and watch... I have two soap operas I really like to watch, and I kind of work my day around them. I watch the one, then I do a little bit of stuff around the house, then I watch the other one, then I go tanning. And then when I come home, I try to start a routine of being consistent with doing something, at least one thing in each room. Whether it’d be wash clothes, fold, you know... or I wash some dishes, or I run the vacuum cleaner. It’s hard to keep a routine, but I try to keep it like that during the summer. When school’s in, I’m more regulated as far as getting out, taking my son to school, tanning, come home, doing my exercises. It’s easier that way. But I try to get stretching in. I do a lot of stretching. It’s mainly to try to keep my muscles from getting real stiff from sitting. Cause I find I sit a lot when I’m depressed. I tend to sit more on the couch and not do things. I have a treadmill in the living room right by the television. If I catch myself sitting there, trying to watch too much television, I’ll be like- you can watch just as much television if you’re on that treadmill. It’s right there, you can turn the sound up, and you can walk while you watch. But it’s... sometimes I really have to talk hard to myself to get going. But I try.

- I know you went throughout the pain program here, in October of 93?
- October of 94.
- How would you say it affected or changed the way you deal with your experience?
- Being on the routine that I was on for the month that I did it was great. And then that month was over. I went through a period- gee, I have no place to go, I’m on my own. And it was very hard to put in in practice until... I guess it must have been in the middle of January before I finally told myself - woah, wait a minute now, you know, let’s get on this program. And I was doing great. I lost a lot of weight, I was feeling better. You know, pain was still there, but I was feeling better. When I had the car accident, not my fault, I put all the weight back on. It was just so hard to get back into a
routine because I was finding pain in other parts of my body because I had pain in my shoulder. In one accident, I did have my seatbelt on, in the other accident I didn’t. I wasn’t treated for that. I had to go for physical therapy. She said by the time that I would get there, I was so tensed up. By the time I would leave, I got myself tensed up again about having to leave the building. So, it really wasn’t doing anything.

- It sounded like, as you said earlier, there were some kind of hints like washing the dishes...
- I’ve gone through a lot of good information of how to bend properly, how to pick things up properly. Sometimes you have to stop yourself cause you go back to the lazy man. I call it the lazy man ways. It’s easier to stretch and bend over where you really don’t have to think about it than position yourself. But I have learned that everything that I was taught in here has benefited me in some way because I can reflect back on it. And, you know, I’m in more pain now, but it still helps out with what I do now. I’ve learned more so that I don’t have to be that perfectionist. It’s O.K. if the dishes don’t get completely done; you can let them stay in the sink overnight. Nobody is gonna yell at you. It’s O.K. if the beds don’t get made, or the laundry is not quite done as much as you want it to be. So that was one of the lessons I learned from here. Just because everybody said it was my job and I had it all to do, didn’t mean that it all had to be done at one time. I could pace myself and I could take care of me without having to worry about everything else around me. It was a great learning experience. I did try to go to another pain program with my doctor. She wanted me to go through it at Doctor’s. But I don’t know what’s with them because they never did call or get anything more and I just never followed up... I figured I knew enough (laughs).

- How would you define chronic pain?
- Chronic pain is very hard to describe. It’s... to me it’s like having a friend with you all the time, but it’s not a very pleasant friend. This friend can be very annoying at specific times - he’s always there with you. He never goes away. But there’s times where he’s so much worse and there’s times where he’s tolerable. Pain is so different for everybody else and I’ve learned to deal with the harder pain a lot easier than the smaller pains. If I cut my finger, you’d be surprised at how I scream and holler and yell. Little things tend to be really overly painful to me because I try so hard to deal with the bigger pain.

- Do you feel that having pain always in the background gives you lower tolerance for additional pain?
- Probably. It’s just that you dealt with so much pain, to think of the little ones coming along and it’s like -why this? I’ve had all this to deal with, why this? (laughs). And it’s hard sometimes to get people to understand acute pain and chronic pain. Just recently, I had something in my foot, and because of my past history they wouldn’t give me anything. They numbed my foot and went through this big hallway. I had some on my foot. They dug it out, I had this hole and I’m in pain. They’re telling me I should take Tylenol and that would help it. I’m trying to tell them I have no tolerance towards Tylenol. I could take a whole bottle and it’s not gonna help because ?. It’s like I have chronic pain, don’t let me deal with this. I know this is gonna go away, but don’t let me deal with this like this (laughs). I tend to overreact to the little things because it’s like I know it will go away, but it’s like nobody recognizes that this will go away, but this will be here forever and that’s not gonna go away.

- Is there anything else that you’d like to talk about that we didn’t bring up?
- The only thing is that, you know, with chronic pain is it’s very good to have support from your family and your children. They’re the ones that end up the worst of it because, especially if they were in it from birth. Like my son. I catch him becoming a hypochondriac a little bit, you know. He has a hard time dealing with just any kind of pain. And I guess it’s until I learned to show what I’m going through to him. Before, if I hurt, he knew I hurt. So I guess I kind of sent him a message, too. It’s good to have people who understand where you’re at so they can help out and to have people who can take your children and do things that you can’t... I have a couple good friends in the neighborhood with kids that they don’t know a family, they... you know, it’s just me and my son right now, there’s no man. So they do family things and they know I can’t so they’ll take my son, because they understand that it’s hard for me to do. It’s supportive. It’s a tremendous thing to have if you have a lot of chronic pain.
• One thing I wanted to ask you before you were done, how was this interview for you, was it O.K.? Is there anything else we can do to improve the interview?
• No, I'm comfortable. I figured it wouldn't be this comfortable, but (laughs).
Appendix R

Jennifer's Second Interview
Jennifer’s Second Interview

• We have a few minutes to look back. Do you have any questions or concerns or things that you’ve thought of while you’re looking through?
• No, the only thing really that I think is important with chronic pain is that they get some sort of support from the doctor in charge somehow, the therapist, maybe a psychiatrist who knows about medication. You really need someone to work with you cause you can’t do it by yourself. I guess that’s the biggest thing. Try and find out someone who’s willing to work with you because a lot of people just don’t want to deal with back pain and chronic pain. Nobody knows how to deal with it.
• I know you had frustration last time about wanting a doctor who you felt would work with you.
• It’s really hard because you get times where you feel like o.k. maybe it is in your head, maybe your body’s way of trying to... you know, I read a lot. I just finished reading on Take Control of Your Life. You know, according to his theory, a lot of this I bring on myself. It’s my body’s way of saying stop something and let’s do it the right way. It’s kind of scary that maybe I have control over all this amount of pain I go through.
• ... (muffled).... how much control do you feel you have right now?
• I feel out of control. I don’t feel I control a lot of the situation ( hard to hear).... It’s kind of hard cause I catch myself like in the morning from depression, it causes me to overeat and that adds to my chronic pain because the weight is heavy on my legs and heavy on my back. I don’t feel I have control over making my body do what my mind tells me I have to. Everyday it’s a battle to get out of bed. Do the things that have to be done. I feel like I’m just existing right now just to do what I have to do. Not a very good life right now.
• So you don’t have the control right now?
• No,
• Who does... the doctors, the pain?
• I feel like I don’t have control over me. I’m not really sure who does...That’s a hard one. Sometimes I think my son is in more control than I am. He’s aggressive and I’m very passive.
• Have you been able to, since your injury, to have times when you feel you do have control?
• After finishing the pain clinic, I didn’t put it into effect right away. But when I did start do the exercising and putting myself in a routine, but allowing myself (?) too. Right now I’m denying myself all the things that I need... I’m more like a four legged chair, but I’ve only got two legs right now. I’m not giving myself the things that I need to enjoy myself. If I don’t go out of the house it’s because of the pain.... I just purchased a trampoline to help try to conquer my fear of moving. Even with this, if I move on the trampoline, there’s nowhere to fall! And yet I have a hard time moving my legs. It’s like they’re cement and they will not move.
• Is it one of the big ones or...
• A fourteen foot one. It’s big and it’s in the back yard. I got it basically to help him with his weight problem. Nothing I try is enjoyable to him. I have a treadmill, I have steps. I have all sorts of work out equipment at home and he won’t get on any of it more than one day. But the trampoline, I had it for three days now, and he can do flips, practices karadi jumps all the time. It’s a benefit for both of us because if I can conquer my fear, just moving around again, just doing something, just taking a chance. I feel like I don’t take no chances no more. I don’t achieve nothing because I don’t take the chance.
• How did you feel when the pain program was over?
• It’s very hard to go from having to get up into a routine and then knowing all of a sudden that you have no schedule. It’s like me not being able to work. I haven’t worked in so long. I would love to just say I’m going to work. You know, I’ve got some place to go! It was very routine coming here for eight hours. You know, I felt like it was a job. When it was over, it just (?) me. It’s like there’s no place to go, there’s nothing to do, nothing to look forward to.
• So emotionally, you felt kind of down when the program was over?
• Yeah, cause I didn’t have the support of the people that were in the program with me, nobody was there to push. I was here, it felt like I had to do it for me but I also had to do it to show everybody that I could do it. At home, I do it... I don’t really feel like I have to do it for me. I’m working on that in therapy.
• So it was helpful to have other people there for you?
• The problem is that at home there’s nobody there to push you. My son, he’s not into pushing me to do anything. motivating... He wants to do the things that are fun to him, but that are very hard for me to do. My fun and his are a different thing, so...
• So it’s hard to be motivated on your own.
• Well, it’s worse. I had a very hard time this winter. I’ve noticed that I really can’t deal with the household like I used to. (hard to hear). In the wintertime I have to deal with that. And I knew I had to do something, or I was going to end up spend the winter in the couch. I rearranged furniture and put my treadmill in the living room and my television. I figured I couldn’t come up with no excuse. There’s no excuse why you can’t get on there. If you watch a half hour soap opera or whatever, treadmill the whole time you’re doing it. I feel like I really push myself, plus I broke up with an old boyfriend, I want to make him turn around and look twice.
• When you are able to get your routine going, how does it feel?
• It feels good, it feels very good. I’ve always felt like I’ve been very independent and able to do things on my own. Plus when your family dies and there’s nobody left... I guess I’m afraid to do anything right now. I’m afraid that something’s gonna happen and there’s nobody to bail me out. It’s all me now.-(hard to hear)
• Me and my sister are very much ? after my father died. She’s gotten herself into a little trouble.
• Have you experienced changes in how you see yourself since your injury?
• I don’t feel like I’m much of a person now. I don’t feel self-supporting, I don’t feel like I can do much of anything. I have a sense of I have to do it more than I want to do it. Where I used to be able to take care of my family and do things I’m supposed to do. And I enjoy doing things! It’s just no fun anymore when you have to think about doing something before you actually do it. It takes the spontaneity out of it. It does because... and you get so programmed to do things a certain way, you know, from the time we’re born. Even the way we see pain goes all the way back to there. It’s hard to change when you got it constantly every day.
• When we talked before, you indicated that having constant pain seemed to lessen your tolerance for even small amounts of additional pain.
• I feel more conscious of my pain now and I find myself more or less wanting to complain about it more than before. I could hurt myself in my ankle and still go in to work a 16 hour shift. It was like I could handle anything. But it’s harder now, because you know the pain is there and it’s there everyday. And it doesn’t go away. -(hard to hear)
• ... you hurt... for so long you had to deal with pain. If it wasn’t something that could be seen, you didn’t have a problem. Nobody in my family could believe my pain, back pain because I was never in a cast, it was never broken. There was no proof of anything going on because nothing’s ever been broken where my sister broke her leg and she was in (?) for her pain.
• So would you say if someone has an obvious sign of injury, a cast for example, their pain is easier for others to understand?
• It’s more acceptable... so you have pain that nobody can explain and you go to the doctor and they say well you got this wrong with you, but we don’t know why you’re having all that pain. You try to keep it to yourself. You learn to hide away how you feel about things and you don’t complain about it. You just shell off and keep it inside. That’s not good.
• I’ve talked to some people who do not do things they enjoy out of fear of losing benefits. Do you ever have those concerns?
• Yeah, I’m caught between a rock and a hard place cause I’m like I have an insurance policy which has a cash value and I wouldn’t touch it because this is my protection for my children and they’re not gonna be caught up with what I was caught up with my father. My sister and I were left with bills because (hard to hear). I didn’t do anything with my life insurance, but I’m in a category where if I
make like $13 more than I'm getting from that I lose my medical card automatically. And $13 in no
way covers what my medication costs. So it's kind of like I feel morally I can't go out and do
anything that's wrong because I don't want to set double standards for my son. He's very bright, he's
very intelligent. I think kids need to know what their parents are going through. I feel like I'm left
in the dark not knowing my medical history. I don't know nothing about it. So, you know, I don't
like doing that. I tell him about his medical history, possibilities that things could happen, you know,
about being overweight. My older son is chunky and when he hit puberty (hard to hear). In the
meantime I have to deal with that and with self-esteem. It's hard because I have a low self-esteem.

- Has your self esteem changed since you were injured?
  - Yeah, because I don't feel comfortable around people. I suffer greatly from panic attacks. It's hard to
group people. I don't know what's gonna happen or how I'm gonna feel even though I'm fine
now. -(hard to hear)
- They put me on permanent disability.
- How does that feel for you?
- I'm no longer working. I'm no longer supporting my family. I still have a household, but all else has
been taken away from me. I no longer go out and bring a paycheck in. I'm having a hard time
teaching my son about work, about responsibility, things that you do that make you feel good. He's
not in that context because I don't work and I've never worked around him. A lot of time he doesn't
see the things that I do because he's in bed or he's out playing. So he doesn't understand the things
that I do.
- What kind of things do you think society expects (hard to hear)...
- I think society looks down on people that don't work, you know- work hard and take care of their
own. You know, I feel sorry for the ones that work and are paying their taxes and supporting me, you
know. I didn't like it when I was paying the taxes and there were other people out there. I feel that
something has been taken away from me and that's my right to earn my way. I guess sometimes I
just feel like... it's hard because I don't have any work as far as working.
- How do you adapt to that situation?
- I learned to try to appreciate the little things that I had done and not to concentrate on things that I
don't get done. The housework never gets done, especially if you live in the house. If you stay in the
house, like I do, the house will never get done because I will always find something else. So I learned
to do a couple chores a say. I'm glad...that's one thing that I've done and less than I have to do. So
every little thing I get done I look at like an accomplishment and not -oh. I didn't get this and this
done. I try not to overburden myself with oh, there's so much more. And that's hard sometimes.
- It's to focus more on me and my needs and not the needs of the house, It will survive, you know, it's
not gonna go nowhere. I need to concentrate on me, on my relaxation, tanning -that's top priority on
my list now. I do that once a day, I don't get to do that on Sundays, but I do it everyday. I have 20
minutes where I do what I want. It makes my feel good.
- You said last time that you didn't get your routine at home started right away. How did you get
yourself to make the transition?
- At first, it was hard. You know, you've got to get up and go out of your house. It's a little bit more
difficult when you're getting up but you know you're going nowhere. But you've got to do these
things for yourself. I've tried to set up a routine of taking my son to school, I go to tanning. I come
home from tanning and I'm still feeling nice and warm I get into my workout. And I have myself
scheduled pretty good. You need that. You need to have a routine... summertime's hard because he's
not on a routine, therefore I'm not on a routine either. It's hard to make a schedule for yourself. I'm
just simplifying things for myself.
- Is there anything that would have made the transition easier?
- Probably a little more contact and support, maybe from people in the group, you know. Maybe call,
but I know it's hard because a lot of people live far away. But maybe from the program itself to see
how things are going.
- So it might be helpful to have a continuous support group?
It’s so hard to get out of the house. This is the first thing that I have accomplished at all this year. Just get out of the house, I’m not helping myself, but maybe if one of the things that I’ve been through maybe somebody can (?). Everybody has pain, even doctors. You have doctors that don’t understand why you’re feeling what you’re feeling. You’re not supposed to be feeling that. They’ll get aggravated because they don’t understand it and it makes it hard for the person cause it feels like nobody understands what you’re going through and there are people that do.

Why do you think it’s hard for doctors to understand?

Because .... it’s like going through a very terrible catastrophe. Nobody understands what you’re going through unless they’ve gone through the exact same catastrophe. People react in different ways, and it’s hard to tell a doctor exactly what it is you’re feeling. I guess with the generation I’ve grown up in, my first response is the doctor should help me, why am I having to deal with this pain?

I want the doctors to stop it from hurting! Give me needles, give me whatever it is to make it stop. They don’t understand the intensity of it and I know it’s something I have to work through. The medicine is not gonna solve the problem. It might temporarily .... maybe to start me back on something that’s functional. But it’s not gonna be there the rest of my life. I don’t think so.

Do you think some people tolerate pain better than others?

It’s the same thing as with giving birth. Some women have no problem at all. My sister had three babies. No problems, no stretchmarks, no nothing. No pain. Where I’ve had two, I’ve had pain, birthmarks, I had misery. I’m not saying she didn’t have no pain, but she tolerated it. But when she broke her leg, it’s a different story. She had aches and pains, some of what I’ve dealt with, but it’s because it’s affecting her work. But now she’s starting to understand

Do you feel like your pain has changed you as a person?

It’s tough because when you first start dealing with the chronic pain, you pull away from relationships, and you pull away from everything that’s close to you. You just stay in your own little world and you do lose who you are because you’re not the same anymore. All of the xxxx(her name) I used to be is no longer that xxxx. This xxxx is very cautious, very hurt, overly sensitive to things now - more so than before. She don’t roll well with the punches like before. Not so outgoing.... so you do, you change who you are. All of sudden you become xxxx with the pain instead of just xxxx. It’s like a whole new person has come into your life and you have to do things a different way, cause if you don’t she’ll let you know she’s there.- (hard to hear)

... there’s nothing left of that old xxxx because everybody else that knew me was gone too now. So there’s very little reflection of who I was. Now I have to go back and I don’t want to be this xxx with pain. I’m tired of my new friend.

It’s time to redefine yourself again.

Right, maybe it’s because I passed the 40 mark. It’s like all of a sudden who I am and what I am are changing again. I don’t want to be the person that just sits there, I want to go and do things again. I don’t know what I will accomplish if it’s nothing more than maybe going back and getting my GED. To do something for me to show that I’m still capable of doing things.

-(hard to hear)
-(hard to hear) I need to get up and do something.
-(hard to hear)

Today I’m in more pain because it rained. I get achy, sort of a hurt kind of a day.-(hard to hear)

After I got out of the pain program, I had to have a doctor. And I found a doctor right in the corner from where I live. (hard to hear). That worked out pretty good. With pain pills, I take so many of something for it to just effect me.(hard to hear)

I think that what a person with chronic pain needs the most is that you can’t do it by yourself. (hard to hear). It’s O.K. to be angry, it’s not a bad thing. (hard to hear)
Appendix S

Kelly's First Interview
Kelly’s First Interview

• Why don’t we start out by you telling me a little bit about where your pain is, when it started, what was the situation when that happened?

• Well, back in 87, I slipped and fell at xxxx (grocery store), where I worked, and messed up my back. Well then, from my back I protected my back and I walked crooked on my knees so my knees are out now and I also messed up my right hip when I fell and it was an industrial case from 87 until last year, until 95. And then I had to retire because of the pain, because I was missing more, more, and more work and so I had to end up retiring. And so I went ahead and settled with my claim work, industrial, so now I’m just on social security and my pension.

• What was your occupation?

• I worked at xxxx bakery for 32 years before I retired and it was a factory assembly line. So I had a lot of reaching, stretching, bending, lifting, you name it.

• You slipped and fell in the same area that you were working?

• Yes. There was grease coming off of the conveyor belt upstairs coming down with the crackers on it and the oil came off with the rollers. It usually had a drip pan there, but the drip pan, somebody hadn’t cleaned it and it overflowed. One minute, I was working there and the grease wasn’t there and the next night it started dripping and I didn’t see it. I went down and busted my rear end pretty good (chuckled). They said that I came down and I smacked everything. I got everything all crunched up. And then in the process of going through all that, they said that surgery would not help unless they put a rod in my back and then I would have more problems. And so I told them no, and in the meantime, while they were checking all that out, a doctor come up with the idea that I had fibromyalgia. So right now, they’re trying to base everything on fibromyalgia. So a lot of doctors don’t believe in it at all and the couple that I ended up getting a hold of believe in it too much, I think. Because no matter what I do to inform, and I’ll say, “Oh, my jaw is killing me” or “my knee is killing me” or “my side is killing me” — “Well, you know, you got fibromyalgia. Learn to live with it”. So I’ve been taking support groups and it. And running a lot of hours. Mt. Carmel East, third Tuesday out of the month, they have a support group.

• And how is that going for you?

• Ahh.. going very well because I finally talked to my mother into going with me and I think she understands me a lot better because there’s days, as a matter of fact there’s weeks, that I just stay in bed. And then, if I got some... I know it sounds crazy.... but if I got something to do, I usually get up and do it. I mean, positively. I don’t mean like cleaning my house. certain chores that can be put off. But if I got an appointment, I very seldom ever miss an appointment. I’ll make myself get up and do it, just like this morning. My mother said “I gotta get to the doctor this morning. I’m gonna have to call a cab cause you don’t drive”. And I said “ Well, if you make your appointment early, I’ll come get you”. So I had her at the doctor at 8:30 this morning and then we went out to lunch and I took her home and then I’m here early because I’m here (chuckles). I didn’t have nowhere else to go for a while, so I’m here (chuckles). But umm.. I can do it, you know, but if I don’t have anything to do, I’ll lay in bed for days. That’s part of what I’m going to Interact for (chuckles).

• What’s it like for you to no longer be working?

• It’s hard, it is really hard. Umm... haven’t worked for two years. I was out the first eight months on sick leave, and then the doctor told me “we’re not letting you go back, there’s no way”. I fought him about three or four years ago in 92 I fought him and they didn’t want me to go back. Well, from 92 to 94, I only worked for five, six weeks. I couldn’t do it. I’d go in and I’d work a week or so and I’d be out six months. I’d go back in I’d work two, three, four weeks, I’d be out six months again. So be just told me...you just can’t do it.

• What was your initial reaction?

• Umm... the first time, I was not ready for it at all. I mean I would have probably had a nervous breakdown. Umm... this last time, I knew I couldn’t take it anymore. I mean I knew I was hurting more, and more, and more and I’d get off from work.... and I go to work six o’clock in the morning, get up at three in the afternoon. Well, that made me.... I had to start getting up like four o’clock to
put up with the pain because in the mornings I can't roll out of bed. I have to get up about two hours earlier just to get up and move and I gotta sit there and move my knees, and move my back, and do stretching a little bit before I even get out of bed. So I would turn around and I found myself having to start to get up, you know, three thirty in the morning to get ready to go to work by six. And then we had to walk a block and a half down the street to the parking lot. And I found out I couldn't do that anymore. And when I came here, I didn't have this - I was just walking. But this (pointing to cane) looks worse, but I think in lots of ways I'm a lot better now than when I was when I came here.

- In which ways?
- Well, it's a lot better to deal with it. I wasn't dealing with it too good then. And too many people was hurting my feelings. Because they couldn't believe that I could go in there and work eight hours... like I said, when I worked - I worked ... and when I didn't - I didn't (chuckled). And I mean... I worked just as much and I was off just as much, you know. I don't know how to explain it. But when I go in, I could work say, go to work six o'clock. O.K. If they'd come around at about two o'clock, they had to give you about an hour notice. They'd come around two o'clock in the afternoon, they say "anybody want to work three hours over?", I was a workaholic. You know, I'd do it. As long as I kept moving, I was O.K. The minute I went and clocked out, I fell apart. I could work eight hours, I could work ten hours, I could work twelve hours, I fell apart no matter what hours I worked. It was just that to me work was everything. And just... I found that the people, my coworkers, couldn't understand, they said "there's nothing wrong with her if she could work all these hours". But they didn't realize I would go home. I don't know how many times I cried up the freeway, I hurt so bad. To me, it was worth it because I loved my job. And I felt needed and felt useful. And, like I said, I thought I was kind of over it until the other day, I never had a reason to go south on 71. I go to my mother's, I got on 315 and down, 'cause I live north, I go 315 and down to her house on the west side. Why? I don't know. But I just never went down 71. The other day, they said something about 315 being closed because of a big truck. So I thought, didn't even think anything about it. I just turned around, well - I'll just have to go down 71. I went by where I used to get off and I couldn't breathe. It just felt like somebody grabbed me and I said I'm not over it yet (chuckles).

- What were some of your thoughts at the time?
- Ahh... hurt and wishing I was back in there. Even with the pain and things, there's lots of times I wish I were still working. And I used to fight with the girls because they'd make smart remarks and they'd get back to me, "there's nothing wrong with her if she can do all this work", and you know, and then they'd turn around... and if I took off, the doctors put me off, well then they'd talk about me being off... getting the money being off, not working. And then I tried to go back to work and then they'd smart off because I wasn't working. I guess just, it always was a fight when I was coming here. It was a fight, and I used to talk to xxxxxx (psychology intern) about it. But it... it just hurt going by and thinking that, you know, I used to go there and I always thought I'd work 'till I was 70. You know, I never thought of having to retire and it really, really shocked me.... you know, because for what I think and because I've got to stop and keep telling myself I'm not on welfare, you know. Sometimes I get to feeling where like I'm on welfare or something, getting something that I don't deserve.

- You don't feel useful?
- Well, that too (chuckles). And because it seems like when I got industrial, industrial rules your life. They got control of you. I mean, they tell you where you can go and what you can do, and when you can do it. You know, because they come right out and tell you, "if we catch you out cutting your grass or out painting, you know, or something, you know you're off industrial". I never even thought about it, but now social security is doing it to me. I might think it's more than they really are, but...

- What's it like for them to have that control over you?
- It's not fun (chuckles). It's not fun because... I tell my psychologist that the system stinks (chuckles) because really it's just like I would like to take a while and even if I had to get down on the ground and work in my flower bed a little bit, I think I should have the right to and then put up with the pain, and say ... go out there maybe ten minutes a day, maybe half hour a day, you can't do it for eight
hours... and I know I can’t do it for eight hours. But they tell you, my attorney told me “don’t get caught working in the yard, don’t get caught working on your car, washing your car, anything”. And I said “that’s not...”. Because they said if they come by and take pictures of you, they’ll say if you can do that, then you can hold down some kind of a job and they’ll take you off. And I said “that’s running your life”. Because what am I supposed to do? I mean, what am I supposed to do? There’s some times I get so down in the dumps, I sit there and cry ‘cause I don’t know what I’m supposed to do. I mean, I gotta have a life... and yet, you got a feeling that somebody’s behind you. You know, across from you... you see a stranger or you see a car parked there, you think “oh shoot”, you know. This shouldn’t be... like I said, the system stinks because anybody knows... I mean if I go out and work twenty minutes or half hour in the flower bed, and come in and have to sit in the tub or lay on the couch for two days later, that’s helping me really. Mentally, that’s helping me. But they don’t take it that way. They say, “well, if you’re doing that, you could go work as a florist or something”. And I said it’s not.... and my mother says I worry too much, but my psychologist said that she could understand, you know, what I’m trying to say because... the idea that you feel like... I didn’t feel this way with bosses because I was always the type of person... I gave them my eight hours, I earned my money.

- You always did what you were supposed to...
- Yeah, I knew what I was supposed to do and I just jumped right in there and did it. I mean, I could be hurting like heck, but I’d just jump in there and do it. And I would find different ways of doing it to be easier on me and that’s what a lot of the people got upset because I was responsible for changing three or four things at work (chuckles). They didn’t like it because I added change and like I said as long as I kept busy, you don’t think about it as much. Like I said if I got appointments and things, I get up... sure, I hurt. Like right now... right under my knees feels like somebody’s taking an axel and just keeps hitting me right there underneath the knee and but I’m up here.

- What’s your daily routine like now... or your usual day?
- I don’t really have a usual day. It seems like I got a problem about going to bed at night.
- You have a problem going to sleep?
- Ahh... well, it’s not really the idea of going to sleep. I know after I do go to sleep, so I think I make myself stay awake because I don’t want to go to sleep because I know when I go to sleep and go through the routine of sleeping, I feel worse getting up. I’ll go to bed feeling better than when I get up in the morning.

- So your pain is worse in the morning?
- Yeah. And late at night if I’m up quite a bit. Now, tonight, well, I haven’t been on my feet too much today, I’ve been sitting most of the time, but tonight it will be a little bit probably worse than what it was yesterday ‘cause yesterday I didn’t go out of the house. I got up and I did some paperwork and then ate and I’m having trouble going up and down the stairs. So I have to watch the steps, so I usually stay upstairs for three or four hours in the morning and...

- You have a two story house?
- Yeah, right now. I’m in the process of trying to... I either got to get me an apartment or another house, and right now I’m living in a townhouse more like a condo, but it’s a townhouse. But so I’ve got to figure out whether I’m gonna buy one story or whether I’m going to rent one or whatever I’m gonna do, but it’s not gonna be too much longer. Because I can’t make it up and down the stairs.

- You stay upstairs for four hours?
- Yeah, and when my knees are real bad, there’s been times I stayed up there for a whole day or two days.

- What are some of the things you do while you’re up there?
- Well, I have my two babies - my two cats and I’ll sit and play with them and, I don’t know if you’ve had cats or not, but they know you and they know when I don’t feel good and they give me extra attention and I got this one... a little female... all I have to say is “mommy gotta go to potty”, she knows exactly what I’m saying. She gets up, and I have to walk around my bed to get to the bathroom, so she’ll go ahead of me, walk into the bathroom and sit there like “are you coming now?” , then she gotta walk me back to bed. And so, like I said, they’re a lot of comfort...
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caught working in the yard, don’t get caught working on your car, washing your car, anything”. And
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understand, you know, what I’m trying to say because... the idea that you feel like... I didn’t feel this
way with bosses because I was always the type of person... I gave them my eight hours. I earned my
check as far as I’m concerned and I never had any complaints out of the bosses. I earned my money.

- You always did what you were supposed to...
- Yeah, I knew what I was supposed to do and I just jumped right in there and did it. I mean, I could
be hurting like heck, but I’d just jump in there and do it. And I would find different ways of doing it
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then she gotta walk me back to bed. And so, like I said, they’re a lot of comfort... they’re really

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comforting. And I got cats because I didn’t have to take them out (chuckles). You know, they got their little box and they’re well trained and everything, so they’re easy to take care of. But I play with them... well, I’ve had them for ten years- about eight years. I had the one and then seven years for the other one. But they enjoy my company, so I feel like I’m needed. They sit and wait on me if I go away. They’re sitting on the window right now waiting on me. But...

• How has the pain affected your relationships?
• I don’t have any. I don’t have any (chuckles).
• You were saying with your mom, that she understands what you’re going through?
• I find out, and I’m trying to work on that with Interact, I find out that I’m too snappy with people. I feel like they don’t understand me and I go to talks at the fibromialgia groups the other night, she explained it the best that, I mean, I saw myself standing up there in her, because she says, you know, family and friends do not understand; and I’m having trouble right now with a 75 year old friend that I’ve been friends with I’d say for 35 years. And she retired quite a few years, well she retired about fifteen years ago and, well she retired when she was 62 - she’ll be 76 next week. But she thinks that I can still do the things I did like take her to the grocery store, run her to the bank, run her to the post office, I can’t do it anymore. I mean it takes everything I got to do for myself. And yet I’ve tried to say it in a nice way to her, but then when we get on the phone, I get a guilt complex. And then I get snappy with her. Because last few times I took her to the grocery store, she bought sixty seventy dollars worth of groceries. I had to carry them in. I mean I must have made ten trips out to my van. And she got a pretty good size front yard that you have to walk them up through, she don’t have a drive way, you know, that you just go in. You had to walk quite a distance up... I bet it might be what you consider like three car length.... could have parked in her.... well, she doesn’t have a driveway.... I’m trying to say it’s about that length.... I mean, it’s quite a ways. And it goes up a little hill too. So, I just come right out and told her one day, I can’t.... she turns around and she goes in and walks away.... for 76 years old, she’s in a lot better condition than I am. And yet she gives me the guilt trip because I’ll say “Well, I went over to the store and picked up this or that... ”... ‘cause she’ll ask me what are you doing all day? And I’ll say “well, I just ran out to go get a couple of things from the store”... She’ll say, “well, that’s nice, you can drive”. And I... oh no, here we go. I can’t do it. And then ‘she’ll call and she’ll say “nobody ever comes and sees me anymore and I can’t get my checks to the bank”... I said, xxx, I put my checks in the deposit. I mean, and I’ve even tried to tease her, I said “xxx, I hurt like hell, but I’m not crazy. I try to figure out things that will work the best for me so I have my checks... I drive, but I had my checks put right into the deposit”. She don’t drive, she wants her checks in her mailbox. Then she don’t have a way to go to the post-office or to the bank. Then that gives me a guilt complex.
• Do you feel guilty?
• Yeah, I really do.
• What’s some of that guilt about?
• I wish I could do it for her because it’s not that I don’t want to do it. And then I think, then it backfires on me and then I think, well does she think there’s anything wrong with me or does she think, you know, there’s nothing wrong with me? And then I just fight with myself. I know I’m my own worst enemy. Because I really had down drawn out fights with myself.
• How would you describe your social life now?
• I really don’t have one.
• Is that the same or that different from before your pain began?
• Really, really under different circumstances - it’s the same. But my social life was my job. I worked fifty sixty hours a week. That was my social life. Because I never was a person to go visiting. So I mean, that part hasn’t changed I still don’t like to go visit. I don’t like to go and sit at somebody else’s house. Really, like right now, I’m really uncomfortable sitting, but I know I’m supposed to be here sitting, so I will put up with it. But to go visit, to go visit my mom, I’m walking all the time, I’m standing. And I don’t... like I said, if I go somewhere, usually to a doctor’s office, a doctor’s appointment, I take my mom to the doctor’s, take her to the... but she will call and ask me - are you free this certain day? And I ... she’ll make an appointment with me. That’s great....this other lady,
she don't every ask me to do anything, she just tells me what nobody's doing for her. So if she would say, "well, xxxx, could you come over... what are you doing tomorrow... let's go have lunch...let's go the bank.". I'd say O.K. if I didn't have anything to do. I'd say O.K... we'll make an appointment, I'll see you tomorrow. But she don't.

- She complains...
- She complains and it makes me feel like that I'm wrong...(turned tape)
- How has your pain affected your beliefs or your religion?
- Well, I'm not that person really that went to church because I never had time, and for some reason I kept kicking myself to go now when I've got nothing to do. It's funny. I do less now than what I did when I was working and I said I don't have time. To me, that's not thinking right (chuckles) because I got time, but I just don't make the time. But...
- What about your beliefs?
- I don't think they've changed any. Every once in a while I'll say why and then I stop and think that it's all happening for a reason. So I mean, I'm not blaming anything... this happened for a reason... so there's a reason it happened. I can't figure it out yet, I wish there wasn't a reason, but it's done for a reason.
- How do you see your role in terms of what's happened to you in your life?
- I don't really know, I haven't really thought about that. He's done all of this for some reason and I've had twenty-three surgeries and quite a few different things so, like I said, he's watching out for me. He just hasn't... I think he's letting me make up my own mind what I'm gonna do. And I just haven't been able to do it yet. I need help (laughs)! But like I said, he's done it for a reason, I just haven't been able to figure out the reason yet.
- How has your pain affected your dreams and your goals? or has it?
- Oh yeah, that shot quite a few things to heck. But I always thought that... well one time I'd say "well, I'm gonna work till I'm 79, you know". And then I always planned on vacation. I was talking to my mother the other day about this, I'm really on vacation. I could say I'm on vacation indefinite. But to hear somebody else from work saying "we're going on vacation next week", that hurts. It ..., you think "I don't get a vacation." Then you gotta stop and tell yourself, you're on vacation! You could go on vacation! I've got the money, I'm not poor! But I don't know whether I'd enjoy it anymore or not. I went on vacation two or three times, and it's got to be more of a hassle. I'd almost rather be home. Where I can lay across the bed, do what I want to do. Well, two weekends ago, an old friend of mine, we weren't really ever really serious-serious, but twenty some years ago I met this guy, we were friends. Well, he just lost his wife in December and decided to see if I was still around. So he called me about two months ago and said he'd love to get together and see each other and talk. And we kept putting it off back and forth cause I didn't know how he would take all this and everything. So finally I made myself. He's got a campsite up to Hiddenlakes. So I thought, well you know, I always thought I'd like camping. So I told him, I said "I'll drive up. You're gonna be there tomorrow?". He said "you want me to come by and pick you up, go up there?". He said, "if you want to stay the weekend, you can. I've got two bedrooms", he said "you can have one", he said, "we'll just sit around. chat about old times and everything". "I will promise", I said, "no, I can't go today. Is there a way that you can leave me a pass or something to get in tomorrow?". And then he said "will you come up?". And then I said, "I might just do that". I didn't want to make a..., I said "leave me a pass and I might just do that". Then after I got off the phone, I kept telling myself you've got to do this, you've got to go get him see it, and if he don't ever want to call you back again then that's his problem". So I had to really lay the law down to myself and I went. But you know four hours of it, I was going crazy. I had to come home. The only thing I could think of was ...we did everything. We drove up and down with the golf cart...And I enjoyed my four hours... I was stir crazy, I wanted to go (laughs). And so I kept thinking "oh, I want to go lay down on the couch... I want to go...".
- So you were thinking of things back home and the comfort?
- Yeah, I'm getting too comfortable in the house. I want to be able to lay down when I want to lay down, lay down watch t.v... and up there they didn't have good reception on t.v.. at all, so it aggravated you even to have it on and then it just wasn't what I thought. And then I always

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thought... well, when I did retire I was gonna take care of kids. Well, I don’t think I can do that. And then now I’m not allowed to have no gainful employment. So you see, it rules your life. So it... so right now I’m battling... I don’t know what I’m supposed to do. Now, the one guy I talked to for social security, he said “well, you can volunteer all the hours you want to volunteer, but you can’t work”. Now that does make sense? (it sounds contradictory) That’s what I said, it doesn’t make sense! Then it got me all upset, I thought... I wouldn’t mind the idea of volunteering, it’s just the idea - if you’re going to volunteer, why can’t you be happy and have two or three kids in and try it, you know, even if you just tell them to bring the food or something, you know, because that’s what I’d be willing to do just to have company and, you know. But they said no gainful employment. And then I said something about well a yard sale... I’d get in to yard sale. xxxxx and I used to talk about that. When I’d retired I could get into yard sale. I was told “no, that’s gainful employment”. So that’s shot. So right now I’m trying to figure out what can I do? Because right now I feel like I’m a prisoner. And, you know,...

- Do you feel like a victim?
- I don’t know whether I’d call it a victim or not. I call it a prisoner. And I go out every once in a while. Last year, my psychologist told me “if you have any problem whatsoever, I want you to get out there and work in your flower bed a little bit. If you have any problem whatsoever, I’ll give you a letter stating that that was mental therapy”. So I can’t bend over that good, so I actually went out there and about fell on the ground and then scooted on my rear end around planting some flowers. I was so proud of myself, I couldn’t see straight. It really looked good and I did it. And I stayed in bed three days later, but to me that was worth it. But I took a chance and evidently I didn’t get caught because that was before I got my social security. But now, they say if you do it, they take your social security away from you. And it’s not fair because, you know... Right now, I wrote social security a letter because they wrote me a letter saying wasn’t I sure I could do something and I said the trouble is that if I do something. I don’t know how to word it... if I do something to keep myself going, then I can’t do the next day. Like coming here, it was wonderful. I mean I got myself built up, it really helped mentally and physically coming here to the program when I came. It really helped. But then, when they took me off of here, put me back to work, I could see going right back downhill. It... a lot of it in my head was lasting. But the program itself didn’t last in the job because they told me you got to... at first they told me I wasn’t being.... they had a lady here xxxxx, she was supposed to be.... she stayed with me, I don’t know what they called her, but she stayed with me in the cooking classes and in the walking and her and I fought constantly because she told me that I fixed my can of chicken noodle soup in a pan and I’ll eat it out of the pan. I only got the one pan to wash and a spoon. I told her I have reasons for doing that because I can carry the pan with the handle. So things worked out, and she told me that I didn’t like myself very much or I would sit down at a table and put it in a bowl or a dish, sit down there, and even light a candle. Now me, that’s not me (chuckles). To me, that was crazy. And I mean I told her that, but she told me I wasn’t being.... wasn’t trying. And her and I kept getting into it because we made pizza one day and she was trying to tell me chop up my stuff and put it in little bowls and I told her I wasn’t Julie Childers. Why do I have to use all those dishes? You’re trying to teach me how to do less and still do the same thing, and I cut the vegetables and everything and then I went to take the sauce and put the sauce on the pizza and take the same knife - and she said no, that’s what a wooden spoon is for. I said I’m fifty years old, I don’t have a wooden spoon, I never had a wooden spoon, and I’m not going to buy a wooden spoon just to put spaghetti or pizza sauce on a pizza. And I told her - then you got a whole sinkfull of dishes, but she couldn’t see it my way and she told me that I was just fighting her all the way. And but it....

- How has the pain affected your.... or has it changed your sexual activity or your sexual drive?
- I don’t see nobody and I haven’t had any for years. So that really hasn’t changed. That really hasn’t changed. I was only married twenty-one days out of my life. And it wasn’t for me then. So I’ve been kind of a loner, you know, all this time. So that part hasn’t changed a bit. I just never got into all that. Like I said I put work before everything.
- Have you seen any changes in your sleep?

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I don’t sleep very much anymore. I sleep for two three hours and then I’m up four or five. I lay down two three hours... They try and give me medicine... two or three different... they tried all different kinds and some of them knock you out. I don’t want to be knocked out, I still want to do things. I don’t want to... So I know really for the best, I should do a regular routine, but now I don’t have any regular routine.

Have you noticed any changes in your appetite?
- I eat more. I’ve gained about forty pounds since I came here a couple of years ago.

Have you noticed any changes in your level of energy?
- It’s less.

What about in your self-esteem? Have you noticed any changes?
- Um... I have good days and I feel, you know, fine and then I have some days that I feel like I ain’t worth nothing. That’s mainly triggered off of somebody making a remark or I get up and I can’t do something that I used to do, then I get upset and I’ll have a bad day and start crying or start....

Have you ever thought of suicide or of hurting yourself?
- No, not really. Like I said I’m supposed to be here, I went through twenty three surgeries. Each one I woke up and I said - well. I’m here again. So...(turned other paper)

You were in the program in which year?
- 92 or 93

In terms of the other people in the program with chronic pain and maybe other people outside the program with chronic pain... how do you... do you see some similarities or differences in their feelings and in yours... any commonalities...

Well, really when I came, there was only one other girl.... well there was two when I started. One came one or two days and she wasn’t even going to try. So it made me feel a lot better about myself because I was bound determined, I was going to give it a try. And but she wasn’t going to give it a try, and she quit. She only came two or three days and she quit and they tried to keep calling her back and she wouldn’t even try to get off of Percocet. She wouldn’t even try to get off of it. She actually told us she wouldn’t get off of it. She said “I’m not getting off of it”. And they tried to tell her she was addicted and she said “no, I’m not. I take a couple of them and I work through my house. I get all sorts of things done”. And I said “I don’t want to be...”. You know, I gave it a good try. The other girl, she was only with me for about a week and then I was all by myself. So there wasn’t really anybody else to compare with.

Have you met other people with chronic pain outside of the program?
- Ummm... well, the fibromyalgia group I have.

How does your experience compare with theirs?
- A lot of them is real similar , you can understand yourself better because you think “gee, you know....”. And that’s why I was saying I was glad my mother decided to go with me. It’s free seminars, so I asked one day if she’d like to go with me, and I asked that other friend too and she wouldn’t go. But you can bring in any amount of people you want to with you and I wish that she would go with me sometime so she could hear it because she don’t believe that there is such a thing as fibromyalgia. Which I didn’t either, but I’m trying to read up on it and I have a whole big pile of paperwork and trying to read up on it and I associate myself with it and then we had a real good speaker Tuesday night. Like I said, I agreed with her. She said that she did the same thing that I do. She said she’s only working part-time now about two, three, four hours a day. She’s got it so bad. And yet for her to stand there, you didn’t think there was anything wrong with her. She was just cheerful, and yet she did the same thing I did and joke about it. And I said, you know, you can joke to a certain extent and then it backfires on you. And that’s what it did to me. I would joke around and try to make light of it while I’m in front of somebody then I’d cry all the way home in the van. And sometimes couldn’t even get out of the van. And I know there’s been times that I got in the van, went over to the shopping center, to go in to get something, and even since I got the handicap parking, I’ve been right in front, all you gotta do is cross the drive, get into the store, and I couldn’t get out of the van. I just couldn’t... and I’d sit there and start crying. And...
• What are some coping strategies that you use right now to cope with the pain when it increases? What are some things that you do to deal with it?

• Uhh...well there’s been times that, but if it’s just pain-pain, I try to lay down, prop my feet up, and lay there, and watch TV, or get...I have those little hand video games and I’ll get those out and play, but other... and if I have to, I do get...I think he gives me thirty Darvocets a month...and there’s days I don’t take any...and then, like I said. I’ve had ulcers so I have to watch it, so I turn around and there’s days that I don’t take any and then there’s days that maybe I take a second or third one, if I’m not trying to do very much or get in something unusual, you know, that I haven’t planned. Like today, I’m not gonna try to, but my knees are on fire, they’re just burning like heck. But I didn’t even bring any, so I wouldn’t take them (laughs). But then there’s times if I get kind of upset with myself if I get the pain and messed up in my head (laughs), or whatever you want to call it, I’ll take a ride and that seems to, now it hurts if I try to go home without getting out, but to me it’s worth it. And that goes back to another thing, when I was trying to fight to get my social security. I went to an attorney, I’m not gonna mention his name, cause I never will say his name to anybody (laughs), but I went out there and I drove up in my van, and I had to change from a car to a van because, you know, it sits up straighter for my back. So I provided some help for myself by knowing the van would be better to drive for me. And then I paid extra for better seats. So...but then, like I said, to me it’s worth the drive. But I drove into this lawyer’s office, and I got out, and this was before this...I got out and I used to...this foot totally went in when I walked...walking with a cane before I got this helped straighten it out and then also this helped straighten it out, but it seemed like, I don’t know why, but that leg quit turning in.

• We have a couple more minutes on the tape. I just want to make sure I ask you a couple of things...how would you describe the quality of your life now and maybe if you want to compare it to before the pain?

• Gosh...I don’t really know exactly what you mean by that. I don’t really know what you mean by it.

• Let me see...um...I guess the richness in terms of enjoyability of your life.

• Well, it’s worse. The part of that is my own fault because I won’t get out or get into something. And that’s what my psychologist tells me “you won’t try, you won’t give it a chance”. Because I say I don’t know whether I want to go on vacation, I don’t know whether I’ll be able to make it, or whether I’ll hurt too bad when I’d get there. So I just don’t do it, and she told me you’ve got to try. Then she said...then I...she told me it was and excuse...I told her I don’t know whether my van would make it cause I had an invitation to go to Canada to the casino up there and I kept telling her I didn’t know if I wanted to, I didn’t want to be a burden on anybody, I didn’t want to go there and not feel like going, and the lady I was going there would think she had to stay there with me and I just kept fighting myself and I said I don’t know whether my van will make it that far because I had almost 100,000 miles on it and she said “what will be the worst thing?”...and she said if your van didn’t...and I said “well, I would pull over, I have triple A, so I’d call triple A, if I had to stay over night, I’d stay in a motel...she said “then what’s your problem?”. She said “you got it worked out, then why don’t you try? Your van might make it.” But she said “you don’t want to take a chance”. And I said...So that’s what made me decide to go to Hiddenlake. I find myself scared, more scared to do things. And, like I said, I get hurt because other people go on vacation. I could go on vacation everyday of the week if I wanted to cause with my pension and social security I’m almost making what I made at work.

• What are you scared about?

• Umm...I don’t know, I just keep thinking, you know, you have to go with somebody and then, like I said, what if I start hurting real bad and then make their time miserable so they’d better go with somebody else and then they don’t have to put up with me. So, like I said, now something else came up so I can’t go anyways...so (laughs).

• How would your life have differed if you didn’t have chronic pain?

• I’d still be working. That’s number one. I’d still be working. But it’s been going on three four years now. And probably that would be hard to do because that’s all I did before. I’d be working forty, fifty, sixty hours a week.
• What are some thoughts that you have about yourself? How do you think of yourself? (laugh) In the next minute or so?

• I get disgusted with myself because I can’t do the things I used to do. I can’t help take care of the people that I used to. Umm... I get disgusted with myself because I can’t do the things I used to do and right now it’s kind of bothering me. I gotta get something worked out because I have a new little grandbaby, she’s about seven weeks old and my daughter in law, I love her dearly, but I think she thinks that I can’t watch her. Her mother watches her all the time and she won’t leave her with me. So my mother tried to talk to my daughter in law, telling her that I wouldn’t hurt that baby for anything. I would take no chances with her, but she kind of just takes her to her other grandmother all the time. And she lives two blocks from me. But she’ll take her clear out east to the other grandmother’s to watch and she always tells me - well, we were out there and decided to do it. So it kind of hurts. She watches two little kids now. So I thought I’ll break the ice, she had to go to a doctor’s appointment one day, so I broke the ice... I told her, I said “how you gonna take three kids to the doctor’s office”. Because it was supposed to be for her six week check up. And I said “I’ll take the two kids”. I didn’t include the baby that time. I said “why don’t you leave the two kids you take care of, just bring them by here and they can watch t.v. with me and will have fun”. I mean I don’t think I could do it... right then it changed my idea I don’t think I could do it like every day. But I had them for four hours and I fixed lunch for them, we sat there and colored, we sat there and watched videos, took them out on the front porch and they blew bubbles. I really enjoyed myself. So I thought maybe that’ll break the ice... Then next week, the kids turned around... they say kids say the cutest things.....they say the truth too.... I turned around and when she came home and brought the baby. The one little girl is her step sister. She’s eight years old. She didn’t compare me with being the baby’s grandmother... (end of tape)
Appendix T

Kelly’s Second Interview
Kelly’s Second Interview

- Do you have any comments or any questions? Have any things come up for you since the last interview in terms of what we talked about?
- No.
- O.K. I had a couple of questions that I wanted to ask you. In terms of making the decision to do an activity, the way I was looking at that and I’d like your input if you have ideas as well. The results (making a diagram on paper), if you have positive results from doing an activity, you really enjoy it. It’s something that you really want to do. And then the payment, (a) maybe the pain that you’re going to have afterwards or for example that (b) social security will see you doing something that you’re not supposed to, so maybe lose financial. Or maybe © doing the activity differently or changing the activity, so not doing exactly what you want to do. Are there other payments for you besides these three?
- Not really.
- Does this cover it?
- Yeah.
- In terms of what that activity is going to give you of positive things, the results, even though you’re going to pay afterwards, the results are greater than what you’re gonna pay. Even though you’re gonna pay, it’ll still be worthwhile. Do you see yourself doing the activity? How does this fit for you when you decide or don’t decide to do an activity? What happens for you?
- Depends on what mood I’m in. Now the mood I’m in today, I don’t want to do nothing. I didn’t want to come here when I got up this morning. If I’m in a fairly good mood, I’ll try to do different things, even if I have to do them different. But if I get in a raunchy mood, like I’m in today, I don’t care to do anything. As a matter of fact, the last few days I laid on the couch all day. I haven’t done a thing for three days. But there’s other things that came up that stopped me from doing it. They didn’t put me in the mood, let’s put it that way.
- To not do them?
- To not do them.
- All this depends on your mood. If you’re in a rotten mood, it’s just not gonna happen.
- Right. Yeah, I’m not even gonna try.
- Would it take the results to be really, really, really good for you to do something?
- I have to have a reason to do things when I get in a bad mood. Like I said, I made this appointment, so I kept it. If I wouldn’t have this appointment, I would be laying on the couch during the day.
- So if you make the decision beforehand, before you’re in a bad mood, then when you’re in a bad mood and you have an appointment already, then you’re gonna go ahead and do that. But you’re not going to try to do something else, make another decision.
- -(laughs). Yeah, if I make appointments, I try not to break them. I mean that’s just really out of respect for the other person that I made the appointment with. But now if it’s something for fun, or something like that, if I’m in this kind of mood I’ll cancel it. Just drop it.
- Is it good for you or does it help you to stay active? In terms of having appointments and doing activities...
- It does if I make myself (laughs).
- So if you make yourself do something, you end up having a positive result.
- Right.
- Or it makes you maybe feel better.
- Yeah, it makes you feel better cause I keep active. It takes a toll. Just like two weeks ago, I had to run my mother around to different doctor appointments, she was having some heart problems and I was able to do it all and keep up with her and take her and have the different tests and all and then when it became.... like last month between her and I, I think we went to about 14 different doctor appointments. Some hers and some mine. I was on the go, just kept going. The only thing I had time for was to clean my clothes and get ready to go again. And I was able to do it. But then all at once we had four days that we didn’t have any appointments and I fell out. So now I don’t know
whether I fell out because I didn’t have nothing to do or I would have fell out anyway because I was hurting so much.

- And it was a good thing that you didn’t have appointments...
- Yeah... I don’t really know. I don’t know whether I could have done it if I would have had another appointment or wouldn’t have been able to.
- When you were in the program here, that’s a daily routine of appointments, how was that for you to be active that whole time?
- I kept up, I didn’t miss a day. I started looking forward to it, getting up and knowing that I had to come. But I did the same thing - the minute I quit going, I fell apart.
- So something that helps you is to keep active.
- Yeah.
- That’s something that’s good for you.
- That’s what I did at work, until I just couldn’t do it anymore. I worked 8, 10, 12 hours some days and as long as I was on the clock, I was doing it. But the minute I’d clock out, I would fall apart.
- To keep active for you is a positive thing, a good thing. Wearing out yourself working 8-12 hours, that’s not good.
- Well, yeah.
- That’s something that’s good for you.
- Yeah.
- You have lots of negative effects from that. You have a lot of pain.
- Well, I did when I took mom. Like I said, when I had to stop, when we didn’t have appointments, I sat back and I thought - whew, I don’t think I could have made it if we had one today. Now, I don’t know whether it was in my head or whether it really was. My knees were hurting, my back was hurting, I was just messed up. And like I said for 3 or 4 days, I haven’t done anything but lay on the couch. This is the first appointment I’ve had in about a week now.
- What would be some activities that you would be interested in cause it seems that doing activities but not totally wearing yourself down working hard, it seems that that would be something that would feel good for you. Have you thought of getting involved in different activities daily?
- I don’t know what to do (laughs). I’m at the point where I really don’t know right now.
- Are you aware of different opportunities that exist for doing various things?
- No, not really. Unless I have a doctor’s appointment... well, I call this like a doctor’s appointment... if I don’t have an appointment, I don’t go out of the house (laughs).
- If you would set up let’s say for example doing different volunteer activities in a couple different areas and think of those as doctor appointments where you have to go to these, and at the same time you’re enjoying yourself, and not stressing your body out, not physically working. For example, maybe like a daycare center. Hanging out with kids there and then going to another place that maybe has different art things.
- I enjoyed the art work and things here. They all said I did real good, but I just can’t seem to get into it, by yourself. But when you’re in a group, you do do more.
- What about a homeless animal shelter? It seems that you do have several interests.
- We had to put my niece’s dog to sleep Sunday (tearing). So that’s probably... that put a cloud over my head (laughs). They couldn’t help him anymore, so it’s best for him. But I took two strays in. I got two cats. I don’t know.... I keep thinking I got to get out and do something, but....
- It seems that the next step is to find out what’s out there.
- Yeah.
- You have the motivation and the awareness that that’s something that helps you. Now, it’s like what’s out there, how do I go about it...
- I just... people scared me so bad telling me that I’m not allowed to do this, I’m not allowed to do that, so I’m afraid to get into anything. Because I’m afraid of losing my money, cause I can’t make it without it. It’s not much to start with (laughs), but... They just keep telling you - oh, they’re watching you, you’re not allowed to walk over here, you’re not... shoot, you gotta live. But yet, you still got that in the back of your mind that somebody is behind you. So I thought I didn’t know whether it’d do any good to call and actually ask social security what I’m allowed to do. Or they can
start checking on me (laughs) cause my mom said - well, it might backfire on you and they’d get the idea that you’re trying to do something.

- Is there a general rule that when you’re on social security, these are the things that you can’t do? Or is it different for each person? Maybe just finding out in general...
- I don’t know because... see, my attorney told me don’t get caught working in the yard and there was another thing, like I said, I could go out and say I worked 15, 20 minutes then go in. Well, you can go in and to me it would be worse putting up with the pain for two or three hours or a day. If I did, lets say half an hour, 45 minutes work outside of my little apartment and had some pretty flowers, to me it’d be worth it. But see, they told me that social security... Well, you see, I was on industrial at first and industrial I heard is a lot worse than social security. I’m not sure whether social security checks up on you like industrial does or not, but I know they warned me about industrial, but they’d come out and take a picture. They don’t care whether you was out for two minutes, they would snap a picture of you and they’d say she can work in her yard - she can go to work.
- On industrial, you had to be very careful what you did.
- Well, they say that social security is the same. I’m getting disabled social security. So I really don’t know what I’m allowed to do. I’ve talked to the psychologist about it. She keeps telling me -you’ve got to live! And I said yes, but what’s that involve? She don’t have an answer either.
- I wonder how you would be able to find out. It seems that being on disability for social security... it does put strains on what you can do because you don’t want to lose it, but at the same time are you overrestricting?
- Probably, I probably am. I’m probably overrestricting because I don’t know what to do and I don’t want to get caught doing anything that they would consider being wrong and then have to go through a whole ordeal of fighting it or losing it or whatever.
- It would be interesting to find out what are those things that you can’t do, so you don’t have to worry about those and just enjoy it.
- Well, I read an article in the paper one time, it said that if you’re on social security, something about you couldn’t work, you couldn’t do anything for employment. And then it said you could volunteer all the hours you wanted to volunteer. I said that didn’t make sense. Cause if you was able to volunteer a whole lot of hours, they could consider that... well if you’re able to do that, you’re able to go back to work.
- If you were able to volunteer, volunteering may be two hours here, an hour here, and so forth. At the same time you’re not stressing your body out that you’re gonna be out for three weeks.
- Like I said, I’ve got to find all this out because it’s starting to get to me because it’s been two years now since I worked. And I’m really getting tired of doing nothing (laughs). I’m tired of...
- You want to live, you want to get your life back.
- And then it... I just had an argument with my best friend and we split up. It just seemed like when I get with her, everything is negative and I can’t stand this negativity.
- Is this the woman you spoke about last time?
- It might have been, I don’t remember. There was two friends. The one I’m talking a little bit back to, but the one I finally just severed it. I said it can’t go anymore this way. I tried to get out and then she wants to baby me. She wants to walk me to my car and everything. I can do that myself. Then she just makes remarks that are uncalled for. Then it irritates me, so I just... I tried to get out with her last Saturday and we sat there and we went out to eat, it just seemed like she just started picking on one person after another and I finally just said this is it. I can’t take this anymore and... so I haven’t talked to her now for a week. Well, it was before Saturday. so it’s going on two weeks now. I know how bad it feels to have somebody make fun of you. My weight is one reason, and then being handicapped with that thing (pointing to cane). And then to see somebody make fun of somebody that didn’t ask for it. Just like this one woman was sitting there and this is a little... it’s an Italian restaurant, but we were sitting at the bar. and this one woman, she wasn’t bothering nobody and yet my friend says -that woman has had three drinks since she’s been in here and it just hit me - what made any difference to her? So I turned around and I said - are you buying them? She looked at me and I said what’s the difference? She’s not causing any trouble, you’re not paying for them. Why

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pick on her when she wasn’t bothering nobody. And then another woman come in and she had to start bad-mouthing her. And then a couple of guys come in and she had to put them down. I turned around and said - that’s all you do anymore. You’re either drinking or your bad mouthing, and I can’t take it anymore. She got up and walked out and then she told everyone that I got up and walked out on her. I don’t care. I know how bad it feels to... We got into an argument over a handicap parking place. Right in front of the little restaurant is a handicap parking place. Well, there’s a shoe repair there too. So we come out the other day, I go to get into my van, and she has to tell the shoe repair man - I don’t try to park in this place, I let it be for your customers. I looked at her and I said XXXX, do you know what the heck you’re talking about? That’s a handicap parking place. That’s not his parking place. And she told him - well. I try not to park in it when you’re open. She’s not handicapped, she don’t have no business in that place. It just hit me. Like I said. I found out that the last couple weeks, I’ve been on edge and I just thought I’m gonna blow. I know I gotta get myself calmed back down, cause I just feel like I’m gonna blow. People are making remarks and doing things that are uncalled for. Like I said...

- People are getting into other people’s businesses and they shouldn’t be there.
- Yeah.
- Maybe the same way you’re feeling with social security having that control over you.
- I don’t know. Like I said, I’ve been not knowing what to do. But I guess I got something to do. My psychologist and I talked about that last week. All I do is sit at the house and since I’ve been off, I’ve gained about thirty pounds. I gotta do something. It’s not what I’m eating. It’s that I’m eating and doing nothing else. I eat, go in, lay down on the couch, watch t.v.. Three or four hours later, I get up, go eat again, lay back down on the couch.
- It seems like you have the ability and you have the interest to get involved and do things. But the fear of what can happen if you do it has restricted you and then maybe turned into overrestricting you.
- That probably is. It’s like when I was coming here and talked to... He said -well, what would you do if you had to retire because I was on the verge... the doctor didn’t want me to go back there to work. And then I worked it out and went back for 3 or 4 months. But we were confident, and it got me all hyped up. I might get into yard sale work. Then I was told, later, that’s gainful employment. That’s why I said it don’t matter what...
- It seems like you can do activities as long as it’s volunteering and you’re not getting paid for them.
- Yeah.
- And it seems that right now, financially, that if you would do volunteer work that would work out too.
- Yeah. I’ve got to check into something. I’m going stir crazy sitting around the house (laughs). Like I said, I think what gets me in a bad mood and then I get snappy. My own doing, that’s what I told the psychologist. I said I’m my own worst enemy cause I sit and fight with myself and then I get mad at them.
- Could you draw. I know you’re not an artist, somehow draw you and your pain. Somehow get it on here. It could be something very simple. It doesn’t have to be realistic. Do you have an image that comes to mind when you think of the pain?
- No.
- How would you describe the pain?
- I don’t even want to think about it. I try to keep it out of my mind. Like I said, one minute’s my knees, next minute’s my ankles. If you’d ask me four times in five hours, it would probably be somewhere else. It just moves.
- It moves around on you?
- Uh-huh. Well, see both knees are out and my hip’s out. So it stays that way pretty much of the time. Then I got an ankle that I broke and arthritis has set into it, plus it’s in my wrist and in my shoulder. So it’s according to what part of me I use for most of the time. And right now it’s my stomach (laughs). I would have to say right now this minute, my stomach was hurting worse than any part of me, but I’m sitting still too. But I get up, then the pain changes.
- So it’s not something that stays the same?
No. That’s one part of... they finally have decided that I’ve got fibromyalgia. They said that I’ve been going to group sessions on Tuesday nights at Mt. Carmel East. I guess the third Tuesday of the month. But they said that the type of fibromyalgia, it hits the trigger points, and then the trigger points will send to the next trigger point and that’s why it just keeps going. Like I said, my first original being off was my back. Without me doing the heavy lifting and stretching and things at work, my back isn’t on the number one list anymore. It’s probably five or six on the list now. Because since I’ve been off... well, my knees did bother me then but my knees have taken over now cause my knees and my hips are really the most. They hold you up, you can fall flat without your knees.

In terms of control (drawing a diagram), (a) thinking of this as having control of your pain, feeling like you’re in control of your life, (b) control struggle is when you’re struggling with the pain, and © no control is when you feel that the pain is overpowering you that you can’t do anything. Where do you see yourself?

About right in here.

Do you see yourself go back and forth or do you see yourself just staying here?

(sighs). I really bounce back and forth. Cause sometimes I feel I got a little bit of control and other times I don’t have any control. Well, like yesterday, for some reason, I couldn’t do anything. I just .... I don’t know whether it was pain, I don’t know whether it was my mood, I didn’t want to talk to nobody. My mother called, I talked, she said what’s wrong? Nothing’s wrong and I had to actually tell her, I had to go to the bathroom and get off the phone. I just didn’t want to talk to nobody, didn’t want to listen to nobody.

That’s when you feel like you’re here (no control)?

It even bugged me to listen to the t.v., and usually I watch soaps. It bugged me to do that, so I turned the t.v. off, pushed the recorder on, and I watched it at three o’clock this morning.

Do you ever feel like you’re here (control)?

I have to say yeah, sometime. Usually when I have to take mom to the doctors and things and I go and I do it and then I think - well, I did it, so.

So this is when you have an appointment or something you have to do.

Yeah.

So when you’re around here, it seems it’s when there’s an activity.

That’s funny because that’s the same thing my mother said the other day. She said I don’t ever get to see you unless you’re here to take me somewhere. And I said - you know I’m not a visitor. And she said -yeah, I’m learning that more and more.

If there are things that you should do, that you have to do, then you’ll do them.

Now it’s have to do. Not like if there’s a party or a movie. I don’t go.

If there’s something that you think you have to do, you’ll do that. But if it’s up to you to decide, then that makes it harder to go and do it.

Right.

So for example, this, thinking of this as an appointment that you have to go, there’s no room for you to think - should I go or should I not.

Well, I made the decision that when I said yes to you that I won’t put you off, that I would be here. So I got up this morning saying I had to go.

Thinking of things as I have to do this, then you go. You could have also thought of this as you’re helping someone on the study of chronic pain. But you chose to think of this as an appointment that you have to go to and you came.

Just like that group therapy that I go to at Mt. Carmel, I don’t have to go there, but I make myself go there every third Tuesday.

You’re thinking of that as an appointment.

Yeah, I have to be there. And I actually say it. This is the way I used to do with overtime at work. I never, ever said I volunteered. I had to work.

So by thinking that way, you end up doing it and then you’re actually feeling better.
I used to tell my mother when I lived there I had to work over. And I volunteered a lot of it, but I had to work over. To me, I had to work over.

Which is interesting, now thinking back to the other interview that we had, you had noted that your friend, instead of asking you what you were doing the whole day, if she would say let's make an appointment for lunch, then you'll go. So thinking of things as appointments, then you think I have to, which end up having positive results for you.

Well, you're talking about the other friend, cause I've known her for thirty-some years. But my psychologist told me I created the monster because whenever she would say I'm out of milk, she's 76 years old and she never drove, and I worked with her, she retired when she was 62, but we kept friends. She's in better shape than I am physically wise. But she turned around, and if she was out of bread or out of milk, or out of cigarettes, or just say she's out of something, I was there. I had to go take her. And now, I get mad at myself because she gives a guilt trip now. She has changed to the point where I ain't got nobody to take me to the store. So she has changed her wording around, which changed how I react.

So her wording changed...

... the way I feel about it.

So her wording before made you feel more active and better about yourself, and her wording now makes you stay at home and feel guilty.

That's why I'm trying to keep cool with her. Hoping that we won't loose what we've got. Cause I dearly love her, but it's just the idea that I can't take the guilt complex. And she has not accepted me being handicapped and I know that. She sees me the way I was and I can't get her to understand that I don't go to the store like I used to. I used to go once a month and fill the whole van full of stuff and take an hour to get it all in the house and put it away in an hour. I can't do it anymore. I have to go three or four times a day, a week I mean. A lot of times, I go two or three times a week and just do a little shopping, or if I go to the doctor's office, I'll say - well, maybe I need cat food. maybe I need... I go and pick up a half dozen stuff. And she cannot accept, I don't think, that I have trouble.

Do you think that you have accepted it or are you having difficulty with it?

Ahhh... I think it's been pushed in my face. I think I had to.... I don't want to accept it.... but I think it's been pushed in my face long enough that I know there's things I can't do anymore and even if I want to.

At the same time, there's things that you can still do.

Yeah, but it's just the idea that we'll go to the store, and she'll want to go to the grocery store and she'll build me up by saying - I love going to the grocery store with you because you save me money with all the coupons. So she builds me up in one way, now we turn around, walk through the store, and we get back to her house, and it's like walking not quite as far as from here to the cross, but she's got a big long front yard and I pull up in front of her house. She has to get out and she always has to go to the bathroom, that's not a problem, but then she don't come back out.

So you end up doing it yourself?

So I end up carrying up all her stuff in the house for her.

Instead of the wording of I have to, cause it seems that these are things that you feel good about after doing them, thinking in terms of I want to. You want to come here, you want to go to group therapies, you want to go take your mom, and so forth. These are things that you want to do. It seems that when someone doesn't directly ask you, then it's harder to decide -well, I want to help, but they didn't really ask me.

I just don't like to be put into the situation of the guilt complex that she's been giving me lately. She won't say - well, if you don't have anything to do, come on over and we'll go do something. It's the idea that all I hear from her anymore is - nobody comes and sees me. Nobody comes and takes me to the store, nobody comes and takes me to the bank. And then right then, I get mad at myself and I don't like to get mad at myself. So then I say, I don't even want to mess with it.

If she would say...

xxxx, what are you doing tomorrow, how about coming over this week. Or what are you doing in an hour? I would probably say, O.K. I'll throw some clothes on and I'll be there.
What about when she says when are you going to the supermarket, you didn’t call me and so forth. What about saying do you want to go to the supermarket tomorrow when I go?

Well, she lives quite a ways away from me. That’s what my psychologist said, can’t you pick her up and go two or three times a week? I said I live in Westerville, she lives on fifth avenue.

It seems whenever there’s something that you want to do and you do it, that you’re in control. And when...

To a certain extent, yeah...

And when you term it as have to then you have no choice, so you make sure you do it. When it’s really something you want to do cause you end up feeling good. But when there’s nothing that you have to do...

Well, there’s a lot of things I want to do, that I don’t do. So emotionally it’s the have to...

Which actually works for you...

Yeah (laughs).

It works out pretty well cause you end up feeling good and being happy. But when there’s no appointments...

Like right now, I want to go on vacation, or I want to go somewhere or do something, but I don’t do it. Now if I have to, I’ll do it. I can’t make myself get ready to go and do anything.

Unless you have to.

Yeah, unless I have to.

And then you do it O.K..

Well, I don’t do it O.K., but I do it. (sigh).

Is there anything else that would fit in here that maybe I haven’t put down?

Not that I can think of.

Does this fit you?

Yeah. Like I said, I know I gotta get up. I know I gotta feed the cat, I know I gotta clean their litter box. I don’t even think of it. I just do it. I baby-sat for my daughter-in-law’s little dog one time. I don’t want to do that anymore. Now that was something I tried and I don’t think getting up and taking it out and everything. Couldn’t handle it too well. But I’d say yes if she’d ask me again. But I dreaded it. I was glad.... well, it was for three days. I was really glad when... and xxxx is the nicest dog there ever was. That was something that... I can handle a cat, but I can’t handle a dog. You gotta go out and clean it up. That was just way too much.
Appendix U

Bonnie's First Interview
Bonnie’s First Interview

What we’re going to be doing first... I have a list of questions to ask you. It’s going to be a semi-structured interview, so if you feel you have anything to add or talk about - feel free to talk about that too. O.K.? And I’ll watch the time to see that these get asked as well... The first thing I wanted to ask you is how did your pain begin, when, and what was the situation?

I was in a car accident.

When was you car accident?

December 15 of 91. I spent Christmas and New Year’s in the hospital so it was 92 when I got out. So, it was confusing.

What happened to you in the accident?

I went off into a driveway to pull off... and it sucked the car into a ditch and there was a driveway (calbert) right there, and when I hit the (calbert), it blew the tire out and it caused my vehicle to flip and I was thrown out... it was one of those Suzuki Samurai, the jeep type.... and I was thrown out somewhere between where it (muffled) and where it landed. And I broke my leg, broke some ribs, my lungs filled with fluid. I had seven compression fractures in my back, broke my shoulder blade, broke my cheekbone - I had surgery there. That’s about it... but I don’t remember.... everybody told me about it... so...

So you probably have a picture in your head...

I don’t remember the ambulance or the lifeline.

Where do you have pain in your body still resulting from that?

Most of it is in my back. I just had ... before I came to the pain clinic here, I had the plate removed from my leg, and so that’s been getting better. It gets tired, but most is in my back. My shoulder, where I ripped my shoulder, I had a malunion and they had to go back there and do surgery again. So that’s like one year since then.

The most pain that you have right now is in your back?

Uh huh.

And then I guess you have pain in a couple different places?

Yeah, mainly it’s in the center part of my back.

How has that affected your work? Are you still working or...

I got this job after the pain clinic and one of the reasons I took it is because I don’t have to pick up much heavier than paper products or balloons, you know. so I do a lot of clerking and then we do weddings and parties and stuff like that with the balloons and the decorations.

What’s it like working in that area for you?

Oh, I really like it.... I like it a lot. It’s a fun job. But, you know, like I said it’s not physically taxing so...

Did you work in something physically taxing before?

Uh-huh... I was in outdoor landscaping... outdoors work.

That’s kind of different from what you’re doing now.

Yeah, before I did a lot of ... and other jobs like housekeeping jobs and a lot of cleaning. I can’t do none of those anymore. I lucked into this job through a friend. I really enjoy it. I’m not working as much as I was, but I really like working there.

Do you miss not doing the type of work you used to do before the accident? What’s that like not to be doing it anymore?

Sometimes, I still have my rose garden... I can do stuff like that, but it’s not the type of work.... I’m an outdoor person.... I like to do outdoor things. And it’s just hard... I can’t play volleyball, I can’t water-ski anymore...

You used to do a lot of sports?

Uh huh. In my family, we were real active and I’m down to like camping and croquet (laughs). You know, I used to be.... I’d run here and there. Can’t do that anymore.

What’s that like not to be able to do that anymore?
• It's a bummer, it's a drag cause... we go to this party every year and it's all based around this huge volleyball game they play all day long, you know. It's just... I had to be line judge this year so I was involved, I guess. It's hard to tell people... they look at me, they think "Oh, you're fine". I'm like I'm not, you know. I act fine cause nobody wants to hear about me all the time, you know, so they just think "she can do that".
• What's really going on for you that they can't see?
• Well, it's just that it hurts and I get real tired easy. But people don't... since I don't outwardly show it as much, then they don't think about it. They don't realize that...
• Do you try to hide it?
• Sometimes, yeah, yeah. You know, it's just like grin and bear it, but, you know. A lot of my good friends they'll just say to me "you're not feeling too good right now, are you?" cause they've seen me through all of this. So a lot of them can tell. But you know some people go "oh, you're fine" and I'm like no - I'm not fine. It gets to be... and even my husband does it "oh, you're fine". I'm not fine, you know. Remember, way back then when I was laying there and I was almost dead? You know, and he's like... he thinks I use it for an excuse and...
• What excuse, what for?
• Just not to do things, you know. But I tell him... he'll say "come and help me mow the grass" and I'm like - I'm not feeling real good right now, you know. Steering the tractor around the yard gets to you. He just thinks I don't want to do it.
• Does your husband understand your experience with chronic pain and what it's like for you?
• He does and he doesn't. You know what I mean? He knows it's there, but I just don't think he can realize what it's like, you know. I have to live that everyday. Like everybody else has a tendency to forget, you know.
• Has your pain affected in any way your relationships in your life?
• Well, some of them. I mean...
• How did it affect them?
• Well, first it was my sister and she was like everyone else, just didn't realize how bad it was, you know. I recovered real quickly, but I still have lasting effects. They were just like "oh, we're sick about hearing about you and your accident", but I had to talk it out cause I didn't remember it. And I was trying to get all the information....
• Kind of piece it back together...
• Yeah. And then... since I went to the clinic, I got it all talked out pretty much, you know, with people who understood. So I don't talk about it as much, but the physical part is still there. It's hard to convey that to people. No matter what, I still hurt, you know. I can't expect them to understand, they don't live with that. So...
• What's your routine like everyday. Do you have kind of like a usual routine or... what's your usual routine like?
• I used to until when I was working five days a week, until my boss started doing the store full time and then... I would just get up, get ready for work, you know. But now, like I get up and I have a couple cups of coffee and I stay in the house, then I lay in the sun. I got nothing to do. I'm waiting for business to pick up in the store so that I go back to work. They have Halloween costumes and they do have rentals and stuff like that. So I'm waiting for that to pick up. So I could go back to work anyday. So hopefully it'll be really good. We have a computer... I was learning a lot. She would say well, you know, there's a tutorial - go ahead and look at it. So...
• Has the pain affected your dreams or your goals in any way?
• It changed them. I mean...
• How has it changed them?
• Well I always wanted to build a greenhouse and all that, but that's not real. Now I'm at this job. And me and my boss are both going to take a test to become qualified balloon professionals. I didn't really know the things that you can do with balloons. I mean, big arches and hearts and stuff.
• It sounds like a lot of fun.
It really is. They do things... they do stuff like balloons and stuff, too... but... so I really, really like my job. You can make balloon animals, twisty animals. So I really, really like... my boss would like me to stay at the store and I would really like to stay there too. It'd be great if I could get rich and be a partner, you know. I really like working there. I never want to lose my job there. It's like...

Do you think your pain affected your self esteem or the feelings you have about yourself? Has your self-esteem changed after the accident?

Oh yeah, cause I felt like I couldn't do the things I wanted to do. So it was like "you can't do nothing", you know. Depressed and bummed out. but then I figured - I just gotta do what I can do, you know. We went out and bought me a pop up camper and I thought- man. I'll never be able to put this thing up now by myself if I needed to. But I should do it. because nothing is really heavy. You just crank this thing, so I like going camping.

It's great cause you're in the outdoors.

Yeah, my family they're big on camping. My brother has a camper and we'd all go together. It's a lot of fun. He and I get along better since... I had my accident and he had open heart surgery. So...

Your husband?
-No, my brother. We spend a lot of time together. Our family does and now our relationship is totally different.

What's it like now?

We're a lot closer, we don't pick at each other, and yell at each other.

Because you had both had gone through something traumatic?

Uh huh. I think so. It's like you realize, you know. to be thankful for the family we do have. We have no parents anymore so we're all real close.

How has... I was going to ask you how your religion has affected you. but...

I'm not religious.

How has then your personal beliefs affected your chronic pain or how has your pain affected your personal beliefs?

Not really... I mean, it changed my attitude, you know, on a lot of things. How I treat people and how I let them treat me. Cause I was the youngest of five... I just always got walked on, you know, and now I don't let my brothers and sisters walk on me and I stand up for myself because I'm like, you know.... Now I know any day can be the last day. So, and my brother is kind of that way too. It's like let's live for the moment, you know. Don't get all grouched out about stuff and...

For you, after the accident, it's changed that now you live in the moment and more quality time, enjoy it?

Yeah. I don't worry as much about little things. You know, I'm not gonna let that ruin my day. No matter what I do, I'm going to have fun and nobody's gonna ruin my good time.

You have a positive attitude.

I try to have one, yeah. If I didn't. I could just sit around... For almost a year, I did. I just sat around like "I can't do anything, I don't want to do anything, I don't feel like doing anything". And then I was like -well, I can keep that up or I can start doing things, and when it gets too much - just stop.

And it's worked for you?

Yeah, pretty much. Like I said, you gotta have... You know, I lost my dad when I was real young and my mom went on with life. She didn't let it drag her down until you die of depression. She lived life for every day it was worth, you know. So I get probably a lot of that from my mom.

Have you felt depressed at all?

Every once in a while I do have that feeling. And I think sometimes it's because I get too tired.

Is your amount of energy different from before?

It's not that I don't have energy, it's that my body gets tired, you know. I still... I can stay awake for hours, but my body is just so tired.

Have you had any problems since then in terms of sleep?

Yeah.

What's it like now?
I stay up late a lot. I don’t sleep very much, especially when I’m hurting. And I sit and read... I’ll work on needlework or something, but... my husband is always yelling out “are you ever coming to bed?”. I’m like - I don’t know. Some days, I can’t get to sleep. Instead of going there and laying there and tossing and turning, I just do other things. My mom was... didn’t sleep well either. She was a big all night reader.

You got that from her, too?

Yeah (laughing).

Have you had any changes in terms of your appetite?

I probably eat more. I gained weight since then.

Have you had any feelings of feeling helpless or hopeless?

Well, not after the first few months when I really was helpless, you know. I couldn’t... I couldn’t even wash my head cause my shoulder hurt so bad. I sat on the edge of the tub and cried one night because my husband forgot to do my back before he left the bathroom and I couldn’t do it and I cried. He’d come in there and he’s like “why are you crying?” and I couldn’t yell because I have a weak vocal chord now, and I couldn’t yell loud enough for him to hear me. And I just sat there and cried and he’s like “what are you crying about?” “because I can’t even dry my own back”. He’s like “oh, I’m sorry”. “No, don’t be sorry, I wish I could”. You know, it just get to be where, I’ll do it myself, you know. Finally, I had to get up and cook. Everybody was like “are you all right?”. I had all these men cooking for me, I was about to go crazy.

What are some coping strategies that you use when your pain increases? Is there something you usually do or what are some ways that you deal with it?

Well, sometimes I listen to a relaxation tape.

The ones that you got here?

Well, I bought one of the ones that we were listening to. Sometimes I’ll play that and it helps. But usually I do needlework or something to take my mind off of it at the time, try not think about it too much.

So you try to distract yourself?

Aha, yeah. Well, if I do this, I won’t be thinking about that.

You were in the chronic pain program in which year?

April of last year.

How did that experience, of coming to the program here, how did that affect your total experience with chronic pain? What was that like for you?

I think the best part about it was talking to other people that deal with it everyday too. You know, somebody actually does know what you’re saying, you know, and understands. It makes a lot of difference that you can relate to somebody about that. Cause I was in pain when I was in the hospital, I had a couple nurses that had back injuries then. So they talked to me a lot about it and what kind of things I had to look forward to, you know, it’s not gonna get better overnight. But it does help to talk to somebody, you know. As far as the physical therapy went, it wasn’t a whole lot that I hadn’t been through already. I went through a couple of years of going through therapy, going to different places. Coming here, I felt like I had backup when I said this is what I’m dealing with and it’s real. And other people feel the same way. It made me feel like I had the right to feel the pain, you know. Before I always felt like... cause a lot of people would say to me “well, it was your fault; you had the accident”. And I was like “well, but I didn’t do it on purpose. It’s not something I planned on”. It’s like o.k., it wasn’t my fault. But... nobody asks to have something happen to them like that. And I have the right to feel bad because I hurt myself really bad. So...

How would you compare your experience with chronic pain with the other people that you met in the program? Do you see any similarities or any differences in terms of your experiences?

Well, you know, everybody that was in here, had done what I had done - and that was bounce from doctor to doctor, from clinic to clinic. You know, everybody has had it. I’d done everything I thought I could do, you know, and now we’re at this point... where we had to come here and convince people this is what we’re living with. But it was good because everybody here already knew that we had that problem. When you go to some therapy places, and I could just swear I had a temporary
doctor in my office and I don’t think she believed in chronic pain. You know, and she just looked at me like “sure, right; you just want me to fill out another prescription pad”. I was like “no, this is not what it’s about. I’m trying to get into this clinic here and I need your help”. And, you know, finally I got directed back to my original doctor who is down here now and got into the program. Cause I said “a lot of people just look at you like “ooh, sure, right”.

• You can’t see it.
• Yeah, and it’s pretty bad when the doctor does it, it’s like great - nobody believes me now.
• Did you see any differences in your experiences?
• Some. because a lot of those people in my group were older than I am...
• What was it like for you to be younger and to be in that group?
• Well, you know, they had a lot of things, a lot of experiences that they could tell me. but it was different for me because I was more physically active than a lot of them. You know, there was a guy in the group who was 66, I couldn’t imagine him wanting to play volleyball very much. So it’s like... it was the age difference that probably made the biggest difference because I was so much younger than them that my problems were kind of different and the big group of people that I’m with are different because they’re not all older. There are a lot of people that are younger than me in my group.

• How did that fact, the age difference, how did that affect your experience?
• Not badly, I mean I got along with everybody in the group. It’s just that some of the things that we would talk about weren’t a whole lot relevant to me. Some of the things that, you know, me being younger .... I had different expectations, I guess.

• In terms of they had different expectations for the program or for yourself?
• Yeah, to expect for myself and what I really, really wanted, but what I knew wasn’t going to happen. It was just... an attitude, I guess.

• In terms of the expectations that you had for yourself were much different than the ones they had.
• Right.

• In terms of the expectations, which one would you say was the biggest difference?
• I probably had higher expectations, you know, because I wanted so much more to happen that, you know, be realistic - I knew it wasn’t going to happen. I just thought something different would happen. Like I said, much of the physical stuff it’s old hat to me. I got in the therapy pool and I started doing some stuff, and the girl looked at me and she said “you’ve done this before”and I was “yeah, plenty of times”.

• What was your experience in terms of medications or drugs or alcohol... did you have a time when you tried those, are you still on any of that?
• I still take medication. I take elavil at night and I have to take occasional pain killers. But...

• Is that how it used to be since the accident?
• Yeah, pretty much. I mean the elavil they kept increasing it cause I still wasn’t sleeping. So I’m on 100mg now. And like I said , I take the occasional pain killer. My doctor said she has no problem with me using it that way. I’m not taking 40 of them and then coming back and going I need 40 more. I see her every three and a half months. I see her. And then if I need them, she’ll write me one. I mean I was there for 90 days. If I need to put it in the computer at my store, so ... I did have a problem, I think for a while shortly after the accident and ah self-medicating with alcohol cause I couldn’t sleep and now I finally got my medication kind of figured out and I started to sleep a little better. I probably slept better when I was working everyday.

• You were probably more tired...
• Yeah, well, busy. you know, more things to think about other than why I feel bad, you know.

• Has the pain influenced your social life?
• Some, I mean, it was a time that I just didn’t feel like going places, you know. My friends have a lot of outdoor parties and it would get chilly and “O.K., I gotta go”. Cause if I’d start to shiver, my back would really hurt and then I’ll have to go, “boy, is she a bummer”. But, you know, they just didn’t realize that I had done it as long as I could take it that day. So...

• Has it influenced or changed sexual activity, has it affected it?
Well... yeah, my husband would probably say a lot. Sometimes it's just painful for my back, and when it's painful - it's not fun. So I'm not always as responsive as he'd like me to be.

Because it would probably be more painful?

Yeah. Or else I'm like just don't touch me, you know, I don't feel good. And that upsets him.

Is that affecting your relationship?

Well, a little bit, you know. Cause if I feel really bad, I've been sleeping in another room and we used to never do that. Instead of getting into an argument, I'd just the same sleep in the other room. And sometimes I wonder if that's not why I don't want to go to bed at night. I don't want to sleep. I don't want to get into bed and get into that, cause of all the hassling, you know.

It's a lot easier just to stay away...

Aha.

Well, let me... we kind of covered a lot (laugh). It’s gone pretty fast actually. Um.... how would your life have differed if you didn’t have chronic pain?

It’s hard to tell. Everything... it wasn’t like it changed real slowly, it changed all at once. You know, one day I’m just happy happy all about, and then the next I can’t even brush my own hair! And... and it’s so quick, you know. It’s like Monday I was this, and the next day I can’t do any of those things anymore.

So it’s hard to tell what it would have been like?

Uh hum. You know, cause it was such a sudden change.(turned tape)

Is there anything else you would like to add that would help me to understand more what your experience was like? Something that I haven’t asked?

Not that I could think of.

It feels like we pretty much covered it?

Uh hum.

Are you receiving any type of financial compensation?

-No. I checked into it once and they said no, my husband makes too much money. That’s him, that’s not me, you know.

What does your husband do?

He builds buses for ? corporation. They’re going through a bankruptcy hearing right now, so he’s been laid off since November. And he’s worked on construction with a friend of his.

Are you finding yourself in a financial struggle right now or...

Yeah, we still have money coming in, which is good. It’s nothing like we had before with the benefits and that, you know, the insurance. I don’t know how we would have made it through the accident if hadn’t had insurance. The first bill I got from Riverside was $110,000. (wow) Yeah, that’s what I said.

And insurance covered it?

Pretty much. It covered like 89% and then they worked out the rest. I don’t have 14,000 to give you. I was in there for a month and I was in an ICU for three weeks. A lot of that was special nursing. I had an x-ray every single day. My brother started working at Jiffy Lube so ?.

Do you have any comments or suggestions in terms of the interview process when I do this with other participants? Anything in terms of the structure or any questions.

No.

You felt pretty comfortable.

Aha. I guess we’re done.
Appendix V

Bonnie's Second Interview
Bonnie’s Second Interview

- Take a couple minutes to look through the interview. (time passes). Do you have any comments or thoughts?
- No.
- In terms of thinking about pain, do you see pain as something outside of you or something that’s part of you inside... I’m not sure if that makes sense.
- That’s a part of me, it’s not gonna go away.
- So do you see pain as part of who you are?
- Yeah. Now it is. I mean it shifts away. I mean I do things and I approach things.
- What’s it like for you to look back at your interview?
- It seems like it’s me (laughs).
- In terms of control, since you’re saying the pain is a part of you, does the pain have control over you or does it feel like there’s another part of you that has control over you? Maybe you see it a totally different way...
- Well, I used to think it controlled the way I do things. But, I try to keep the upper hand. When I don’t feel like doing something I make sure it’s just me and not just an excuse not to go.
- So you’re saying there’s another part of you that has control, that’s taking the upper hand.
- Yeah, I do now. I mean there was a year where I couldn’t get to where I had the upper hand.
- Are there parts of your life where you feel more of a struggle to have control over the pain, to have the upper hand, more of a battle?
- You know, just the things that I can’t do and I want to do.
- In deciding to do an activity, if you know that you’re going to have pain after you do it, do you still do the activity or...
- Sometimes I will, I mean if it’s something I really, really want to do. I’ll do it. But I just say, well - I know I’m gonna pay for this. You know, I just take the attitude - if you really want to do it, then you’re willing to pay for it.
- So an activity has to be worth paying for it?
- Yeah.
- Does it happen too that you decide to do a different activity just to not deal with the pain?
- Well, sometimes. It’s like they want to do one thing, and I say why don’t we do this instead. I kind of work it so it’s not so strenuous for me.
- How do you see yourself in dealing with pain?
- I think I deal with it pretty good. I think it’s because it’s been a few years, and I guess I had to accept it.
- You’ve accepted the pain and now you’re getting an upper hand?
- Yeah. It’s just so hard to deal with it. Different ways for different situations.
- What are some feelings that are coming up for you in reading this?
- I said it just sounds like me...
- No surprises?
- Not really, no.
- I have an idea.... in terms of how you see yourself and the pain, could you put that down on paper... in terms of a picture maybe a picture you already have or a picture that might come up for you. Somehow put on here you and the pain.
- Me and the pain or me with the pain?
- Whichever way, just get them both on the paper. Whichever way it feels and you don’t need to be an artist.
- That’s good, cause I’m not. (started drawing)
- O.K., can you explain that to me?
- Well, I’m just usually real happy and loud and cheery, but there’s one part of me that’s not right and it’s like an imperfection. In the flower, one petal gives me that.

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And you feel that that part of you is gone?
Well, gone or not right, you know. Something like that.
Which part of you is, would you say, gone or not right?
Probably the vitality I used to have. I used to be springing around, I’d do handsprings for no reason. Now I can’t do that kind of stuff and, you know, I’m still pretty cheery but in a different way.
Kind of like the spark...
Well, some of it, you know. Like a friend of mine said I got my spark back when I got the new job doing something that I felt good at and something to do with my time.
How are you dealing with this situation?
Like an imperfect flower you hide behind the other flowers so you wouldn’t be able to tell.
You try to hide that this part’s not here?
Well, I sort of cover it up.
Does it feel like these other petals are held on tight or do they feel loose?
Everything else feels pretty good. That one part of me is just not the same.
Have you had any thoughts since we met last week in terms of what we talked about in here?
Not really. I talk a lot, so I probably already told you a lot on Thursday.
Yeah. It seems to me, and this is changing too, that in terms of the pain maybe there’s different relationships in terms of who has control. Maybe you or the pain. That’s how I was thinking about it. Let me know if you think about it in a different way because I’m getting lots of ideas. (drawing three circles on paper) In terms of (a) the pain having the control and feeling like you have no control, the (b) control struggle - like when you struggle with the pain, and then (c) feeling like you do have control over your life. So I’ve been looking at these three areas and wondering where everyone seems to fit. Kind of going back and forth... Where do you see yourself most in or going back and forth between... or as your life progressed, you moved on to different ones.
Well, I’m in between the control and the control struggle.
O.K. going back and forth between the control and control struggle... Do you tend to be here more or here more, would you say?
Mostly towards the control, but also in the control struggle - sometimes it’s not as easy.
When do you find yourself going to control struggle? Do you feel that the pain becomes more powerful and you start struggling? If that’s how it happens for you, when do you see yourself going over here? Is it on certain situations?
It’s usually in social situations. I mean with my work, I have all this medical backup. I can tell them what I can and can’t do and they try to accommodate for that. But also it affects the types of jobs you can get. Like I said I’m not an indoor worker, and now I am.
So it’s usually in social situations?
Or, you know, I want to do something but I can’t because they pain just says - I don’t think so.
In terms of doing an activity, deciding whether to do something, .... I was thinking in terms of if you really want to do the activity, if you’re really going to enjoy the activity - I was looking at that as results. Like what results does it have for you. And then looking at paying back with your pain or maybe paying back with this is not really the activity you want to do, so changing an activity. So I was looking at that like payment. Cause it seems like everyone is like I pay with this, payback comes...
It does...especially with people with back problems. You can do it and you know you’re pretty good when you do it, but when it’s done it’s like ‘oh, I shouldn’t have done that’. You start to ache and you’re like “I wish I wouldn’t have done that, but I sure had a good time doing it”.
I was thinking in terms of the payment... I keep hearing that some of the payback is having pain either while you’re doing the activity or afterwards or payment can be settling for something you’re not really excited for. Results is your enjoyment, really wanting to do it, or maybe something challenging- something you used to do before. It seems to me that when you decide to do the activity that the results outweigh the payment. They’re worthwhile. Does this fit for you, is there something extra, or something that doesn’t fit?
Yeah, it’s pretty much. I don’t usually... I don’t try to change the activities that much, I just try to change the way I do the activity.

What do you mean?

Oh, like we went camping, I was like you guys gotta carry all the coolers cause I can’t do that. I just say I’ll get the little sticks, you guys get the logs.

So you change how the activity is done.

Right.

So you can still do the same activity, but you don’t necessarily have to do as much work as you would have. In terms of these three, which one would you say you do more? Is it all three or maybe one or two of them?

I usually don’t change my activity if I can help it.

When you’re here, when you’re in control of your pain, are you doing a lot more?

Oh, yeah. I get out of the house more than I used to. Like I said, the first year, I was in pain and really depressed, and I thought I can’t sit in the house and do nothing all day.

When you move from having control over your pain to control struggle, what is it about social situations that makes this happens?

I go to parties and everybody plays volleyball... I feel like I’m on the outside. Which is a lot of the time because I can’t do the things I used to do.

What would happen if you would do that activity?

If I were to play volleyball, I’d probably hurt myself again. I’m clumsy too, so.

So you would hurt yourself to such an extreme that it’s not worth it.

Yeah. I have to make a decision somewhere of what’s too much.

So when you struggle with the pain, you’re saying maybe the pain is too excessive?

Right. It would be like I really want to do that, but I know I can’t. And that’s when I feel like the pain is in control. And at the same time, you’re making the decision...

True, I’m making the decision.

...to not do it, cause you could still do it and deal with that. But you decided that’s not worth it to you.

Right, it’s too much for whatever the activity is.

So in terms of being in control of the pain, maybe control is being able to make the decisions.

Well, yeah. And I guess changing how you go about the activity instead of changing the activity or not doing it at all.

Does it happen sometimes how you do the activity, you just can’t do it?

Right. I mean there’s just certain things...

And that’s when you feel pain may win.

Uh-huh. I’m like I guess you might as well give up that activity. Like I said, I tried to stay involved. My brother waterskis, so I drive the boat. I can’t water-ski, but I can drive the boat. So I just try to involve myself in non-painful ways.

In the last interview, you spoke about having sexual relations with your husband. Does this fit more in here (pointing at control struggle)?

Yeah.

Is that also when the pain is too high?

Sometimes I hurt really bad, it just feels like here (control struggle). You don’t want to do something that doesn’t feel good. I mean if it hurts, you just can’t get into it.

The payment is too high with the pain. Have you been able to change how the activity is done?

We try. But it’s like- oops, can’t do that.

That hasn’t helped?

Sometimes it helps. Sometimes I just feel too bad before we even think about it.

Are you ever in this area (no control)?

No, I don’t think so. I try to deal with it in a lot of different ways. I didn’t have control for a while, but that wasn’t the way I was gonna live.
• You didn’t in the beginning?
• No, I didn’t in the beginning.
• So you spend most of your time here (control) and this happens (control struggle) when you decide not to do the activity because the payment is not worthwhile?
• Right.
• So here (no control), you thought you didn’t have a decision... that the decision wasn’t yours to make.
• Because in the beginning everything was painful. Walking was painful, breathing, sneezing, and coughing. It did feel like it had control over me cause I was just so overwhelmed by it. There were just so many things that hurt.
• What happened coming here to this area (control)?
• I just decided I wasn’t gonna sit at home on my couch and do nothing, cause I’m not old yet. I’m not ready to rock.
• So you decided that you’re willing to deal with the pain for some things.
• Uh-huh. And if not I’d just sit around. And it would be everyday. And if I think about it, it could be like that everyday. I just choose not to.
• The part of you that’s gone...
• It’s not gone, it’s still there. I’m not connected all together. It’s like the physical and what I really want to do are separate. A lot of people they want to do something, they just do it. I have to think about how it will physically affect me.
• It’s like the spontaneity.
• Yeah, cause I have to think about how it’s going to affect me before I do things.
• This would be your complete self, with being who you want to be, not having to be (muffled), and maybe that’s over here (lower petal).
• And that’s a part of me I don’t necessarily care for, but it’s a part of me and I have to deal with it. Mostly I’m O.K., I have to deal with pain all the time.
• Do you see an image of the pain?
• Not really.
• If you had to put an image to it...
• It would kind of be like a mosquito buzzing around your head all the time. It’s like - stop it! And you just get tired of it and say - go away! It won’t go away, it’s just something you constantly have to deal with.
• Do you have any comments or observations in terms of what we did here? I know it’s kind of strange to put things down, diagrams and stuff. Does this feel like it fits or...
• Pretty much, yeah. -( I explain diagram again).
• Some people just say it’s not control, you just ignore it.
• Do you ignore it?
• To me it’s the same. If I don’t think about it all the time, then...
• So it’s like the pain is always there and sometimes you can ignore it and sometimes you cannot.
• Yeah, and what I’m doing. Sometimes I’m involved and I don’t notice it. But I know it’s still there. And if I start doing something else, it’s like oh yeah- it still hurts.
• What feelings do you have when you’re here? How do you usually feel when you have control over your pain?
• It’s just that I’m not letting it get me down. I know it’s gonna be there. You have to have an attitude about how you’re going to be about that being there all the time. It’s gonna be there, so either ignore it or deal with it.
• How do you feel when you’re here (control struggle)?
• That’s usually when I really want to do something and I know that it’s not gonna be worth it if I’m gonna feel that bad. But I still want to do it, so deciding who’s gonna win.
• Well, great. This is giving me a lot of information. It’s really helpful.
Appendix W

Tina's First Interview
Tina’s First Interview

- Tell me a little bit about where is the pain that you have and when and where it began...
- It’s in my neck, head, shoulders... Did you just hear my neck crack? (laughs).
- It’s in your neck, head, and shoulders?
- Yes
- And when did your pain start?
- Uhm... I guess about three years ago.
- Was it a situation through work or...
- No, it just came on ... what they diagnosed me with is S.T., lots of doctors don’t know about it, even neurologist... and umm... it’s a neurological condition that can manifest in several different ways. Mine happens to pull my head to the left. I cannot straighten my head straightforward or turn it this way and it started out at work I noticed one day my... I can’t do it the way it was then, but my head was pulling down to my chest and ... that’s how it happened for a while and then it got so it was really hard for me to turn my head around, but I noticed the difference - I put my hand on this side of my ... no, on this side, no- this side. I put my hand on the opposite side of my face, I could turn it more. So I would walk around and do my work with my hand on my cheek so I could turn that way. It’s a ... they don’t understand anything about S.T., what I have. Then it got so bad. I couldn’t hold my head up and so I would sit at my desk all day with my head held in my hand like ... When I would get up to walk, I would have to hold my head like this ‘cause I couldn’t hold it up when I was walking. And during all this time I kept turning farther and farther to the left. And, as I still do. I would walk into the wall, or walk into people, knock over this place in the grocery store because I could not see what’s over here. And until... at first I didn’t have any pain with it... and it was probably... I don’t know. It’s hard to go back and remember exactly when I started noticing the pain. But it was a while after it started, and... or after I started having these symptoms. But it started out, I had just excruciating headaches that could not be helped by any kind of medicine and it went clear across the back of my neck and up over my head and felt like it was going up into my...
- The headache?
- Yeah, the pain felt like it was going into my brain. And then from there, the pain went around behind my ear over here and then started going down my neck and it went out over my shoulder. This was just progressively down from here and then it would go down on my back under my shoulder blade and then down over my left chest.
- It was progressive the way that the pain started...
- Yes... uh-hum.
- Right now you’re experiencing that pain?
- I have pain all the time.
- All the time?
- But I don’t have it every place all the time and the severity of it depends on a number of things.
- What does it depend on?
- Usually it depends on the position I’m in, how I’m able to control... sometimes I’m able to control the pain by sitting a different way or lying down or getting up and walking, um... standing up seems to provide more relief than anything else. It also depends on how long it’s been since I’ve had my botax injections. I take botax injections in my neck behind and up in here.
- That gives you relief?
- It paralyzes my muscles and nerves and that gives me relief from the pain. I get those... I get about... it can be anywhere from four to seven injections at a time once every three months and they do it with an EMG machine.
- When did you start to realize that your pain was chronic... that it was going to be something you were going to live with?
- Well, as soon as I knew what I had, I called NIH and got all the information I could. They told me how to get in contact with the national association of S.T. and they have a wonderful news magazine that goes out... I don’t know if it’s monthly or quarterly, but it just has so much information in it.
And so everything that I could find... I even came down here to the medical library at OSU... and so I myself have done as much research on it as I could... and so I found out that there is no cure for what I have. They don’t know what causes it either.

- What was it like when you first found out that there was no cure?
- Uhm... I felt that for me there would be. I didn’t want to accept that.
- Do you think you’ve accepted it or do you think...
- Yeah (starts crying)... I accepted it. It’s been hard to accept. It’s hard to live with just knowing... all your life you have thoughts about what you’re going to do when you get older and retire. You’re going to take your grandchildren, and do this and that. You’re going to have all these crafts you’re going to do and traveling and all this and uh... I couldn’t even ride in a car, let alone travel. I’m just... so...
- It had a big impact on your life?
- Yeah... it has destroyed my life. It’s just destroyed it financially...

Where were you working before?

- Uhm... I was working as an estimator for xxxx on jobs... they do food facilities in restaurants and hotels and they do all the xxxx stores and xxxx and, I mean, that’s just a sample of it. But I did the estimating for the stores that were the one time only deals or overseas, I did some for Saudi Arabia and some for Mexico and things like that. So I had a nice job. I really liked it and... but... I worked until the point where when I was coming home at night I had to crawl up my steps to get into my house ‘cause I was just so exhausted. Just from living with the pain and putting up with the inconvenience of holding my head and trying to do my job right and I was on two kinds of medication at different times to see what would work.

- You were experiencing a lot of pressure? Were you experiencing pressure from work and the pain?
- Within my own self.
- What was going on within you at that time?
- With what?
- What was going on within you at that time?
- Oh, within me at that time? Uh... that I had to do something to make myself better... whatever it was. And with ST, I found out that what helps one person does not help another. And... so... you just can’t go into a doctor and say I have S.T. First of all, he probably won’t know what it is and you can’t just say give me what you’ve given everybody else for ST. You go through a whole, you know, like 40 different kinds of medicines for everything from epilepsy to Parkinson’s disease.
- To find out what works for you?
- Yeah... And... so I knew that I could not.... well some of medicine I took, particularly Artane, which is for Parkinson’s disease, gave me such terrible side effects that I knew that I could not... I couldn’t work with it and especially couldn’t work with it because... I’d be going down the freeway and not know where I was or why I was there or if I was going in the right direction.

Sounds dangerous...

And um... I had difficulty driving, I had to rest on a pillow - put my head against the window on a pillow. And someone followed me one day from work and then went to work the next day and told the big shots that I wasn’t safe to be on the road because I was all over the road. So um... anyway they talked to me and they said that they realized I was having a problem and whatever it was, they didn’t ask me what it was or anything, but they said if you will need time off to get yourself together then you can take some time off. So I did that... well, first I said ‘no, I’ll be OK’, and then it wasn’t but two or three weeks where I said I’m going to have to. And so I thought I would take the three or six months off. During that time, I’ll figure out what it was that was going to help me and I’d go back to work. Nothing helped.

- What’s it like for you not to work now?
- Um... well I know that I can’t work. I can’t sit up at a desk and umm... I don’t have very good concentration ‘cause with the pain you don’t concentrate very well and with the medicines also you have a lot of memory loss.

Are you receiving any financial compensation for not being able to work?
Um... just social security disability.
What's your daily routine like now?
Well, I usually get up in the morning and sometimes I can't stay awake even though I have slept all night long.
You're very tired?
Yeah... and so I sleep again until ten or eleven o'clock, which I don't like to do because I can't get anything done and I'm so slow getting things done anyway that it just kind of ruins my day. But... um... what I like to do is read the paper and then get up and start trying to do things throughout the day. And I know that the more active I am, within reason, the better I feel - the less pain I have. But I find that if I sit for long periods of time, I have more pain. And if I... different positions I'm in will cause me more pain and even into the next day.
What are some typical things would you say that you try to get done during the day?
Housework. By the time I get the dishes done and the kitchen cleaned up, you know, it's almost night time already. And so... I can't do very much through the day. I try to do as much as possible and some days I feel pretty good and then I just work my butt off while I can, 'cause maybe the next day I won't feel like doing anything.
You had said here that you're living with your fiancee, is he working or...
He's supposed to be retired, but he works more hours than if he were working.
What does he do?
Well, he owns some rental properties and he takes care of all those things. And it seems like people move out all at the same time. So he has to get all of them painted and, you know, redone for the next people. And then there's always maintenance to do and all that. And then he also has an icecream store that he has to be there most of the time.
How has your experience of pain, how has that affected your relationship with your fiancee?
He doesn't understand... See, it has caused severe depression also and the things that go with it... the things you lose (starts crying). And the help that you try to get. Everything, it's all very frustrating. And if you try to work with an agency to get some help for something, they lie to you and just give you generic answers and I don't like that and I become so frustrated. And I had a nervous breakdown (starts crying again) and ended up in the hospital and...
When did that happen?
The end of last October. And then um... I've been going to group therapy three times a week until just recently. Um... but he doesn't understand.
He doesn't understand what it's like? Are you able to explain to him?
No... no. Because he... he has had a lot of trauma in his life. A lot of very bad things have happened. He had five children, four of them have died. Three of them all at once. And then the one died about six years ago. So he only has one daughter left and she is not worth cow manure. Because at least with cow manure you can spread it over the field and use it for fertilizer. And if you spread her on a field, she'd just kill the grass. I mean she is... if you can think of the worst possible things that a person can do, she's done them all and enjoys it. And so his time is very much taken up worrying with her, trying to take care of her, trying to make her be a good person, and it's not going to happen. And he won't accept it.
Does she live with the both of you?
No, if she were there, I would not be. And um... she's in trouble all the time and he just tries his best to keep her out of trouble and it's not working. And she's thirty years old. So talking to him about my problems, I can talk to him about them but he doesn't understand and sometimes I'll say can we turn off the t.v... and just let me talk to you for a while (starts crying)... all I get... and so we'll turn off the t.v... and I'll talk to him for a little while and it's because I want feedback from him... all he'll say is 'oh well, it'll be alright... it's gonna be O.K.' And then he turns the t.v. back on and that's the end of it.
What is it that you want to hear from him? What would you like to hear from him?
I guess I'd like to know that he really understands what I'm going through... and have some sympathy... a bit of sympathy... but he doesn't because... it's... at one time it was so bad, and I just
couldn’t do anything with the house and I had somebody to come in and clean and he got very upset, he said I don’t like anybody else in here. And at different times I’ve talked to him about it and he won’t accept it. he says you just do it when you can. So you see, it’s still my responsibility. And he doesn’t understand that I can’t do it. And uh... even when I was telling him that, you know, it hurt,... I couldn’t drive ....um.... he would ask me to drive his pick-up for him so that he could do some stuff, I don’t want to go in to all of that. He was having me drive his pick-up and I would tell him I just don’t... it hurts... and he just didn’t hear it. He just didn’t want to hear. I just... I feel that... I think he cares but....um....he ignores it. And it’s like with his own problems, he doesn’t talk about them... the things that have happened in the past... and as soon as he comes in the house, he turns on the t.v... the radio and everything, and he’s always got something going, and I tell him ‘you know the reason you did that is because you don’t want to experience or feel the pain that you have or to think about the things that have happened to you. As long as you’ve got something going on to listen to, then you don’t have to listen to your own head’.

- What are some ways that you use to deal with your pain... to cope with it?
- -(sigh) Well, sometimes I’ll go lie down on the bed and hope for some relief. Sometimes I take, well I take meds on a regular basis anyway, so it ... usually I don’t take extra medicine because I haven’t... I’m scheduled to take aspirin too every so many hours. I don’t always do that. If I’m not in pain, I don’t do that. But if I do have a lot of pain, I’ll take a couple aspirins and lay down. But then when I lay down, I feel guilty because I know that he’s out working hard....
- So that you should be working...
- So I should be working (crying) and um... so it’s like I don’t ... I can’t really be comfortable resting in bed because I feel that I shouldn’t be there.
- How do you see yourself now in terms of who you are and so forth and how did you see yourself before the pain? Is there a difference or is it the same?
- Well, I’m the same person with the same desires and brains, ambitions. In fact, I’ve had to accept that there are things that are never going to happen. And so I just had to change what um...(turned tape)
- I recently got a new computer, so I play around with that a while and um... I started some crafts that I can’t seem to finish...um... What I have to do is when I feel a little bit good is try to get some of the things done in the house that have been left over for three years. I feel good when that’s done, but I don’t like to do that kind of stuff.
- You had said before that you feel depressed? Did that start happening at the time that your pain started or is that from before?
- Um...I had some depression before because of some things that happened. I had a lot of major things happen to me in the past....last several years. Just everything (starts crying)...just get over one thing and something else would happen. And so there was some depression anyway, but I was dealing with it fairly well and then the pain came, and I couldn’t do anything. And I sat for two years in my chair doing absolutely nothing, except just looking into space.
- This is when your pain had started?
- And it was so bad because it hurt to sit, it hurt to stand, it hurt to lie down. I felt no relief for my pain for so long. (blew nose). It was just there constantly.
- How do you think your life would have been if you didn’t have this pain....what would your life be like?
- I would be working, I’d be able to help my children more than I am able to financially, I’d be more independent... I wouldn’t have my kids worrying about me...
- How is your relationship with your children?
- It’s O.K.
- Has the pain affected it in any way?
- Um... well, yeah because I really can’t do things with them and or very little, and they worry about me because I don’t get out and do anything. But I don’t want to go out and be with people. I don’t want to mingle with people or be with them and have to have relationships where I have to talk to
people. Just being with people is a responsibility... all relationships have responsibility and I just
don't want the responsibility of a relationship.

- How would you describe your social life now?
- It's nothing.
- How was it before the pain?
- Um... it was almost nothing anyway. I had some depression anyway. And I have always been a
  person that could pretty much get on by myself. Never liked to have a lot of people around me.
- You were here in the chronic pain program... were you here, do you remember. ... was it a
  year ago?
- It must have been in 94, it wasn't in 95.
- How would you compare... maybe you could see some similarities and differences between your
  experience with chronic pain and maybe other of the participants that experience chronic pain? Did
  you see any similarities or any differences in your experiences?
- With the ones that were in my group? (yeah). Well, there were, I think seven of us started out, we
  started out with seven, three dropped out. Um... I was disappointed in the chronic pain program
  because it did not really address my needs. Um... there were four of us left... four women all about
  the same age. The others all had fibromyalgia... among other things, arthritis, their legs hurt, their
  backs hurt, their arms hurt...um... everything hurt, but none of them had... my problem was unique
  in even the doctorxxxxx, who sleeps through everything, you know, he just brushed it off. He said
  it's just right neck. It was something that he used to call right neck and it is not right neck. It shows
  that he does not know. In fact, he didn't even know what it was. He would not admit it. He
  wouldn't admit it. But there was not anybody from this place that I found who knew what S.T. is.
  They never treated anybody with it . they didn't know what to do, and so I feel that the time here was
  90% a loss. And umm.. it completely wore me out. I was in severe pain all the time that I was here.
  Traveling to and from here. I wouldn't get over the pain from that until I had to get up in the
  morning and come in and then there were no comfortable chairs for me to sit in where I could to put
  my head back. There were no accommodations at all for my needs. They tried little things here and
  there,... but nobody could really address... they even tried a TENS unit on me and I tried it, but I
  found out later that there's no sense putting TENS unit at all for an ST patient...because it doesn't
  work! Hasn't worked on anybody! And so... they were feeling around in the dark and in the
  meantime I was in pain. They were getting paid for everything, but I was in pain and I was getting
  nothing out of it.
- You said that 90% was ineffective. What was the 10%?
- The 10% was um... in some of the lectures that we had, I did learn about the different kinds of pain
  and why you have them and why sometimes you can have pain and really not have pain. You think
  you have pain, but you really don't. And , you know, in some of the lectures I learned a few things.
  So, but as far as the physical part of it goes, I feel it was a loss as far as my ST goes. Now, none of it
  hurt me. You know, it didn't hurt me to go through the physical exercises and all that. But ... none
  of it did me any good.
- Do you think it was more similar or more different the experiences of the other participants in terms
  of experiencing their pain?
- Well, O.K.... They, some of them, seemed to be able to tolerate a little more.... they were progressing
  a little bit. I didn’t see any great progress with anybody. And um... in fact, one of the women got
  much worse and I don't even know if she's still alive. She got so many things wrong with her. It just
  didn't seem to be helping her any. And I just stopped. in my personal opinion, I don't think that any
  of us in there, well- I know we weren't 'cause we talked about, and we as a group have gotten
  together since then.
- Great. You kept in touch?
- Some, yeah... And , in fact one of the ladies turned up in my therapy group and one of the other ladies
  I had lunch with a couple times and then the other one I kept in touch with on the phone. She was
  good at that. But we all were very disappointed in the program. I, unless you thought a group of
  people who have exactly the same thing, I don't think that a group program like that is beneficial. I
think that when you have something wrong with you like I got S.T., they probably don't have any other patients in here with ST, they hadn't had before.

- You're feeling misunderstood even in the program?
- Yeah...yeah! They didn't understand it, they...I won't mention names, but um...they try to just look up information and they found very little on it. Well, of course, I knew more about it than they did because I had, you know, I have a big file at home on ST. And a lot of the people will end up in institutions, mental institutions. A lot of them will commit suicide from the pain.

- Have you ever thought of suicide?
- No. Um... but I do know that if my pain...see. you're not seeing me at my worst. You're seeing me at my best now. This is the best that I had been.

- What would I see if I would see you at your worst? What would you be doing?
- My head and my shoulder would be cropped like this and down and I'd probably have to hold my head to the left. I'd be running into everything and the pain would be so excruciating that even to walk was bad. People told me that my face was always like this (smooshes her face). Yeah, because the pain was so bad. But since, I go to Toledo to get my botox shots. I used to get them from Dr. xxxx. He's a wonderful man, I just love him. But he would get one of those little needles like this in my neck and they didn't work, so I started going to Dr. xxxx in Toledo. And he gives to me with a long needle like this (chuckles) with an EMG probe, puts it way down deep in my muscles. And so I get relief from that.(turned other tape)

- How do you think your beliefs and your religion have influenced your pain experience?
- That's very interesting because, I... well I have been going to church, but then I had to quit going because I couldn't sit up and .... (crying) I just found it very, very difficult to pray...uhm...or to depend on G-d for help. Somehow, even though I know that I should and it probably would help, I can't do it. I can't think of anything in particular right now. There are things that I know that I should do, and I don't. I can't. Um... also during all this, I had to have a heart ablation. Which I didn't want to have, but I had to. And um... right now I'm having a little pain in my heart... But ah... But the things like praying and going to church.... going to church I can't do. But the praying I find hard to do (crying) and I don't know why.

- Do you feel helpless?
- Uh... about 95%, I guess. Because I guess that from what I've read, 10% of the people who have ST have remission. Now, remission can go from two days to forty years. One woman got remission for forty-three years. And I think 'oh, how wonderful that would be'. So I keep hoping that I would be one of those. So that's my hope. And the fact that I'm going to Dr.xxx, who is a very young doctor. And he's willing, he's more aggressive, and he's willing to try things.

- How would you describe your quality of life now?
- As to what?
- Well, if you compare it to before the pain.
- I might as well say there's no quality. I don't really have things to look forward to (voice shaky). And I just live the days that go by...

- You said you noticed changes in your sleep or you're sleeping more?
- Um... at first it didn't bother me, and then it got...the pain got so bad that I couldn't lie down. And for about nine months, I slept in my chair and that was even painful. And now I take enough medicine before I go to bed that I can go to sleep and I sleep fairly well until about... it can be anywhere from three to five, once in a while six in the morning.

- Is that different from before?
- Uh-hum. I used to be a good sleeper before the pain.

- Have you noticed any changes in terms of your appetite or feeling hungry?
- Uh...yeah...I don't... I don't eat as much, I have lost a little bit. I think some of the antidepressants have done that.

- How would you say your self-esteem is now?
- Well, I don't know. To me, self-esteem I think means something different than it does to some people.
• What does it mean to you?
• To me, self-esteem is what you feel about yourself inside about who you are. What I know inside, what I can do, who I am. But I realize, too, that I can’t do those things anymore (crying), it doesn’t mean that I’m a different person ’cause I’m not. I’m still the same inside. So I would say that my self-esteem is still good inside because I am the same person, I want the same things. But what I feel is, maybe somebody would say low self-esteem, I call facing reality. Facing reality is that my body can’t do what the person inside wants to (crying).

• What is that like for you?
• Depressing...Depressing to think that I’ll probably never get to travel... depressing to think when and if I ever have grandchildren, I want my kids to get busy, that I can’t do a lot of things with them and they will look at me and think of me as old grandma that can’t do anything ’cause she’s sick all the time. I never had a grandmother and I want my grandchildren to remember me as someone who did things with them and stuff like that. Here I’m talking about my grandchildren, I haven’t even had any. I want them so bad. But also the same goes for my kids. You know, I want them to... I wish they could remember me ten years ago... fifteen years ago instead of now. My little girl won’t. She’s not my little girl now, but she’s 20. She’ll not remember what I was like fifteen years ago.

• When you could do what you wanted to do...
• And when I could laugh and smile and do things with them...Take them to their ball games, their soccer games...

• How are you doing right now?
• It’s just sad to think about it. My head’s starting to hurt. I think it’s from this hard wall (chuckles). Next time I’ll bring a pillow.

• I wanted to know if you have anything that you would like to add to help me understand what the chronic pain experience is like for you.
• It’s frustrating. That is the one word that I have felt from the beginning. Very frustrating when you can’t get rid of pain no matter what you do. Now, there are many days that go by that I am without much pain. Like when I walked in here, I didn’t have any pain. But it’s very frustrating that I can’t turn my head, I can’t do the things I want to do. And it’s scary because when I try to... say, when I go out and drive the car, there are certain circumstances that are just not safe for me to be in the car. I have a special mirror across the front, but I need another special mirror so that I can see what’s coming exactly this way. I can see all around me, except from a right angle. So I need some... so I just have to make some allowances with that.

• Do you have any suggestions in terms...for the interview when I interview other participants that will be coming after you. Do you have any suggestions, any improvements, or anything that you would have liked to have been different?
• For the interview?
• Uh-huh. For the interview process.

• Well, you let me ramble on... and I think that I rambled on and maybe didn’t answer some of your questions.
• You actually did...
• ...exactly like I should have...
• You gave me a lot of information...
• I gave you a lot of information. But was it really information you wanted? (chuckles).
• It was exactly what I was looking for.

• O.K. A lot of people who are in pain all the time, you know that’s all they think about, and when they start talking about it, you can’t get them stopped and then they go off and tell things which are totally irrelevant to the pain. I mean I recently experienced that.

• I have actually one question that I hadn’t asked. So there’ll be one, and then we can finish up. Has pain influenced sexual activity in any way? Has that had an affect?

• O.K., see, it’s very interesting and other people have said this too... that when you’re having sex, you don’t notice the pain.

• Is that what it’s like for you?
Yeah. Now, I’m talking about ST patients. Now, I’m not talking about people who’ve had back pain or leg pain or something like that. My experience with ST is that my neck could be hurting so bad, but during sex I don’t notice it. But in that way, I would say the pain itself has not affected. However, the medicine you take affects it. Because I’m on anti-depressants, which depress your sexual desires and also your ability to really enjoy it. So it’s usually, for me, it’s the medication.

It’s an indirect relationship... So we’re going to turn off the tape...
Appendix X

Tina’s Second Interview
Tina's Second Interview

- I see I don't finish a lot of my sentences... that's something I need to work on.
- It's weird to see conversation written down. Have you had any thoughts since our last session in terms of what we talked about in here?
- No,
- Do you feel that we covered what is going on with you?
- I think so. I think probably what I did is spend a lot of time on my disease, maybe more than you wanted me to. I don't know... maybe I should have concentrated more on pain because this is about pain and how it affects our lives, right?
- Right. Also the disease is important. There wasn’t anything specific that you needed to spend more time on. I had a couple of questions to ask you. In interviews, other participants, as well as you.... I get the impression, and you can tell me if this fits for you as well, that when you get chronic pain, that there's a change in terms of your self-concept. In terms of how you see yourself or who you are... kind of like your old identity is altered in some way and you need to find a new identity. An adjustment situation... kind of like a part of you is gone and you need to figure out who you are again?
- That's true and at first you don't... I didn't accept it.... I wasn't going to let it get me down. I was going to fight it and I was going to overcome it and it wasn’t going to affect my life. So I fought everything that was very obvious to me I fought it regarding the pain and what I couldn't do anymore. After learning about ST and what it does to you and there's no cure for it and it stays with you forever. Gradually, I began to accept that there were some limitations and then with that comes a lot of depression. As far as self-concept, are you talking about self-esteem... or not?
- I'm talking about who you are, who your identity is.
- Well, I knew I could no longer do the things that I have been doing. What you say is absolutely right, but it doesn’t happen overnight. It didn’t happen overnight with me. Maybe some people say O.K. this is it and wake up the next day and they’re all adjusted. But for me it was a long, long time. During that time, I became very depressed. For about two years, living with terrible pain and being so depressed. I sat in my favorite chair for about two years and did absolutely nothing. I wouldn’t even pop the t.v. on, but just sit and stare into space.
- For you, learning that you had ST, trying to fight it, and then realizing that you started seeing some limitations.
- I just had to learn that there were certain things I could not fight. I could try, but it wasn’t doing me much good. That's one of the reasons I went to the pain clinic, it was a pain management group. I thought that there I could learn some things that could help me and there wasn’t too much that I learned that I didn’t already know cause I’m the kind that digs and researches and does detective work. I‘m medically inclined anyway. I’m interested in medicine, the medical field. So I pretty much knew all these things already when I came in. There were some things that I did learn. I did learn some types of pain...
- So when you went through the program here, this was during the time that you were fighting it?
- Yeah, I was still fighting it. I was still in a lot of pain. I was getting botax injections, but they weren’t helping very much. Now I’m getting botax injections and I’m almost without pain now. I can make pain. I mean I can do things that I know I can’t do without pain. If I try to turn my head over here. If I try that, I get pain.
- So you were fighting to keep you old identity, your previous identity and then you found yourself in a situation where you couldn’t maintain it and now... have you formulated a new identity for yourself or do you see yourself still in process of doing that?
- I think I’m probably still in the process, but I always said that it has completely destroyed my life. It did destroy my life as it was and now I have had to make a new life. And the way I had to finally put it was I’ve lived different chapters of my life and this is just a new chapter. I’ve had to start over my life about three other times. And I had hoped that that was the end of it. Especially at my age. I don’t want to start over all the time. But I’ve had to. Nothing is the same.
- And you were able to start your life over at those other instances?
• Nothing is the same as it was. I became so depressed that I ended up with the psychiatric center here and stayed for three weeks. And then I was in group therapy for about nine months which became a real drag because I wasn't interested in the other people's problems. I have enough on my own, and what I really wanted was one on one.
• You wanted someone to listen to you.
• And I never really got what I wanted.
• How do you see yourself now, how would you describe who you are, what you are right now? I know you're still in the process of forming more of yourself, how do you see yourself?
• Well, as I feel better because of botax injections, I want to do more and I have started a weekend job which I do from home. It's an answering service, I'm on call for a company and do coordination for a health care company. I can do that from home.
• In terms of you working, that's become a part of who you are?
• Yeah. So the fact that I can do something is better than (hard to hear because crying)
• Is doing something, is that something that's important for you? Is that...
• I found that it is. I always felt wouldn't work unless I had to cause I'd rather be home. But I guess the fact of the matter is I'd rather be home, but I don't want to be home and do nothing. So I have been consciously and devotedly trying to find, trying to do something every day and, that's meaningful, and starting to do some things that I used to do a long time ago. And I haven't for a long time. And I find that on the days that I don't have anything planned, it's very easy for me to get up in the morning take my pills, sit on my chair, read the paper, go to sleep, and sleep until noon after I haven't sleep all night.
• If you have scheduled activities...
• Right, like coming here...
• That makes you feel better (yeah) and improves your mood. But if you don't have anything scheduled, then you stay in the house and you feel more down (uh-huh).
• I don't want to go out. I don't like to go out. Yesterday and then this afternoon, I will be too. I went up to the office that I do the work for on the weekends, And I stayed a few hours, I didn't like it at all. Now I could not have done that a year ago for various reasons. One, because of the depression, and one because of the pain. But, surprisingly, I was able to sit there for a while and do things. But I had to get up and walk around (phone rings)...As I say, a year ago, I would not have been able to sit here in this chair like this without something to hold my head up. I'm holding it up with my hand now. but I can sit here for a little while. Basically, I'm talking about reclining.
• If you have, let's say, scheduled activities daily, then you would be more active and feel better?
• Well, I see what you mean, that's the conclusion you would come to from what I said, but I can't take too much. If I had something scheduled everyday, it would be too much for me. I couldn't handle it.
• O.K., so what would be the right amount, the optimal amount of activity?
• If I have a couple days... or like the weekend makes it nice. And then .... you see, I don't even like to go out and shop anymore.
• So there's some activities that you used to enjoy before and now you don't enjoy (right) and you're finding that there may be other ones now that you would enjoy?
• Yeah. Years ago, I used to sew a lot and I haven't done it for many years. My son recently bought a house, and he decided he wanted mini-blinds on the windows with these little balloon valences and so I offered to make those for him. I told him the other day that I was glad that he wanted me to do that because it made me feel so good. I felt good sewing again.
• Did you feel that you were needed? That you were doing something productive?
• Yeah.
• I think we all have the need to feel productive and sometimes it's harder to find an outlet to do that because what we did before, what you did before that gave you that satisfaction is no longer. You need to find another outlet. That's tricky to find.
• I'm going to try to.... my house is such a mess because I have neglected it for long. I've got to get that done and the garage is ... I don't know a word for it, it's a mess. What I need to do is just set fire to it to get rid of it. It's going to be a very big job, now when I get into it I will feel good. It's getting
started on it and I'll feel good throwing stuff away and what I really need is a dumpster. start throwing stuff away and I called to see how much one is. It's like $200 a day or something. I thought my God, you know, I can't afford that.

- Another question that I had is from hearing you and other participants, whenever you do something and there's a pain in terms of having to pay for it with pain later on or maybe risking financial support - financial compensation, altering an activity, or maybe having to change how you do what you want to do. Does that fit for you?
- Yes, it's true.
- What's it like to have to think about that or do you think about that?
- Yeah. I think about it everyday. A year ago, again, I couldn't have driven to Toledo, but the last time that I had my injections scheduled, there was no one to take me. So I went by myself and I did great on the way up, I did great on the way back. I had no pain. But, boy, the next day I paid for it with a lot of pain because of .... You don't realize when it just comes naturally and you don't have a problem, but you use a lot of muscles and they're tense. I have to sit in a different position and I can't see to the right so I have to make allowances for that. So the next day, I really pay for it.

- How do you yourself decide to do an activity or not knowing that you will have pain during or afterwards? Which activities do you do, how do you go about making that decision for yourself?
- Well, it's like the financial thing that you mentioned. You know, it's like they don't want you to get well or they want you a 100% well. There's no in between. You are either to be totally dependent on somebody else or totally dependent upon yourself. There isn't the kind of help that you need in order to be as independent as you can be and not be totally dependent on someone else. Do you understand that?
- Yeah, so they want you in either one or the other (right).
- So it's like they keep you down because if you make anymore over a certain amount, then you lose your benefits and you don't always feel like doing some things so maybe one month you're feeling great and you can do it, but you cannot keep up the pace. You can't keep up the pace for two weeks in a row.
- So you could do some, but you couldn't do as much as necessary to be self sufficient.
- Yeah.
- That probably makes it harder in terms of developing a new identity. Trying to find a way to express yourself and at the same time you may have the desire, the energy, and the motivation to do that, you still can't do some things that you want to.
- If I could have help with just a few things, I could do so much more. But that help isn't available. You have to be either in bed paralyzed or over 65 or .... if you're able to breathe on your own, getting help..... if you've been raped or abused by some man, you can get help. Those are the only people that really get help. I found that out after my daughter had been attacked and, she wasn't raped or anything, but she was brutally injured by someone she didn't even know. She was in the emergency room and she had her head cut open. There was absolutely no help for her. But the booklet that the police give you when it happens to you, oh it's full. And it's full of places to go. and it's all for rape victims and abused women. If you're just a victim of somebody on the street, you're on your own. That's the way I feel. My position is that if I could get a little bit of help to do something, I could do so much more.

- What about when you decide to do something that's not related to work, maybe in terms of going somewhere or doing something in your house, how do you go about making those decisions and deciding what's worth pain and what's not?
- Um... well, with some of the things with mine, the more active I am the better I feel, but then I get very tired. I do have some pain depending on what I do and so I plan if it's something that has to be done or I want to do it and I know that I'm going to be tired, I allow myself the luxury of time doing nothing, resting, taking a nap. Relaxing, going to bed and reading or reading until I go to sleep or a relaxation tape.
- So what's optimal or best for you is doing a certain amount of activity, but not to the point where you exhaust yourself and then having a resting time.
• That’s what I tend to do is that if I’m feeling really well, I do a lot of work. And then I’m so exhausted, that I suffer.
• Maybe when you get the motivation to do something, maybe you go too long because you’re so excited because you’re in that road (yeah!) and maybe restraining yourself and stopping early and saying O.K. I still feel good...
• Excited is the word that you need. To be excited, to be able to do those things that you haven’t been able to do for a while. And I also live with the fear that tomorrow I could be just like I was a few years ago.
• So you keep yourself active...
• But there’s nothing that I can do ... I mean it’s something that comes and goes as it wants to. You don’t have much control over it.
• Are you talking about depression?
• No, the physical pain. You don’t have control over how it progresses. That’s very frustrating. The term I have always used with this is frustrating. You know what you want to do, you know what you can do and you can’t do it and it’s frustrating. The two things that help me the most are the relaxation and visualization.
• In terms of the things that you learned in the program, how did you find it for you to be able to continue doing what you learned in the program, were you able to do that or did you find you had difficulty?
• When I was here, no one can imagine, and I’m not the only one, the others were too... you can’t imagine how difficult it was for me to come everyday because there’s no chair... well, there’s one... there’s no chair in this place that I can sit in and be comfortable. So my pain all the time was very severe and I just could do some of what they said to do, but it was not helping my problem. Then we went for a walk everyday. When I went home, I tried to keep that, but I just felt so bad.
• Would it have helped in terms of the program to have spent some time in developing a new identity in terms of exploring possibilities for doing things and expressing yourself?
• Give me an example...
• Um... let’s see. In terms of fighting to keep who you are, to keep yourself as you were before, and in terms of having limitations that you can’t do what you did before, and having to find new ways of being able to express yourself, would it have helped in the program, if it included new ways of expressing yourself exploring more who you are and what you’re about?
• More psychiatric....
• Not more psychiatric.... I guess being more in touch with a way to define yourself and express yourself.
• Um...yes, but with the program designed the way it is, there was never time. I understand it used to be a six week program inservice and now it’s three weeks. They just run you ragged. By the time you get home at night, you would be so tired. You just want to go to bed and not wake up until the next morning when you have to.
• If the program was structured differently, exploring self-concept, having that in there. What would have been appropriate timing for you, you said at the time you were still fighting it? So maybe helping you redefine your identity would have been too early? When you’re still trying to keep your previous identity...
• Well, I don’t know .... I think anything along that line is helpful, but I don’t think that it can be accomplished in three weeks. Maybe something very simple and something to give food for thought. Maybe weed out some of the things that I found and the others did too was wasteful for us was how to do things. How to make adjustments like how to make a bed, how to sweep, and how to do all that. I mean we already found out those things on our own. We didn’t need that. There probably are some people, though, that could need that. So just what I said, I don’t feel that the program was designed for someone like me and you could replace that with lectures on how to use different methods to accept and deal with who and what you are and making a new.... not a new person.... but a new life that you have to work with.
• And that’s what you’re in the process of doing right now?

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• Yeah.
• I hope that when we do the group session that it can be an experience for you in terms of hearing what it's like for other people. What I'm gonna do in terms of the group is that I'm gonna bring a couple different theories or diagrams from all the different experiences that I have heard and we'll see how those fit with each of you (hard to hear).
• One thing that doesn't bother me that does bother some people is the reaction of other people. All the time I get, somebody says -oh, you have a stiff neck today? or did you hurt your neck? or were you in an accident? In fact, I like to be able to say to them- no, I have a neurological disease called spasmodic torticollis. What, what's that? So, you know, it's kind of fun for me to be able to do that. Depends what kind of mood I'm in. Sometimes I just say I have a neurological condition. Then they have all these things that I could do to improve - you could go to a chiropractor and get rid of that or you could do this or you could do that - physical therapy. They always want to heal you. Well, nobody wants to heal me better than I do. Something I did just learn and I think I'm going to take advantage of it is that there are massage therapy schools in Columbus whose students will work on you for a lot less than you would have to pay a massage therapist. Just like if you go to a beauty school, they do your hair cheaper. Just hold your breath. I think I'm going to try that out because I know that that will help me, but I can't afford to get that. Nobody wants to pay for it. I'm on Medicaid and Medicare and nobody wants to pay for alternative types of medicine and I know just by when my daughter works, that feels so much better than other things. I just know it will work.
Group Interview

I = interviewer; B = Brian; J = Jennifer; K = Kelly

I-What I wanted to focus on first, if we look at question one...try to think of yourself. Do you see yourself as physically active or do you see yourself at home most of the time? It may not be exactly one or the other...it could be on a continuum. If you had to choose one, which one would you choose? You can go ahead and mark this on your paper if you want.

B-In my case, I don't have much option. I'm home. I'm physically active at home. It's the fact I'm limited by transportation and so forth. The only time I get away from the house is meetings like this, to see the doctor, or whatever.

I-So what's it like for you, K?

K-Same thing.

I-The same thing?

K-Yeah.

I-So one of the factors that limit you at home is transportation.

B-Or somebody being there with you.

I-Or somebody going with you?

B-Because I'm really, in all reality I'm not supposed to drive, but I do.

I-So in order to get somewhere, you would need somebody to help you out, especially with the driving and to help you get there.

K-I drive, but I don't like doing it by myself.

I-You'd rather have company.

K-And most people are working and everything else, so when you have to quit your job and all the other associates are working.

I-It seems what I'm hearing...one of the main reasons for staying home most of the time is because of transportation. Because you would need someone to help you out to get you places or to drive you.

B-I'll give you an example, my wife works here at the hospital and in order for me to get here, I have to get up with her in the morning. We're talking 5:30. She clocks in at 6:30. So I sit and wait in the clinic until my hour comes around. Like when I leave here today, I'm going to sit in the clinic till 3:30 unless she gets out. So these...

I-That's a big issue...

B-Yeah, it is. These are not that easy to attend. But I can see the importance of it in your situation. If somebody were (knock on door). (introductions)

I-What we're gonna do is that we're all discussing this form right now and probably what would help me since it's probably gonna be hard to hear you on the tape is if you could write some of these things down
as we’re going along. O.K.? We just looked at the first one. In terms if you had to choose one, do you see yourself as physically active or at home most of the time? What we just talked about, one of the more pressing issues of staying home most of the time is transportation.

J-Mine’s not transportation, but I’m home most of the time.

I-You’re at home most of the time?

J-Yeah.

I-How did you come to being home most of the time?

J-Just the pain is too much to go out. You have to deal with walking. And sometimes it gets to be too much.

I-How does it affect you, looking at the next one - question one.... how does it affect you to stay home most of the time?

K-I get moody. The more you stay home, it seems like the more you want to stay home.

J-I get depressed.

B-It’s definitely depression because the four walls come crushing in on you especially in the cold months. In the summer time, I can get out and work in my flower garden and so forth. In the winter time, you climb the walls.

I-It kind of drives you crazy?

B-It’s definitely depression. You get to the stage where you actually start feeling sorry for yourself.

I-So in terms of... either because of the pain or lack of transportation... for one of those reasons you find yourself staying home a lot, and this gets you down...

B-Well, the biggest issue there is really you don’t have much choice. Again, you’re forced to do something you don’t want to do.

I-Staying home...

B-Staying home, yeah.

I-What could be some things that you could do to change staying home all the time? Are there any things that may have worked for any of you?

J-I try to walk.

I-Walk?

J-Walk. In my neighborhood, you walk with caution (laughs). So I’d rather stay home than deal with the teenagers.

B-Yeah, that’s a bad problem everywhere. My situation is I live basically out in the country. It can get ten miles before you see a service station. So you can take a walk, yes, but it’s just for exercise only.

I-So one of the things you can do to not stay in your house all the time is to go out and take a walk. It can work in some situations, at others it may not work too well, like in winter.

B-Weather permitting.
I—Well, can you think of other things that you could do to not be home all the time?

K—I just try to be as independent as I can be. Still try to do for myself, but it gets hard when I can go to
the grocery store. I’ve been using one of them carts that you sit in. I went over one night and played with
one. So I started using it...

J—They go so slow (laughing)

K—Myers on north High don’t.

B—North High, where’s there a Myers on north High?

K—Right on Powell Rd..

B—Close to Delaware, O.K..

K—Yeah, brand new.

B—Right on 23.

K—Yeah. But it seems like then I get disgusted because I’ll go and you always buy more than what you go
for.

B—You know what the clue to that is?

K—Don’t take much money (laughs). That’s why I leave my credit card home and try taking only twenty
dollars.

J—Eat heavy before you go.

K—I’ll try that.

I—Don’t go on an empty stomach.

K—Doesn’t work with me. If I see something on sale, I’ll get it. I’ll use it three weeks from now. I’ll get
it.

J—With carts, they put all the good stuff right there. And everything that’s healthy, you got to get out of
the cart to get it.

I—Ha! I haven’t thought about that.

B—that’s suggestive marketing.

J—It’s real hard sometimes cause you gotta get out, you either gotta bend over, you gotta get out to shop.

I—Yeah. you can’t stay in the cart...

K—I get so proud that I can do that, but then by the time I get the shopping done, get it out and get it in my
van and get it home, sometimes it stays out for two days if it’s not spoilage because I can’t get it in the
house and put the rest away. So I gotta depend upon... I hope my son comes. I hope my son comes. And
I don’t want to call him and tell him I’ve got stuff in the car, so I just keep saying I hope he comes and
then I tell him there’s stuff in the car. I just don’t get a good feeling then.
B- With you saying that, that's a structure throughout. I'm sure everybody has the same problem that I have. You don't abuse your friendships, especially with your family. So a lot of things just doesn't get done.

J- You try and do it yourself.

B- That's right.

K- And you end up hurting yourself more by trying to keep with a 12 year old. He's here because I'm his slave. He refuses to do a lot of things and he's capable...

I- ...of helping you...

J- Yeah. And it just puts more on me.

B- Why do you let that happen?

J- I'm working on it (laughs). You know he's been around.... he was born when I had the pain. So he has lived 12 years with me with pain.

B- It's no big deal to him...

J- And to him, he doesn't understand what my pain is. To him, sometimes it's an excuse because you want to be lazy or you just don't feel like doing it, you want to sleep. You know, it's hard for him to understand it.

I- So it seems like what you're saying, to relate it back to getting out of the house, that some ways that you try to get out of the house like being more independent and doing things on your own, and sometimes there's only so much you can do where you need or have to start depending on other people. And what you're saying is that sometimes those people don't help you.

B- Even doing that, it has its ripple effect. If I got out and started doing something on my own without correct supervision around me, my wife reads the right act to me. She says why should I be working everyday and have to worry about you running around? There's always...

I- So you try to be independent and it backfires.

B- Yeah. Of course, she's got my interest at heart. She's got enough problems on her own just facing day in and day out living.

I- So then in terms of getting in and out of the house, there's transportation, there's supervision, being independent. So you can say that you're going to go out and be independent and then all of a sudden you come to a limit where you either have too much pain you can't do anymore or (laughs) you're getting in trouble.

K- Just like the other day now. My mother's over here in intensive care all week, so I don't work, so I feel like they have got to the point where they're pushing me to be there. I want to be there, don't take me wrong, I want to be there, but it's got to the point now where 'you don't work, you're there'. 'We're going back to work, we work'. I told them yesterday, I said I've got a meeting. 'Well, you can cancel that meeting'. I said oh no I can't! I am going to my meeting.

B- Is this all family?

K- Yeah. I said mom will wait on me and I will be back over there. But .... and then my one sister in law....see I got my disability and social security things in early and all, so when ... I don't know whether you've ever been over there over at the intensive care unit over there...but, it's weird. From eight o'clock in the evening, we've been staying sleeping in chairs. From eight o'clock in the evening till about nine....
well, they still hadn’t had a volunteer yet... so it’s about 9:30 or ten o’clock a volunteer comes on and they’re only there from ten till eight. And then after that, the visitors are expected to answer the phone. Well, sure I got this and everything, but the phone rings - I jump up and get it. Or you know, jump up the best I can and my sister walks up, ‘what the hell do you think you’re doing. You’re supposed to have pain, you’re not supposed to be answering the phone’. I was keeping my mind busy. I was making myself do it. Being helpful and I mean I felt it but I had to do something or I was going to sit there and scream. But then if you get your disability, then they say you ain’t supposed to do nothing now.

I-So there’s a struggle between being expected to do things because you’re not working and at the same time when you do something, then being shot down for it.

K-Yeah.

J-Some people with pain get a burst of energy.

B-Is it a burst of energy or is it the fact you’re trying to hide it?

J-I don’t know. Cause I know when I’m in crisis, I just seem to have more energy to get it together to do the things that were necessary than my sister. I just have more energy to do the things that need to be done. You know, regardless of pain.

K-The last year I worked, I was having that problem I would go to work and I knew that’s the only way I got money was work. I didn’t care whether I cleaned house, I didn’t care about nothing else. I had to work. I would go in there and I would work. The minute I clocked out, I don’t care whether I would work six hours, eight hours, ten hours, twelve hours, it seemed like I made it until I clocked out and then I literally fell to pieces.

B-Reality set in.

K-I would... yeah. I would cry all the way home. I would sit there in my van, couldn’t get out of the van. And then everybody at work said, ‘there’s nothing wrong with her, she can work ten twelve hours a day’. I wasn’t doing it everyday, but I knew in my mind I’d always be a workaholic. So to me, I didn’t want to give up.... to me, it was a punishment for somebody else to get the overtime when I want it. I had the seniority, it was supposed to be mine and I’d do anything I had to do. And yet they would go home, go out and party; they was married, go home and cook supper. I’d grab me a Wendy’s or a McDonald’s on the way, eat it on the way home, went straight to bed. See, nobody ever knew that side of my life

I-This brings me to the next question... well, actually we’re gonna skip a few.... number four, do you see yourself.... can you share feelings of pain or do you hide your pain?

B-How in the world would you share feelings of pain?

K-Nobody wants to hear it.

B-Seriously...

K-Nobody wants to hear it...

B-Hide the pain, yes. But even with family, close ones. Like in my case, even my wife. If I’m continually complaining about my pain, before long she’s gonna turn me off. And I’ll become a nuisance or a burden to her. But if you have love for your wife or caring, you can try to keep the pain away from her because she has to live her day too.

J-I try to hide my pain as much as I can so that he doesn’t feel like gee - you can’t do this, you can’t do that. I try to hide it as long as I can to do things with him.
B-That’s process of elimination. You’re already, in your mind, you’re a burden to everybody around you. So in order to keep pace or keep some kind of respect or even a phase of love, you try to hide this. Because you don’t want them to look at you and feel sorry for you.

J-Bad enough as it is. I can’t work. I feel like I’m not supporting my son. You know, and then on top of that to say, you know, gee - I’ve got this pain, that’s very hard.

I-How does that affect you to hide the pain? What does it do to you?

J-It tears you up inside...

B-It just shoves you further in that hole. If you build that wall around you, then the hole keeps getting bigger and bigger.

K-Then you’re afraid to say - well, I want to go here or I want to go there cause you feel like they’ll talk about you if you do then. It’s like, you know, we’re going through a whole hassle over here and I hurt and I go in there and if I’m quiet - ‘what the hell is wrong with you today’? You know, ‘who pissed you off’? I said, to my brother. maybe I am. And he says ‘what the hell got you?’ And he just kept at that. I said, ‘shut the hell up’. And then I’m wrong now. Everybody is mad at me because I took my side and I just wanted to be left alone. I mean I was joking and teasing a couple days. I’m just completely tired now and now this afternoon I’ll get a little spurt of energy. I’ll be O.K.. I just want to be left alone. Now, I was wrong because I yelled at him. But I tried to say just leave me alone. They think if you’re quiet then just stop that, something’s wrong.

B-What works for me, I know the situation you’re talking about, I developed and became callous to the fact. I don’t care what they say about me. Let them say whatever, doesn’t hang on me.

K-That’s what I said yesterday.

J-If I’m having a bad day. I usually let people know - look, this is not a good time. I’m having a bad day. You know, we’ll talk about it tomorrow or whatever. But today is not my day.

K-I almost want to cry -‘I’m all right, just leave me alone, I’m all right! No, you have to be pissed, what’s wrong?’ I just say, just leave me the hell alone. Just leave me the hell alone.

B-But the bad thing about that attitude, it shoves you into that corner that much more.

K-It does.

I-Which actually, let me jump into that.... do you feel yourself socializing with others or do you feel isolated? And it sounds like when you get into the mood of you just want to be left alone...

B-If these ladies are like I am, I shy away from socializing because you don’t want to be the person they’re talking about or the person they’re running down. There’s always some person around that knows everything and he’s always the one or her sitting in judgment of you. And you defend yourself only so much. Other than that, you don’t go.

I-You find yourself having to defend yourself when you’re around people?

B-Oh yeah.

J-You get into a query and everybody will sit there -oh, she really came, she’s not as bad as she says she is. You tend to avoid things.

K-Just like over there. I mean, it is a long walk back to mom’s and when she was first back there, they’d get together two at a time, but not anybody - well, you can’t make it. I don’t care if I crawled, I should have been asked. I’ll go back with you if you want me to, but they just kept saying - well, let’s not ask her to go because she can’t go. That’s their opinion. I would have crawled if I had to. That’s the way people treat you.

B-That’s the same effect that a black person goes through basically.
K-Yeah, it honestly is.

B-You’re shot out. Or if you’re included, you’re talked about.

K-I’ve got... this year lately, I’ve felt more with this... I was running around with an older lady and all at once, she has just got so... I think we have talked about it... so negative. Everything’s negative. You know, this person does that, this person does that. I don’t want to talk about somebody else because I hurt and I’m just tired of hearing the negativity. And I had to come right out and tell her that I can’t do it and she’s on with the black deal and everything and I said...Well, you get into a situation like this and you think hey, wait a minute, you know. It’s not fun to be on the other side.

B-I had found out that when people have that kind of attitude, it’s a cover up for them. Because they don’t know how to handle you or your situation.

J-They don’t understand it.

K-Well, I wrote a letter telling her that I dearly... she’s about 22 years older than I am.... I told her I dearly loved her but I couldn’t take all this negativity and her talking about other people and getting into their business that didn’t have anything to do with her. And then she wanted me to go away to Canada to a Casino and I was gonna go. Well then three weeks before that, my mother started having problems. So she turned around and told some of her other friends -there ain’t nothing wrong with her mother. And now my mother is in intensive care and yet I want to..... we haven’t talked so much. She don’t even know it as far as I know. I keep wanting to pick up the phone and calling her and say -now see. Then I think - no, that’s belittling me.

B-Yeah, and you’re not the kind of person that does that.

K-That’s belittling me because she don’t care because she would have called and said I’m sorry, we’ll work it out. So she really didn’t care. And then she’s a smoker, I’m not a smoker. I have asthma. I don’t have anything against smokers, but.

B-As long as they keep their cigarettes away from you.

K-Yeah. If it bothers me and we’re friends ...if I smoked and I bothered a friend, I would do it elsewhere or I think I would. We would go to this little Irish pub and I’m on so much medicine that I can’t drink. but I drink 7-up or Odoole’s. She would just light one cigarette after another and then she gets up and just runs and talks and she socializes all over the place, but I don’t think she really has friends. I don’t really think she has close friends, good friends. She has them to where she buys drinks for them and you know all this, that’s the kind of friends she has.

I-And that.... in terms if you look at number six, do you feel like you have genuine relationships or do you feel like you don’t have close relationships or the relationships that you have are fake or shallow? Where do you see where you fit?

J-Lately, I’ve been learning that I have very shallow friends. It seems that they take advantage of the fact that you don’t go nowhere.

I-They take advantage of that?

J-Yeah. You’re always home. I can count on you, let me drop the kids off a minute, or you know, would you mind running this wash for me?

B-They’re actually that bold to bring their washing over for you?

J-Some. I get paid for it. It’s like they don’t seem to treat you....

I-As a friend?

B-They take you forgranted.
J-Yeah. You don’t feel like you’re a friend. You know, your problems they don’t care. They want to come run and tell you all theirs and take advantage of you.

B-It doesn’t take you very long to find out who’s genuine. My answer to that question is I’ve got members of the family that I’ve got a genuine friendship or an understanding, but I also have people that are fake and people that are shallow. When you have somebody that’s fake or shallow and they own up to that fact, they’re a better friend than the relationship.

I-They’re being real by saying that.

B-You know where you stand with them.

I-How do you think it became... do you think it’s always been that way in terms of relationships or do you think it has changed? How did you come to this point of realizing in terms of ... are friendships less real?

B-Being hurt.

J-Friendship change when, you know, you always have to say no just with things that you do, you know. ‘Oh, let’s go camping’ - no, I can’t do that. Or let’s go bike riding or doing things...

B-Physical.

J-Physical, I can’t do.

K-Or they quit asking you...

J-Then its like true friendship turns into something more like do this cause I’m going out for fun.

B-Maybe kind of distant.

J-Yeah.

K-Or you’re sitting there in a group and you know you got asthma and you’re coughing your guts out and you know you can only and I told them - ‘Well, I’ll come over but I’ll be there only a couple of hours and I’ve got to go cause I can’t stand the smoke’. And then you hear them say ‘well aint nobody gonna tell me where to smoke and where not to’. Here I am sitting right next to her and she’s supposed to be my best friend. And she makes a remark to somebody else and I’m sitting right there. Well, it hurt and I said I can’t take it.

I-In terms of those relationships where you used to be active and do something physical and go have fun.... in terms of question number two, it seems like from what you’re saying that it relates to being spontaneous. Do you feel as though you still have that spontaneity or do you feel more like a robot? Like you’re becoming more programmed, you have to think ahead too much?

B-Well, you do to cover up your own inadequacy.

J-(?) what you’re gonna do, you can’t be spontaneous.

B-To eliminate embarrassing them or putting them on the spot...

J-Or putting yourself on the spot...

B-That’s automatic, you actually putting yourself out like that. It’s a ... you’re almost in the limerod of, individually speaking, to be a robot.
K-You’re almost a prisoner of your own life.
B-Yep. Because you can’t hide the pain. I don’t care what facade you put on, that pain is gonna come through and it’s gonna irritate people. The people that are narrow minded that is. A lot of time I get vindictive I say ‘well, I hope someday you have to go through it. then you’ll find out what isn’t fake and what is’. It’s a horrible thing to say, but...
K-Then you get mad at yourself for feeling that way.
B-Yes.
I-Is it hard to find people that understand what you’re going through?
J-No
B-Most people don’t want to.
I-Don’t want to understand?
B-They got enough trials and tribulations in their own life. That’s the way this world is becoming. This world is becoming very callous. That’s the reason you have the attitude of kids today. I don’t want your problems. I got enough problems of my own.
K-Or they won’t accept you the way you are now. Do things... I’ve always been a giver. Do things for other people....Not the same lady friend, but another one that’s 75 years old. I’ve taken her for 20, 25 years to a grocery store once or twice a month. We get groceries, carry them in the house. I can’t do it anymore and yet....
B-She can’t understand it...
K-She can’t understand it. And then, like she was saying earlier, if I go to the store, ‘well, it must be nice’. And then she’ll call me ‘I haven’t had bread for two days; I can’t get up to go to the store; nobody will come get me take me to the bank’. And then I get mad because if she would actually say ‘hi, would it be possible for you to come over and take me to the bank?’. Then I would say we’ll make an appointment, you know like an appointment, and I will make myself do it. But she just calls and gets on the phone like she’s crying and everything and I mean she’s not crying but she’s whining. And then I used to jump in the car and go right then. And now I can’t do it that way, so then it makes me mad at myself because I can’t do for her.
I-It’s like the person that you were before, like as you were saying you’re a giving person...it’s hard to express that now, to be that way?(end of side 1)
B-....don’t expect it and forget it. Thank yourself for getting some help. I have totally closed my mind basically to the outside world. Becoming a robot. I know the situation. I know I have to go through day in and day out. Why should I add to my problems the fact that John Doe won’t help me? That’s human nature! They don’t ....they just can’t think any further than their nose!
J-They can’t think that you as a person still needs people. I do.
B-But you.... I found out I’m ahead of the game by being callous. Really. Because if you keep expecting it and you keep looking over your shoulder or you keep wishful thinking, you’re just adding frustrations to your life. You get yourself upset and then basically in time you’re still upset, but you can’t remember what you’re upset about.
J-I’m a person that don’t ask for help to start with. I’m in therapy to learn to say no and I need help.
B-I don’t shove (?) because again it’s a form of friendship, love, or respect.
J: It depends on how it's handed to me. You know.

B: Yeah, if it's a thing where I did for you, now you do for me, that is the tactic involved. Then you turn it down.

J: At times there's all these people coming in... what I learned when I went to the pain clinic here was don't try to be a perfectionist. If it doesn't get done, it doesn't get done. And I'll have people come in and say, 'oh, I guess I'll have to do your dishes for you'. So I look at them, 'no you don't... there's the door'. (laughs) They embarrass you so bad because there's little things that you haven't done and they'll

B: That's not friendship.

J: That's family (laughs).

B: It's not a real friend if he has a tendency to do that. But again, there's ways of working around that. I... basically what I do... I'll sit back and since we're all alone by ourselves most of the time, there's a lot of opportunity to, I'll sit and make a list on a paper of what my frustrations are during the day's time. If you don't do it, try it. You're scared to try it? And then eliminate those frustrations. Because the fact that your pain, wherever it comes from, is always gonna be there. Don't make your mind work overtime, but make your mind work harder or smarter than harder. That's how handle my frustrations - I eliminate them.

J: I read a lot of books. Just finished one, Take Effective Control of Your Life. Try to learn how to know who I am and what I'm about. And it's hard with pain.

K: Did you read one, Who's Grabbing Your Vest?

B: I had someone tell me about that.

K: That's pretty good.

I: Do you feel as though you've become a different person since your pain?

K: Yeah.

B: Definitely, for sure. I'm not the go-getter I used to be. I'm not the crowd pleaser I used to be. I'm not the joker I used to be.

J: I'm not the supporter of my family. You know, they've taken my livelihood away. I can't go out and work a job and that's the part I miss. You spend eight hours that you should be working at home and then you're there the other sixteen hours. It's just...

K: Like I was talking to a psychologist that I go to, and she told me, well you did too, told me to check into some volunteer. So I was starting to do it before mom got sick and I had to put it on hold. But, I mentioned it that I thought I would try to do a couple hours, you know, a week. Build myself up trying to do some volunteer. And I guess my one sister-in-law told my sister, 'well, if she can go out and volunteer, she can get her ass out and work like everybody else does'. And... so I'm doing everything I can do in my power to even look at her over there. And I don't like it because I feel that way. But if I come up and tell her that I know it, then I'll get my sister in trouble because she told me. It's starts a vicious circle.

I: And it seems to be able to get in touch with yourself and to feel fulfilled again, to feel productive again, there's a lot of obstacles out there - either other people, the system. At the same time, that's something important to benefit yourself.
J-I feel there’s no quality of life left. It’s like you wake up every morning to the same thing. There’s nothing quality to go out and do, you know, to say ‘gee, I feel good today because I accomplished’.

B-Everybody is in judgment of you.

K-That’s what I was gonna say. Now somebody will look at you and say, ‘you’re not allowed to feel good’.

J-I like to feel good if I accomplish-

K-Or I want to be on the drugs that you’re on (laughs). That’s what I get a lot of the time. I’ll have a good day or something, I’ll laugh or joke, or pep up or something - ‘what the hell are you on; I wish I had what you’re on; you always on drugs’.

B-Are you on any now?

J-You always on drugs. Right now I’m on antidepressants and then on I’m something for my bladder, which is also an anti-depressant. They’ve had me on 27 pills. I’m on xxxx and xxxx.

K-I like xxx. I’m on xxxx and xxxx.

B-In the clinic, I was taking Percoset. Anything I could do to (?)

J-I told them I function better if they would give me six Percosets a day. Two in the morning, two in the afternoon, and two in the evening. I don’t care, I get up, I function, and I feel better.

B-Do you know they say that’s the strongest drug you can get?

J-I was paying seven dollars on the street for it.

B-Wow!

J-I tried to find a doctor that will... cause for three years. for five years I was on Percoden and now they told me nothing’s gonna help you, go home and drink a bottle of booze everyday.

B-No kidding.

J-I said excuse me - I don’t want to be an alcoholic. I don’t want to be a drug addict. So I moved down here and I have been trying to find somebody that will work with me with medication. Right now I’ve lost... I’ve had 9 deaths in my family in four years. I’ve lost my whole family.

B-That adds to your problems.

J-I’ve had been beat twice and in two head-on car collisions. And all my doctor does is sign my papers ‘you have back pain and you’re a dope addict and you got pain, so you got to exercise’. They look at your chart and they see what you used to be.

I-They’re not looking at you as a whole person.

J-Right. I had something stuck in my foot. They have to dig into my foot so far. First time they numbed it. It started to get numb, they put some more in. I could still feel it. The doctor got so mad at me because he couldn’t get my foot numb. He starts jabbing a needle in that. I said I have a very high tolerance. I said I was on Percoden, Demarol while I was pregnant. I said, you know, I have a high history of drugs. I said don’t hurt me because you’re mad. And they had a hole that was about that deep in my foot. He walked up and said ‘but you’re not getting nothing for pain’. That’s what they tell you.

K-I got to the point where I was on over 27 pills. Just about six weeks ago and I’m down to taking four a day now.

I-Twenty seven. wow.
K-I just... I got up one day, I started to take them and I couldn't swallow and I literally threw them up against the wall. And then I went to my doctor and I told him, I said I'm tired of it. I'd rather hurt then be on all the drug because I was literally dopey. And then they said you're staying in bed too long! Why wouldn't you if you're on all these pills? Every three or four hours you have to take it and they knock you out for two hours. By the time you become alert again, it's time to take them again and you're knocked out again then. And then he turns around, he put me on one and then I was taking three other ones because I took the one. Then it gave me ulcers and tore up my stomach. So I told him, I said I am not taking the damn pill.

J-I don't take anti-inflammatories because they were making me real sick.

K-I had two ulcers.

J-When I took Percoden, it was like energy. Not sleepiness, I wasn't drugged. All the other medications I took, I was very groggy. I tell them you cannot be groggy with a 12 year old. He'll set my house on fire. He'll kill me. You don't know what a 12 year old will do. I said I cannot be in the bed all the time. I don't want to.

I-In terms of hearing each other, and I'm hearing you say a couple of the same things. Kind of supporting each other in what you're saying... I'd like to hear from you what it's like just to hear the other participants share with you what it's been like for them. What's your reaction of what it's been like in the last 45 minutes? We can start with you, J.

B-Well, it's not anything I wasn't thinking was the same as mine. Because after a while of living in pain, you know how people are. I can tell that woman is in pain. I can tell this woman is in pain. As far as effect, it has none on me because I know the situation.

I-What about you, C?

K-Not really. It's about the same, you know. You figure at least these two understand it better than, you know, a lot of the other people. If you haven't had it, I don't think you understand it.

I-And what's it like to feel understood?

K-To me, for me to be understood is to have people let me alone. Leave me alone and let me do what I could do when I can do it and when I want to do it and when I don't want to do it. Just let me control my life instead of always -well, you can't do this. They'll invite you to a party cause -oh, we were going bowling or we were going to do.... Well, why can't I sit and watch? You know, I can't throw a ball, no. But it should have been my choice. Well, we're going bowling, would you like to go? No. And that would be my place to say no or yeah I'll go watch or I'll go keep score. But you're not invited anywhere anymore. Unless it's something serious or sad. You're invited to something serious or sad just like it's my duty to sit up there now. Because I don't work, I don't have nothing else to do. So I have to sit there. They're going to work, and they're going there, and they're going there. I have to stay there, which is my place I want to be there, but they told me now that that's my job.

I-What about you, J?

J-Well, I think it's nice to know that there are other people that understand what I'm going through. You know, it's hard thinking this is me or this is only happening to me. You know, and sometimes you get caught up that nobody understands, nobody ever will. But then you meet people who are in pain, so you know that they have an idea of what it's like going through hard times with a son. I take a rubber band and wrap it real, real tight around his finger to try to explain to him that's how I feel in my legs. And sometimes he gets the message, sometimes he doesn't.

B-They don't want to hear it.
J-But it’s hard to explain to him who’s wrong. Now he suffers from jumpy legs. It must be in my family cause we all have, you know. we move our legs all the time and he has pains in his legs sometimes, but they’ve never been as severe as mine. So he understands, but he don’t.

B-Now her attitude - you want to be by yourself, just leave me alone. Again, that’s your.... I had the same feeling or the same desires. Again you’re supporting the fact that you’re a robot. My true feelings.... my true wants.... I want I’d love to live on a mountaintop somewhere all by myself, maybe just a couple of dogs or something, a vegetable garden, my flower gardens. To hell with the rest of the world. Because all that the rest of the world is gonna do is make you more miserable. Seriously. I’d just love to find a mountaintop somewhere, where you could pull the road in, and have a twenty foot fence.

J-He’s got my idea. I want a nice little place way out in the country, but then I start thinking who’s gonna mow the lawn, who’s gonna do the handiwork? You know...

B-Again, that’s the ripple effect of your desires.

J-Cause I...

B-You have to pay for anything you do anyway.

J-I got a small house now and it is so hard to keep up with it. Everyday repairs.

B-One thing my wife and I have done, to have something on your mind as far as being useful or having a function in life, we run a Boxer Rescue. We find homes for stray boxer dogs. We placed 135 boxers last year. Take them away from the street. That’s rewarding and plus you’re giving the wheel of your mind something to do.

J-I take in stray dogs. I have two and they’re both, they had traumatic childhoods. I think I’m the fourth one that each one of them has had. And then I have an iguana.

B-What in the world do you want with an iguana?

J-Let me tell you something. He is beautiful and he loves me. And they are the lovingest animals you’d ever want to meet. You know, personality...

B-Well, I’m gonna give it to you, because I don’t want one.

J-He’s so beautiful. He’s a pepperoni...

B-You call them beautiful and I say they’re ugly.

J-They’re not. When you really get them and feel them, they have... they have like pearladescent places in their face and it feels so beautiful.

B-They had a girl on T.V.. They were interviewing her and she had an iguana walking all over and sticking the tongue in her ear.(laughs).

J-He gets a little tough on my head. He thinks he’s my barrette. He’ll sit there and gawk at people. I call him my watchdog (laughs).

B-They have those rotating eyes anyway.

J-Well, but his don’t

B-They protrude, but when they look they look like they’re rotating.
I-I want to share with you that for the three of you being here...sitting here....I had contacted a lot of chronic pain patients to be in the study.... you three are part of the group of people that are more...that even though you’re dealing with all the hard things that come with chronic pain, you still have the motivation.... you still have the interest, you want to make things good for you, which is one of the reasons that you’re here or then you wouldn’t be here.

J-Mine’s more to try to help somebody else.

I-Well, what I wanted to do since you three are here, we have gone through common things, but of course it’s different because you have different lifestyles and different households and families and so forth. How can you, the three of you, how can you help each other, how can you support each other, how can you three together help other people with chronic pain? There’s not much right now that’s out there for chronic pain patients to help other people like them. The three of you have an opportunity here being together if you want to help other people, either by creating support groups where you can feel understood and supported or either social activity to get yourself out of the house and get you interested in.

J-I do tanning once a day (laughs). I go for tanning for twenty minutes and those lights make me feel so good.

B-Aren’t you scared of the ultraviolet rays?

J-The benefits I get out of it overwhelm me.

B-You can do whatever you want to do, but I was one of these creatures that whenever I’m outside working, I would never wear a hat. You see this block of skin right here? That was skin cancer and that’s artificial skin. It’s not real skin. But when they removed the skin cancer, they didn’t have enough skin to stretch across to reach over here. So they had to put false skin.

J-My sister is a constant sunbather. This is the tannest I’ve ever been in my life. I really.... I looked into it and as far as it goes with some benefits for people who are depressed and who have chronic pain and ....see I had a fear of going outside after I was attacked twice. I mean I was beat up real bad twice. So I got to the point where I didn’t even want to go out. This woman was after me. She hit me with a car, you know, so it was like (?). So just going tanning can and being in a locked room and knowing all these body builders were out there (laughs).

B-Now you tell the truth (laughs).

J-They were there to protect me.

B-The hidden desire.

J-They were not gonna let somebody come and beat me up. That started it, but then I noticed the benefits of it because when I do it in the afternoon. I get that burst of energy back. I can’t lay out in the real sun. because I get sick, but under there I feel healthier.

B-Of course you got the comfort zone of somebody around you.

J-Right. Like my therapist says, it’s like being in a womb. You know, because it closes you in and it makes you feel safe.

I-We have this room probably for about five more minutes, and I just lost the paper clip (laughs)...We have this room for about five more minutes and I wanted to make sure that if the three of you - if you wanted to continue staying in touch and if you wanted to start to think of other ways to help people with chronic pain, that you have a chance to do that. Would any of you be interested in something like that or do you have some ideas?
B-I definitely won’t.


J-There’s nothing like this outside of any kind... of any kind of support.

B-With me, it’s like taking on somebody else’s burden. I know, speaking for myself. I’ve got enough burdens in life just to handle myself. What little time I have left...at my age. I don’t have that much longer to live.

I-Would there be things that you would enjoy that you could do for yourself as well?

B-Perfect situation - leave me alone.

I-That works for you.

B-Yeah, really. The only person you got to answer to is yourself.

I-What about you, k?

J-I still feel I’m young enough... I want to be involved.

I-You want to be involved?

J-Yeah. This is not the way life is supposed to be and I want to go out and I want to enjoy things. My son just joined the soccer team. I want to go sit on the bleachers and enjoy watching him and not have to find a dozen pain pills just to go and watch his game. I don’t want to go like this.

I-You want to participate and if there is an opportunity for creating something to help other people...

J-I did everything that they told me at the pain management program. The exercise equipment at home. I use it. I just went out and bought a trampoline to fight my fear of ... I have this terrible fear now of falling and getting hurt again. So I got a trampoline.

B-Are your problems in your back?

J-I have degenerative disc disease in my back and....

B-And you’re using a trampoline?

k-Yeah. I have...they don’t know what it is in my legs. They call it neuropathy...I have real bad legs. But I do low impact. All I do is just bounce. Just a little bit of bounce.

B-That would kill me.

K-I was told that... I got degenerative disc disease and I was told to watch even going up and down steps.

J-I do treadmill. If you don’t pull your feet up off of it, you’re not getting the resistance bounce. What I’m working on now is strengthening my legs cause I do the treadmill and I got this (?) and I do that for my back. I do a lot of things. But part of that to is my son.

B-You know, I can ride in an automobile. I go to all the home games and I sit...

J-I drive.

B-Just walking from the car up into that stadium when I finally get there and I can sit down, I’m in pain. I’m miserable. I was just taking a ride in an automobile and I cried pounding up and down.
J-I use the hole that you put behind you... I can’t think the name of it, but...lumbar support... I use that, but then I know that like when I take my kid, I try to take him to the fair every year and that’s a ton of walking and that does it for me.

B-You say you’re still taking drugs?

J-The only drugs I take right now are the depressants. But when my pain gets real bad, like when we have a real bad winter, with all that pain, my doctor wouldn’t give me anything. I go to my nearest neighborhood druggist. What gets me is there are doctors out there that give all these prescriptions to people that go in and say ‘oh, this hurts’. I go in and I’m honest with them, and I don’t... you know, they won’t even work with me.

B-Do you have a history with that doctor about having had...

J-No, I’ve only had this doctor for three years. But since I’ve had her, I’ve been very honest with her. My mother passed away seven years ago, I got caught up in cocaine, marijuana. I still do the marijuana for jumpy legs. The doctor knows it. She...

B-They’re starting to prescribe marijuana in critical cases now.

J-I had a... a person I knew that had aids and he couldn’t get (?) and I couldn’t get pain pills. So we would help each other out. You know, cause pot would help him eat and then he passed away and so now it’s really hard for me to get anything. But the pot, if I smoke a joint, I could have a descent night sleep where if I don’t smoke one, I’m up all night long. I get real bad cramps in my legs.

B-That’s one of the things that I put the Chronic Pain Clinic on the back - they got me off of drugs and there’s no way I’d go back on them.

J-I don’t want to be on drugs. Being around people that smoke a joint every once in a while, this is what happens to me. You know, and then I have to suffer with this - with a chronic cough, doesn’t help the bladder problem, doesn’t help the back problem. You know, I’m in a cycle where I don’t want to be on any pills. My body wasn’t made to be on pills.

B-I take too many pills for my... I take Cumadin blood thinner for my stroke. And I take (?) to relax my brain.

J-That’s an inhaler, right?

B-No, it’s a capsule. And I take (?) for cancer of the bladder.

I-C, before we’re done, they’re actually coming to the room soon.... in terms of... do you have ideas or do you have a desire to continue something, somewhat of a support group. what are your thoughts on that?

K-I go to a support group on fibromyalgia cause I have fibromyalgia, too.

B-What is that?

K-Like a form of arthritis, but it’s with muscle instead of the bone. Your muscles hurt like heck across your shoulders and then it jumps from trigger point to trigger point. And you have trouble staying on a lot of drugs. You don’t know what hurts really. I mean, you get so numbed up you don’t really know what’s.... and this is where I’m going right now - I walked from the hospital over and for one reason I didn’t want to wait on the bus and for another reason, I wasn’t gonna get wet. So I said well.

B-I can’t get wet or I’d melt (laughs).

K-So I says ‘well, I might shrink’. So I says ‘well, I’m going through that tunnel. Now my leg is vibrating and I am going to make it back, but I will probably be in one of these moods that my brother will hit me again this afternoon. (laughs).

J-I can drive you back over if you would....
K-No.

J-I’m right downstairs in the parking lot.

I-What I wanted to say is I wanted to thank each of you for the time that you have spent in helping me with my study. I think, in terms of information you’ve given me and personal stories and histories, all that is gonna help me greatly to try to do the most that I can to ...

B-Question. I ... when do you get your doctorate?

I-My doctorate in six months. This is part of the dissertation I’m doing for my doctorate. And I worked in the chronic pain program last half the year and I want to know more about it and there was limited time in terms of individual counseling to see the participants.

(End of tape).