CONFRONTING AGING AND SERIOUS ILLNESS THROUGH JOURNALING:
A STUDY OF WRITING AS THERAPY

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ABSTRACT

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This pilot study asked whether people suffering from illness, injury, or the often dehumanizing effects of aging could benefit from the integration of written discourse as non-medical but parallel treatment options. As such, it focused on implementing writing as therapy, and involved three separate workshops, ranging in duration from 6-8 weeks throughout the fall of 2005. Workshop participants from each group were volunteers recruited through advertisements developed by the researcher and disseminated through the cooperation of three separate institutions located in Northwest Ohio. Specifically, one group of participants involved senior residents at a retirement community; a second group included clients at a local organization that offers non-medical support to cancer survivors and their family members. The final group was recruited from a hospital cancer support service, bringing the total number of participants across all three groups to approximately fifteen. Writing workshops were conducted separately, and in the case of the retirement community participants, workshop material was geared more toward reflective and autobiographical writing than toward illness and recovery. Ultimately, the variation in materials reflected participants’ reasons for joining the workshops, and the resultant exigencies from which their writing emerged. Implementing and expanding upon the work of scholars who advocate the therapeutic effects of writing, the study methodology relied upon triangulation of data, including participant interviews, written artifacts, and surveys whose analysis produced thick description of the extent to which written discourse provided therapeutic benefit to individuals experiencing: 1) latter stages of life, which trigger a confrontation with mortality and the subsequent desire to create a permanent record that validates existence, 2) life threatening illness that hastens awareness of mortality, 3) loved ones’ life threatening illness, and its emotional repercussions. The study’s findings incorporated service-learning theory and community literacy programs as natural extensions for writing-as-therapy projects. More specifically, it sought to nurture a perspective of written discourse that transcends the academy to include not only health care services, but communities in general, as a bridge for service learning and community literacy programs; furthermore, it argued for the inclusion of such theories in writing curricula, with a purpose toward balancing academic writing with writing for personal growth.
Dedication

To my husband, Jeff: You not only “held down the fort.” You held my hand. Sometimes, you even held me up, so I could reach this goal. Your sacrifice, support, and devotion have been immeasurable, and my love and gratitude are beyond words. Thank you for believing in me.

To my mother and father, Guy and Nada Nicoletti: I couldn’t ask for better parents. Every day of my life I am honored to be your daughter. You taught me the value of education in so many ways. Without the strength of your love and convictions, I never could have completed this journey. Dad, I still remember the day you defended your own dissertation. Remember the “Lite Brite”? You walked this road before me, and paved the way; I am proud to carry on your academic commitment. When I first undertook this project, I never could have guessed that in the middle of it all you would fight your own battle with cancer. Watching your struggle brought my dissertation topic front and center for me; witnessing your courage provided me with the motivation to finish this work. I love you both.

To my children: Ashley, Molly, Melanie, and Timmy. It’s really true when all of you say, “Mom, you’ve been in school forever!” It seems like you were just babies when I started out. Now that it’s over, I want to thank you so much for your sacrifices: for putting up with all the times my face was buried in the laptop, all the night classes when I had to be gone from home, all the projects and reading I was always working on, and the times when I was just too tired and stressed-out to talk. Each of you, in your own way, has born a part of my burden, and I am grateful for your support. I love you all very much, and want you always to believe in yourselves and in the value of life-long learning. Never stop learning; that’s how we grow!

To my sister, Elise: Remember that phone conversation, several years ago now, when you said to me, “Do the journaling project, if that’s what you really want to do!”? Well, here it is, and I must thank you for spurring me on to make the decision to write a dissertation about a topic that is truly meaningful to me. Without your advice, this dissertation probably would not exist in the form it is today. This is for you, for Kristin, and for Caleb too.
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# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Chapter</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>CHAPTER I. THE THERAPEUTIC VALUE OF WRITING</strong></td>
<td></td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Drawing on the “Sacred Repository” of Writing</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Employing “Fluid Intellectual Boundaries” Toward Illness and Recovery</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Writing as Therapy: Birth of a Pilot Study</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Literature Review</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Classical Perspective on the Purpose of Rhetoric</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Psychotherapeutic Roots and the Therapeutic Value of Poetry</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>Poetry Therapy versus Journaling: Self-help Texts and the Emergence of Rhetorical Principles</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>Writing-as-Therapy: Bridging the Disciplines</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>The Connection Between Writing and Health</td>
<td>12</td>
</tr>
<tr>
<td></td>
<td>Writing-as-Therapy: Implications for the Writing Classroom and Beyond</td>
<td>17</td>
</tr>
<tr>
<td></td>
<td>Justification for Further Study</td>
<td>22</td>
</tr>
<tr>
<td></td>
<td>Brief Overview of Pilot Study</td>
<td>23</td>
</tr>
<tr>
<td></td>
<td>Overview of Dissertation Chapters</td>
<td>25</td>
</tr>
<tr>
<td><strong>CHAPTER II. THE PILOT STUDY</strong></td>
<td></td>
<td>27</td>
</tr>
<tr>
<td></td>
<td>Introduction</td>
<td>27</td>
</tr>
<tr>
<td></td>
<td>Settings</td>
<td>28</td>
</tr>
<tr>
<td></td>
<td>The Victory Center</td>
<td>28</td>
</tr>
<tr>
<td></td>
<td>St. Vincent Mercy Medical Center</td>
<td>28</td>
</tr>
<tr>
<td></td>
<td>Swan Creek Retirement Village</td>
<td>29</td>
</tr>
<tr>
<td></td>
<td>Research Questions</td>
<td>30</td>
</tr>
</tbody>
</table>
Research Methods: Writing Workshop, Case Study, Interviews and Questionnaires......30

Use of the Workshop Setting .........................................................30
Use of Case Studies ........................................................................34
Interview and Anonymous Questionnaire Creation .........................35
Limitations .................................................................................36
Subject Selection ...........................................................................37
Variables ..................................................................................38
Data Collection and Analysis .......................................................39

Researcher Findings .................................................................40

CHAPTER III. CASE STUDY OF ELENA ...........................................42

Introduction ................................................................................42
The Intrinsic Motivation to Continue Writing ......................................44
The Ability Cope with Trauma or Serious Illness ...............................46
The Ability to Promote a Sense of Ownership and Control .................48
The Ability to Positively Affect Interpersonal Relationships ..............50
Writing is Self-affirming and Other-affirming ..................................52
Writing is Therapeutic when it is Reflective and Reflexive ...............54
Individuals Should be Comfortable with the Media Used to Produce Writing ..........56

CHAPTER IV. CASE STUDY OF BARB ............................................58

Introduction ................................................................................58
The Intrinsic Motivation to Continue Writing ....................................59
The Ability Cope with Trauma or Serious Illness ...............................62
The Ability to Promote a Sense of Ownership and Control .................65
APPENDIX E. VICTORY CENTER/ST. VINCENT’S INTERVIEW QUESTIONS ........182
APPENDIX F. SWAN CREEK INTERVIEW QUESTIONS .....................................184
APPENDIX G. POST-WORKSHOP QUESTIONNAIRE ........................................187
APPENDIX H. PRE- AND POST-INTERVIEWS OF BARB.................................188
APPENDIX I. POST-INTERVIEW OF CAROL.................................................214
APPENDIX J. PRE- AND POST-INTERVIEWS OF DALE.................................222
APPENDIX K. PRE- AND POST-INTERVIEWS OF ELENA.............................249
APPENDIX L. PRE- AND POST-INTERVIEWS OF DUANE.............................280
APPENDIX M. PRE- AND POST-INTERVIEWS OF KAREN.............................297
CHAPTER ONE: THE THERAPEUTIC VALUE OF WRITING

"Writing transforms thought, animates it. Through writing, we sense ourselves in action. It is often the start of therapeutic behavior and many times a complete therapeutic act in itself."


**Drawing on the “Sacred Repository” of Writing**

In Plato’s *Gorgias*, Socrates and Polus engage in a lengthy dialogue to determine whether philanthropists are happy people and evildoers are unhappy; they also dialogue to decide whether it would be preferable to suffer evil or to commit it (Plato 101-108). While some would argue that neither discussion could end in a definitive resolution, Plato was not preoccupied with reaching a resolution; rather, he was interested in demonstrating the “journey” of the dialogue, a journey known as the practice of dialectic. Plato held this practice of entertaining seeming contradictions in high esteem, its value resting largely in how it facilitated conversation and discussion about controversial topics. Similarly, over a decade ago, in his text “The Uses of Binary Thinking: Exploring Seven Productive Oppositions,” Peter Elbow commented on the particular power of dialectic to encourage prolonged communication among individuals:

One important way we learn it is through interaction with others: through dialogue. After all, that’s the original link that Socrates and Plato had in mind in their original conception of “dialectic”: bring people into conversation in order to create conflict among ideas.

(199)

In view of current political and social conflict, some might question why anyone would want to promote more; however, Elbow, much like the classical Greeks, is referring to intellectual conflict that stimulates “large-minded epistemology,” or open-mindedness: The kind of open-mindedness that allows for building communicative bridges across disciplines; the kind of open-mindedness that allows for the exploration of possibilities among disparate fields of study.
Several years ago, although I wasn’t aware of it then, I had my first glimpse into exactly how strong the lines of demarcation could be when defining the “accepted work” of different disciplines. At that time, I worked full-time as a physical therapist assistant in a hospital setting. Among my patient treatments on a given day was an elderly woman who had recently undergone a total hip joint replacement. My colleagues at the time just shook their heads, muttering about the “poor rehabilitation potential” of this noncompliant patient. Adequately forewarned, I had decided ahead of time that I’d be satisfied if my patient even attempted one or two exercises from her bed. With this goal in mind, I introduced myself, and idly conversed with my client; after several minutes the conversation strayed to my past experience as a high school English teacher. Suddenly, my patient’s entire demeanor changed, as she excitedly reached for her bedside table and the poetry she claimed she often wrote and kept there in a drawer. Within a few moments, we had begun a routine that extended beyond that day’s treatment. From then on, our physical therapy sessions usually began with her sharing one of her poems, after which we progressed through the usual protocol of therapeutic exercises for a total hip replacement. I marveled at the progress my elderly client made, and began to wonder about the exigency that had facilitated our patient-therapist rapport: the serendipitous sequence of events that had resulted in a shared writing experience. Years later, I found the words of Quintilian to more than adequately describe that experience, “In writing are the roots . . . by writing resources are stored up, as it were, in a sacred repository, whence they may be drawn forth for sudden emergencies, or as circumstances require” (Quintilian 404). It had certainly not been my plan to draw upon the strength my patient stored in her repository of poetry; however, doing so had worked for her circumstances.
Patient progress notwithstanding, my literary prelude to this client’s treatment constituted “non-billable” treatment time, and resulted in the dreaded health care provider reprimand, a sentence of “low productivity.” The irony of the situation struck me, nonetheless: there was seemingly no place for writing here among the sterile hallways and time-honored treatment plans; yet, in all my classroom teaching experience to that point, my students had never expressed such joy in writing as did my elderly client, much less viewed sharing it as a reward earned for hard work. While I never articulated this paradox, it remained dormant in my mind for some years to come-- an observation that eventually led me to ponder the relevance of writing beyond the classroom walls.

Employing “Fluid Intellectual Boundaries” Toward Illness and Recovery

Although not clear to me at the time, I eventually came to attribute the lack of enthusiasm for my hybrid treatment style to the traditional dichotomy that exists between science and art, or what Richard Rorty, in the chapter “Science as Solidarity,” has criticized as our culture’s preoccupation with “the notions of “science,” “rationality,” “objectivity,” and “truth” (35). Instead, from a philosophical perspective, Rorty advocated for communities with “fluid intellectual boundaries” that allow for the shared interests of all its members (44-45). In such an ideal intellectual community then, one might reason, writing poetry would not need to remain separate from a patient’s physical therapy treatment plan if the activities of both disciplines appeared to be working together toward the patient’s ultimate recovery.

Elbow broadened Rorty’s argument to include our culture’s more general tendency to categorize things “in terms of oppositions, contraries, dualisms,” often referred to as binary thinking (179). According to Elbow, “More and more people are noticing the problems with either/or rhetoric (as opposed to both/and rhetoric): the assumption that in order to argue for a
position we must argue against the contrary position as wrong” (Elbow 197). Like Rorty, Elbow’s words called to mind my previous experience that apparently infringed upon the boundaries of binary entities, science and art, and the disservice that often results from such thinking. Yet while both Rorty and Elbow debunk traditional attitudes that simultaneously privilege some disciplines while marginalizing others, Elbow in particular argues for the necessity to maintain channels of communication that allow dialogue to continue (198).

Much in the same way that classical rhetoricians relied upon dialectic to stimulate dialogue systematically and blur the boundaries of seemingly oppositional ideas, Elbow posits that binary thought should not be abolished, but rather utilized appropriately. Such appropriate use of binary thinking, he might further argue, eschews its use as a framework for perpetuating traditional lines of demarcation among disciplines, but rather recognizes it as a tool to facilitate continued conversation and insight into how the distinctive characteristics of all disciplines can support the work of others to mutually benefit the communities they serve. Personal experience with people suffering from illness, injury, or the often dehumanizing effects of aging, suggested that integrating written discourse in the form of poetry, narrative, or journaling, as non-medical but parallel treatment options might benefit such individuals. My subsequent research into this supposition has supported that experience.

Writing as Therapy: Birth of a Pilot Study

As a result of my combined personal experience as a writer, educator, and physical therapist assistant, this pilot study was born. Consisting of three separate workshops involving the use of writing as therapy, and supported by a large body of research acknowledging the important physiological benefits of telling our stories in written form, this project has intended to address gaps between the medical, humanities and liberal arts disciplines. More specifically, it
seeks to nurture a perspective of written discourse that transcends the academy to include not only health care services, but the entire community, as a bridge for service learning and community literacy programs; furthermore, it argues for the inclusion of such theories in writing curricula, with a purpose toward balancing academic writing with writing for personal growth. Achieving such a balance, this work posits, might assist educators in exploring and defining the meaning of a “writerly life” both inside and outside the academy. Human beings are naturally born storytellers. We love to listen to stories, and we love to tell them. However, each person’s story is uniquely synchronous with who and what one is, and telling one’s story grounds a person in difficult times, validating the uniqueness of each life. The subsequent review of literature within the field of writing as therapy not only demonstrates humankind’s need to validate the human condition through writing, but also supports the body’s healing physiological response to that process, lending credence to the research questions posited later in this chapter: in summary, to what extent can writing enable a positive outcome as a coping mechanism for significant life challenges?

Literature Review

Classical Perspective on the Purpose of Rhetoric

Classical rhetoric abounds with debate regarding exactly what purpose rhetoric served: whether it should be classified as art or talent, whether the spoken word is preferable to its written counterpart, whether a person employing rhetoric is bound by an ethical code to approximate Truth or simply to use any available means to persuade an audience to accept his way of thinking. Although a reader would not expect to find a discussion of health or medicine amidst such subject matter, within Aristotle’s arguments supporting the purpose and function of rhetoric, he also addresses the practice of medicine, referring to it as an art, “In this [rhetoric]
resembles all other arts. For example, it is not the function of medicine simply to make a man quite healthy, but to put him as far as may be on the road to health; it is possible to give excellent treatment even to those who can never enjoy sound health” (Aristotle 181). Such sentiments can be associated with contemporary notions of the field of medicine and health maintenance in general; indeed over the past two or three decades it appears that our society has adopted a rhetoric of “wellness” and “prevention,” placing significant emphasis on achieving and maintaining optimal health.

*Psychotherapeutic Roots and Contemporary Theorizing on the Therapeutic Value of Writing*

Into this arena, contemporary theorizing about the therapeutic effects of writing emerged, although publications bifurcated along the genres of poetry and journal/diary writing. The first significant text was edited by Jack Leedy, M.D. in 1969. His work focused on the positive effects of poetry as treatment for mental illness within the field of psychotherapy. His ten-year clinical experience with psychotherapy in Pennsylvania and New York earned him a directorship at the poetry center of New York. Leedy’s edited publication, *Poetry Therapy*, included the case studies of colleagues in the field. Additionally, he authored a chapter within the book dedicated to establishing principles of poetry therapy, the most important of which he named Isoprinciple. Isoprinciple is a term borrowed from music therapy that suggests the importance of matching a poem to depressed patients’ moods to increase their likelihood of overcoming that depression. Both individually and in group sessions, Leedy encouraged his patients to write their own poetry as well as to read that of others, maintaining that, “poetry encourages patients to explore their feelings, to feel more deeply, to extend their emotional range, yet to discover patterns, also, of control and fulfillment” (70). It was this combination of increased emotional range coupled with feelings of control to which Leedy attributed many patients’ eventual recovery. Most
importantly, Leedy’s work called for the establishment of a National Association of Poetry Therapy where qualified professionals could become certified as poetry therapists in much the same way as occupational or music therapists become certified.

Although still firmly entrenched within the field of psychotherapy, almost a decade later, Arthur Lerner edited *Poetry in the Therapeutic Experience*, another text defending the therapeutic value of poetry. By the time of this publication, and as acknowledged by Lerner, poetry therapy as a field was characterized by “divergent experiences and interests” and in want of a centralizing theory or rationale. Therefore, the articles in Lerner’s text reflect the field’s drive toward establishing professional recognition by focusing on topics such as ethics, standards, professional policing, legislation, and certification. Moreover, the last article, “Approaching Poetry Therapy from a Scientific Orientation” is a statistical study whose empirical data proposes that an individual’s appreciation of a particular poem correlates to that poem’s degree of success in helping him or her recover from illness (140); it also offers a prototypical chart that attempts to correlate an individual’s specific psychiatric symptoms to a preference for certain poems (141). Most importantly, the statistical nature of this article indicates a clear move toward more quantitative research in the field.

*Poetry Therapy versus Journaling: Self-help Texts and the Emergence of Rhetorical Principles*

Other scholarly work of the mid-to-late 1970s focused on the therapeutic value of the journal; however, these works extended beyond the theoretical nature of Leedy and Lerner’s therapeutic poetry texts by employing rhetorical principles and entering the realm of practical, self-help text. Three works in particular bear attention, including the works of Progoff, Baldwin, and Rainer. Though still rooted in psychotherapeutic theories, rhetorical principles also appeared when these mid-1970s texts shifted focus toward the use of heuristic methods and processes to
structure and organize writer-generated content; these methods guided users through such rhetorical principles as choosing an audience and clarifying purpose.

Ira Progoff, also a psychotherapist, attributed his publication to ten years of instructing his patients to keep journals that recorded their inner thoughts. From this practice he eventually developed a structured model, or “psychological workbook,” for his patients to follow, reasoning that such structure would remove the “authority figure,” thus, enabling individuals to maintain complete control over their journaling process. Later, he expanded this psychological workbook to create “a structured journal capable of rechanneling a person’s energies in terms of new patterns of behavior that would regroup themselves.” Progoff reasoned that, “The directive and reintegrative factor had to come from within and not be imposed [upon patients] by a concept from the outside.” The culminating result of this process was Progoff’s *Intensive Journal* process; a structured journaling practice involving meditation, Progoff likened the practice to a channel through which “a person’s life experiences could be fed back and forth” (29). Progoff’s process also resulted in a series of journaling workshops offered worldwide.

Christina Baldwin’s text, *One-to-One*, which eventually enjoyed a resurgence of popularity with a second edition in the nineties, was perhaps the first text of its type to rid itself of the psychological tenor of earlier works in favor of placing more emphasis on the pragmatics of beginning and maintaining a journal. Beginning with basic concepts, such as “What is a journal and why keep one?” Baldwin’s text resonated with a rhetoric of self-understanding and personal growth that previous writing-as-therapy texts lacked. Much less intimidating than its predecessors, this work offered sample journal entries and even a chapter on how to start a journaling group of one’s own. Clearly, by making the text more practical and less discipline
specific, Baldwin attempted to transition the field of therapeutic writing toward a more accessible audience.

Similarly, Rainer’s text adopted the same pragmatic readability as Baldwin’s. One interesting feature of Rainer’s work, however, is that it reflected the burgeoning principles of writing process theory, offering a chapter dedicated to techniques for generating writing; these techniques included tips like making lists, guided imagery, and other “brainstorming” or “prewriting” techniques. Like the Baldwin text, Rainer’s also offered excerpts from personal journals and specific advice on how to generate a topic, such as writing “spontaneously,” and “honestly.” However, despite these positive features, this text’s sheer length and density make it less appealing than Baldwin’s earlier work. Additionally, Rainer uses highly technical psychological jargon and theory that hinder the text’s accessibility to the general reader.

*Writing-as-Therapy: Bridging the Disciplines*

In the 1980s, literature pertaining to writing-as-therapy diverged yet again; this time, however, the divergence did not occur along the lines of genres, i.e., poetry versus journaling; rather, the topic began to bridge disciplines. Although writing for its therapeutic value continued to be explored through self-help texts, it also took root within the disciplines of Education and English composition, in addition to psychology. For example, in her doctoral dissertation, Alice Brand described an 18-week writing workshop she implemented with a group of eight junior high school students. Brand, who staunchly advocated that teachers should concern themselves with the emotional development of their students, focused her workshop topics on the psychosocial development of the adolescent, namely personal growth, familial conflict, and the improvement of self-concept. Her subsequent monograph provided detailed case studies of two of her students and then, to a lesser degree, addressed the progress of her other six students,
concluding that the discipline of English studies must devote greater acceptance and additional research to the therapeutic aspects of composition and creative writing studies. Later work by Brand expands her discussion regarding the relationship between writers’ experiences and emotion, emphasizing the significant connection between cognition, emotions and writing behavior. Concurrently, Joanna Field, who had great success with two editions of *A Life of One’s Own*, used personal experience to target the self-awareness, and self-enriching nature of keeping a diary. “By keeping a diary of what made me happy,” she claimed, “I had discovered that happiness came when I was most widely aware” (206). Thus, her text was more a personal narrative of gaining life fulfillment than of the specific use of journaling in a therapeutic sense. Within the field of Education, on the other hand, Margaret Hatcher in *Centering Through Writing: Right Brain/Left Brain Techniques Applied to Writing* took a more scholarly approach to writing, citing not only the work of Progoff, but also that of Elbow; she also drew upon educational learning theory, how the brain functions in learning, and upon multi-sensory approaches to teaching and learning. Written from an educator’s perspective, the overriding purpose of her text was to illustrate how the writing process could be used to bridge the disconnect between the right and left hemisphere’s of the brain, “It struck me that the process I have been using to teach writing (a left brain function) has right brain functions, a process of centering, balancing” (xii). Hatcher’s text is valuable from the educational perspective that writing should be viewed by all educators as a tool for learning and to facilitate balance in students’ education, and not solely as the function of the English classroom.

By the late 1980s, the writing of two notable scholars in the field of English Composition addressed the therapeutic benefits of writing, James Moffett and Donald Murray. Moffett’s text “Writing, Inner Speech, and Meditation,” a chapter in his larger work, *Coming on Center*,
defined writing as the result of inner speech and asserted a direct connection between this inner speech and meditation. Although a decade earlier Progoff had combined journaling and meditation, Rainer had advocated the benefits of using guided imagery as a prelude to journaling, and Hatcher had skirted the topic with terms like “centering” and “balancing,” Moffett’s work went as far as to unabashedly claim, “Writing and meditating are naturally allied activities. Both are important for their own sake, and through each people can practice the other” (90). Consequently, Moffett argued that teachers of writing should become adept at teaching meditation, which in turn would significantly improve students’ writing ability. Additionally, he praised the therapeutic value of writing as a byproduct of the focus on meditation and inner speech:

> The therapeutic benefits from writing are natural fallout . . . They inhere in the very parallelism described here. Good therapy and composition aim at clear thinking, effective relating, and satisfying self-expression. Precisely because it is not thought of as therapy and works toward another goal, writing can effect fine therapy . . . At any rate, self-awareness is the means in both cases, and this requires focusing attention on one’s inner speech. (101)

Donald Murray concurred with Moffett’s assessment of the therapeutic benefits of writing, claiming, “Writing is therapy for this writer and for most others I know” (185). In Expecting the Unexpected, Murray outlines how his unique experience with personal tragedy was mitigated through the writing process, and resulted in a cathartic publication about his twenty-year-old daughter’s tragic death. Individuals’ ability to relate to others’ personal accounts of their experiences is what Gerard Benson in his text “Creative Writing: Where is that Pen of Mine?” may have had in mind when he explained, “We have such richness of common emotional
experience but our individual experience is unique . . . We have much to tell each other. That is why creative writing is important. Writers have always known this but it is only comparatively recently . . . that wider implications of this in terms of therapy, community social work and the like have been recognized” (53). Clearly, both Murray and Benson inferred that recognition of the therapeutic benefits of writing is innate for most writers and that those benefits should be extended to those who do not write professionally. Certainly, Benson’s comments indicated that even two decades ago, awareness existed that writing should be implemented therapeutically.

Perhaps the most prolific scholar, and the one whose theories posited a direct connection between psychological and physiological health, and the role of writing in that process, is James Pennebaker. A Psychologist by discipline, his work spans three decades and consists of both qualitative and quantitative studies on the subject. For example, one of his earliest works, *The Psychology of Physical Symptoms*, although it did not directly reference writing as a form of therapy, provided excellent groundwork regarding the phenomena of physical symptoms. When examined in conjunction with the Broskowski, et al. edited text, *Linking Health and Mental Health*, clear correlations emerge between psychological and physiological well-being. To explain this connection, Pennebaker introduced his “perceptual specificity hypothesis,” the idea that certain emotions are connected to discrete manifestations of symptoms (99). What is significant about Pennebaker’s symptom-emotion clusters is that this theory began to underscore the importance of self-awareness and the ability of individuals to control their health and well-being.

*The Connection between Writing and Health*

While today the importance of individuals seeking increased physiological awareness may not seem unusual, the significance of Pennebaker’s work in the early 80’s provided the
foundation for his later theories regarding the direct link between writing and how it enables people to control their physical and mental well-being. For example, in “Confession, Inhibition, and Disease,” Pennebaker expanded upon his theory regarding the ability of individuals to control the way stressors affect their well-being; he referred to this ability as one of the goals of psychotherapy—to facilitate a person’s ability to talk about, analyze, and interpret past experiences for the purpose of realigning or reintegrating those experiences with their concept of self. By this time, however, Pennebaker was directly theorizing about the ability of writing to facilitate this process:

Interestingly, the writing technique appears to accomplish some of these same goals without the traditional client-therapist relationship. When individuals write about traumas, their defenses are almost automatically lowered—because it is difficult to accomplish the task otherwise. Writing about traumas also forces individuals to dredge up psychological conflicts and intimate emotions that few other topics arouse. Once the defenses are lowered and conflicting aspects of the self are salient, the individual actively seeks to resolve the conflicts. (238)

Later work by Pennebaker further extended his thoughts regarding the therapeutic connections between writing and health, and quite possibly paved the way for additional work by both Pennebaker and others in the early 1990s, work that underscored the value of using autobiographical narrative as a way of overcoming trauma. For example, in Opening Up Pennebaker theorized about the unhealthy effects of repressing past traumas and emotions. This repression that Pennebaker termed “inhibition,” served as the catalyst for the text’s theme that writing is a form of “confession,” i.e., of releasing inhibitions, and thus in itself becomes a
vehicle through which psychological healing can take place. Keep in mind the significant findings of the earlier Browskowski et al. publication:

> Stress, diet, exercise, smoking, and a host of psychological factors are being implicated in an increasingly greater range of medical disorders previously thought to be related exclusively to genetic, biological, or chemical factors . . . . Clearly, we are likely to witness increasing use of behavioral interventions, such as exercise, meditation, and changes in lifestyle and habits, as adjuncts or substitutes for orthodox medical treatment, such as drugs and surgery. (19)

By extrapolating the conclusions of both the Browskowski and Pennebaker work, it seems logical that Pennebaker would at this point conduct experimental work to determine precisely how the physiological benefits of the writing process occurred. This study, conducted within a laboratory setting, then published in the text Opening Up, involved monitoring subjects’ immune functions before and after a weeklong writing workshop. Pennebaker’s findings showed that:

> People who wrote about their deepest thoughts and feelings surrounding traumatic experiences evidenced heightened immune function compared with those who wrote about superficial topics. Although this effect was most pronounced after the last day of writing, it tended to persist six weeks after the study. (47-48)

In a follow-up study, “Changes in Circulating Lymphocyte Numbers Following Emotional Disclosure: Evidence of Buffering?” conducted seven years later, Pennebaker and colleagues were able to replicate the earlier findings, concluding that writing intervention actually serves as a buffer, protecting the immune system. Given Moffett’s earlier assertions regarding the positive connection between meditation and writing, in addition to Browkowski’s conclusions about
mounting confidence in the ability of such non-orthodox medical treatments to improve health, the findings of Pennebaker’s study, while exciting, should not be entirely surprising.

By 1990, White and Epston, both family therapists, had already published what was then considered to be groundbreaking work about the healing power of the written word. That is, in Narrative Means to Therapeutic Ends, they linked consistent improvements in patients’ health to their increased proficiency at rewriting traumatizing past events. A central focus of this research was their patients’ conceptualization of personal identity, which the two researchers define as “constituted by what we ‘know’ about ourselves and how we describe ourselves as persons” (viii). A markedly important focus in the White and Epston research was the degree to which patients were able to reconceptualize their identities as a result of what the authors termed “re-describing their lives”:

Since the stories that persons tell about their lives determine both the ascription of meaning to experience and the selection of those aspects of experience that are to be given expression, these stories are constitutive or shaping of persons’ lives. The lives and relationships of persons evolve as they live through or perform these stories. (40)

Similarly, by observing that “the very act of re-authoring requires and demonstrates personal agency, Freedman and Coombs in their work Narrative Therapy: The Social Construction of Preferred Realities, described the importance of narrative therapy in terms of “continually and actively re-authoring our lives” (11), positing that “The very act of re-authoring requires and demonstrates personal agency” (97). Similar to the work of White and Epston, Freedman and Coomb’s therapeutic interventions emphasized patients’ use of autobiographical writing to assist them in re-visiting past experiences. Specifically, by refining these experiences through the filter of time and space, autobiographical writing becomes a lens through which
individuals can revisit a painful past. By so revisiting the past, these therapists posited, emotionally traumatized individuals are able to reclaim control of painful, disturbing memories by reshaping their negative effects.

In 1990 alone, a plethora of texts appeared, touting the therapeutic value of narrative and autobiography. Christina Baldwin in One to One: Self-Understanding through Journal Writing, Alida Gersie and Nancy King in Storymaking in Education and Therapy, and Marilyn Chandler in Healing Art: Regeneration Through Autobiography all extended both Pennebaker’s research and that of White and Epston by asserting the value that traditional societies place upon oral narrative, “Whereas in traditional societies shared myths and rituals provide meaning by revealing patterns in human experience as paradigms for individual lives, in an alienated culture such as ours autobiography begins to assume this function” (Chandler 5). Chandler’s observations relayed how traditional societies view oral narrative as an anchor whose mooring provides a template for living life; in doing so, these societies depend upon oral discourse to preserve that template. Literate societies, however, no longer emphasize oral narrative; therefore, written narrative, namely the genre of autobiography, has of necessity, become paramount.

Chandler’s acknowledgement of the important role autobiography plays in the cultural transmission of a society’s concepts, values, and practices was previously noted by Walter Ong whose Orality and Literacy addressed the major differences between literate cultures and traditional oral societies. Like Chandler, Ong noted the important function of oral narrative—to provide stability in primary oral cultures through the use of maxims, riddles, proverbs, ritual formulae and genealogies (138). Just as importantly, Ong recognized the value of transferring oral narrative’s lost role to written narrative, “By isolating thought on a written surface,
detached from any interlocutor, making utterance in this sense autonomous and indifferent to attack, writing presents utterance and thought as uninvolved with all else, somehow self-contained, complete”(130). The work of these researchers on the importance of written narrative intersected with the later work of Elbow who, in “All Writing is Autobiography,” argued that all writing is autobiographical, to a degree, and innately therapeutic because it is strongly influenced by a writer’s past experience, “I wrote, and write for therapy. Writing autobiography is my way of making meaning of the life I have led and am leading and may lead” (69-70). Elbow and others’ affirmation of written narrative’s therapeutic value has interesting implications in terms of its ability to reconnect us with Memory, the oft considered “least important rhetorical cannon,” especially when the audience is the writer her- or himself. Because written narrative approximates the transference of the lost speaker ethos of oral cultures, its value as a therapeutic medium may well lie in its ability to enable the writer-speaker to converse with him- or herself for the purpose of personal meaning-making; conversation that occurs within the safety of a detached environment that is free from the “interference” of an interlocutor.

Writing-as-Therapy: Implications for the Writing Classroom and Beyond

In 1993, Wendy Bishop applied the discussion of the therapeutic nature of writing to the writing classroom in particular and to writing program administration in general, acknowledging that the very nature of the composition classroom occasionally places the instructor in the role of therapist. Bishop wrote “Writing is/and Therapy?: Raising Questions about Writing Classrooms and Writing Program Administrations” to address the legal and ethical implications of assuming this role, arguing that the academic preparation of both faculty and graduate student composition instructors should include basic counseling strategies and awareness that the writing process can sometimes elicit the emotional turmoil of cathartic experiences.
By the late 1990s, not only was the amount of scholarly work on the value of therapeutic writing noteworthy, but also the breadth of the work. In addition to numerous full-length texts on the topic, its inclusion in a range of scholarly publications, including Psychological Science, The Family Journal, Health Psychology, and The Journal of the American Medical Association indicated a pervasive interest in the field and its strengthening acceptance. Of note, a randomized trial recorded in “Effects of Writing about Stressful Experiences on Symptom Reduction in Patients with Asthma or Rheumatoid Arthritis” (Smyth, et al. 1999) provides evidence that after writing about stressful life experiences, the health status of these subjects significantly improved up to 4 months after the study’s completion. Smyth and colleagues claim, “gains were beyond those attributable to the standard medical care that all patients were receiving” (1304). This study also reflects collaboration between medical and non-medical disciplines to study the effects of writing as a therapeutic intervention. Another such collaborative example that appeared in The Family Journal: Counseling and Therapy for Couples and Families expands upon the work of White and Epston, and involves graduate nursing students who opt to enroll in a year-long course exploring collaborative therapies (Andrews, et al. 1998). White and Epston’s work is significant in that it popularizes interest in narrative therapy, describing how the graduate nurse interns apply these researchers’ theory of “circulation” to their own practice of writing letters to clients after each therapy session. Circulation is a stage in the therapy process where clients develop new and emerging stories of their past experiences, and is particularly dependent upon feedback that enables clients to “resolve” their past conflicts. By communicating with their clients through letter writing between therapy sessions, the intern nurses provide this interim feedback, thus facilitating their clients’ recovery process.
Similarly, Cameron and Nicholls’ 1998 study, “Expression of Stressful Experiences Through Writing: Effects of a Self-regulation Manipulation for Pessimists and Optimists,” focused on implementing a writing intervention protocol with first semester college students to determine whether regular written discourse about stressful events could become a coping mechanism for reducing stress, thereby decreasing visits to the health center and improving overall GPA. Their findings support the findings of other researchers, demonstrating that “writing is therapeutic when participants write about their thoughts and emotions in ways that enable them to make sense of their experiences and to identify ways to resolve conflicts” (84).

Although, during this timeframe, most literature about the therapeutic value of writing was positive, some researchers began calling for theoretical underpinnings to define therapeutic writing as a field. Specifically, three publications, “Autobiography and the Psychotherapeutic Process” by Celia Hunt, Writing Well: Creative Writing and Mental Health by Debra Philips and colleagues, and Gillie Bolton in The Therapeutic Potential of Creative Writing: Writing Myself, attempts to develop such a framework; all texts originate from research conducted in the United Kingdom and focus on health care application. Hunt and Sampson’s edited text, The Self on the Page: Theory and Practice of Creative Writing in Personal Development, features individual articles about studies on the uses of writing as non-medical intervention in various aspects of health care, such as with individuals suffering from terminal cancer (Archer 1998) and dementia (Killick 1998). Another article, “Writing or Pills: Therapeutic Writing in Primary Health Care,” also written by Bolton, describes a study where therapeutic writing was actually “prescribed” as treatment by a group of general practitioners, and advocates for the widespread continuation of this practice. Furthermore, The Therapeutic Potential of Creative Writing: Writing Myself, a later publication by Bolton, expands the discussion, justifying the numerous appropriate settings
for such a prescription, such as in the hospital or hospice setting and the retirement community.

Bolton also devotes this latter publication to sharing practical information on initiating therapeutic writing and how it connects to the personal development process. Like Bolton, Sampson and Hunt also underscore the benefit of creative writing in the personal development process, and, in “Towards a Writing Therapy? Implications of Existing Practice and Theory” argue in favor of formalizing a “writing therapy” in order to disperse the positive outcomes generated by the intermittent research in the field. In much the same way as Bolton and Sampson’s work, Philips and colleagues base their 1999 text, Writing Well: Creative Writing and Mental Health, on a creative writing project conducted at an adult day hospital in West London. These authors, whose professional training consists of creative writing instruction and occupational therapy, ground this text on their experience and include specific writing activities and other materials they developed. The authors also address theory about writing as therapy, in addition to specific implications for practicing this process within group settings. Other important concepts include how writing provides opportunity for individuals to externalize their feelings, how it can promote trust, a sense of community, and an awareness of others and the environment (17-19). Indeed, several participants in this researcher’s pilot study expressed similar sentiments, their observations punctuating those theories advanced by the work of other researchers.

By the beginning of the new millennium, publications abounded about both the physiological and psychological healing properties of writing, many of which reflected multidisciplinary overtones. Louise Desalvo’s 2000 text, Writing as a Way of Healing, like Hatcher’s earlier work, was written from the perspective of a professional educator. Although her theories strongly correlate with those of previous researchers mentioned, her writing
teacher’s lens adds a humanistic dimension because, like Moffett and Murray, she describes writing’s therapeutic nature in terms of a process available for her readers to replicate. Indeed, like many of the authors before her, and like several of the participants in this pilot study, she suggests a strong connection between writing as therapeutic intervention and the increasing awareness of one’s identity:

We are the accumulation of the stories we tell ourselves about who we are. So changing our stories . . . can change our personal history, can change us. Through writing, we revisit our past, and review and revise it. What we thought happened, what we believed happened to us, shifts and changes as we discover deeper and more complex truths . . . we use [writing] to shift our perspective. . . And it certainly can help us heal. It can enable us to accomplish that shift in perspective marked by acceptance, authenticity, depth, serenity, and wisdom that is the hallmark of genuine healing. (11-12)

In 2001 Michele Weldon paralleled DeSalvo’s claims regarding the healing and self-development made possible through the writing process, and Weldon also advocated the value of nurturing personal identity through narrative. Each chapter in Writing to Save Your Life: How to Honor Your Story through Journaling addresses individual concepts and approaches for each stage of writing; additionally, Weldon offers exercises to help the reader attain certain goals before proceeding to the next. “The therapy of writing,” she posits, “is not only medicine for the soul but also a microscope to analyze intellectually and creatively your role in the world and your reactions and insights to whatever it is you need to tell” (2).

Lepore and Smyth in The Writing Cure: How Expressive Writing Promotes Health and Emotional Well-being and Sampson in Creative Writing in Health and Social Care both applied the concepts of writer wellness specifically to healthcare. Lepore and Smythe’s edited volume,
substantiated Smyth and colleagues’ earlier 1999 work by extending the use of expressive writing to the treatment of medical ailments like high blood pressure and cancer; the focus of this text is to show how expressive writing promotes health and well-being, and to increase the generalizability of results from the laboratory setting to the field.

**Justification for Further Study**

In conjunction with the work of Lepore and Smyth, Sampson’s edited work, *Creative Writing in Health and Social Care*, focuses on mapping an introduction to creative writing in health and social care by providing examples of good practice, examples that this researcher implements in the subsequently described pilot study; to this end, Sampson’s text includes articles on justifying the inclusion of creative writing and reading in the health care curriculum and a long-term poetry project in a Swedish hospice that explores the issues facing dying patients and their families. However, the articles in Sampson’s publication also attest to tension and debate within the fledgling field. Namely, this dissent is caused by divergent perspectives surrounding the importance of nurturing the individual writer’s creative uniqueness versus the institutionalization of the therapeutic writing practice itself. Moreover, the text points to key areas that might impede the growth of the field, such as limited evaluation and research, since the presence of these elements in a discipline both affirm and help to professionalize it.

In spite of whether there may someday be specialists with the label “Writing Therapist,” what does not change is the consistent, if somewhat sparse, number of studies that undeniably show positive outcomes in people’s health and well-being as a result of regular writing intervention. Bolton, in her latest publication, *The Therapeutic Potential of Creative Writing*, writes that formalizing the field is not as important as continuing to provide opportunities for post-trauma individuals to express their emotions through writing. Likewise, *Writing and*
Healing, the 2000 edited work of Charles Anderson and Marian MacCurdy, devotes a significant number of contributions to extending the connections beyond the classroom to the community by fostering writing projects that promote both physiological and psychological healing. It has been the intention of my pilot study to facilitate just such an opportunity in the hope that additional insight will be gained about the benefits of this developing field.

Brief Overview of Pilot Study

This pilot study involved three separate workshops, ranging in duration from 6-8 weeks and conducted by me throughout the fall of 2005. Workshop participants from each group were volunteers, solicited by advertisements I developed and disseminated through the cooperation of three separate institutions located in the Toledo, Ohio area. Specifically, one group of participants was seniors who reside at Swan Creek Retirement Community; a second group included clients at a The Victory Center, a non-profit organization that offers non-medical support to cancer survivors and their family members. The final group was recruited from St. Vincent Mercy Medical Center Cancer Support Services. While the total number of participants across all three groups numbered approximately fifteen, all three workshops were conducted separately, and in the case of the Swan Creek community, workshop material was geared more toward autobiographical writing than toward illness and recovery. Ultimately, the variation in materials reflected participants’ reasons for joining the workshops, and the resultant exigencies from which their writing would emerge. Hence, these diverse exigencies permitted the study of writing as therapy from differing perspectives:

- An individual’s arrival at the latter stage of life that triggers a confrontation with mortality and the desire to create a permanent record that validates her existence (there were no male participants among the Swan Creek group). Additionally, there was the simultaneous impetus of relatives’ request for such a record, or the individual’s intent to leave relatives the record.
• An individual’s confrontation with life threatening illness that hastens awareness of mortality and the desire to validate one’s life by creating a written record that expresses the range of emotion elicited by the illness. Additionally, there was the simultaneous desire to create a permanent record of sentiments and memories to be gifted to loved ones after the individual’s passing.

• An individual’s experience with a loved one’s (spouse in this study) life threatening illness that created a need to express and validate the range of emotion elicited by the experience by recording events associated with the illness and treatment; this record served not only as an outlet for emotions, but also as a method of achieving a sense of control over uncontrollable circumstances.

• An individual’s acquiescence to the desire of a loved one who is confronting life threatening illness (a spouse in this study); here, the seriously ill spouse believed that writing about her emotions would assist the healthy spouse in coping with her illness.

In all three groups, the methodology involved both pre- and post-workshop interviews, a six- to eight-week workshop, and an anonymous post-workshop questionnaire. The study implemented and expanded upon the work of scholars who advocate the therapeutic effects of writing. For example, Sampson and Hunt define therapeutic writing as “writing practices linked with personal development . . . that can be carried out in a variety of contexts. They may form part of a therapeutic intervention in the writer’s life, or may take place in a health or social care context, where they represent a significant opportunity for the participant to reflect on or celebrate his or her individuality” (198). Through informal, structured workshop environments this pilot study encouraged self-exploration and self-expression to facilitate wellness through reflective writing and by establishing a writing community of individuals who were undergoing similar healthcare challenges or stages of life. Participants in this therapeutic writing pilot study were provided with a layered informed consent form prior to the start of the program. This informed consent form notified them of the various levels of participation they could elect, including the:

a. right to remain anonymous.
b. decision to have their writing quoted directly, by first-name only, under a fictitious name, or not at all.

From both participant and group administrator responses, the introduction of a therapeutic writing program met an authentic need in the Northwest Ohio community and addressed a gap in our health care system: to wit, the need for seriously ill and marginalized groups to find a venue for empathic support through writing and the companionship of others who share similar experiences. Moreover, while in recent years research using writing as therapeutic intervention has increased, the bulk resides in the professions of psychotherapy and psychology, justifying an exploration of this genre from the perspective of composition studies.

Overview of Dissertation Chapters

The following text provides details of a pilot study that used workshops to explore writing as therapy. Chapter Two addresses the methodology applied in these informal but structured workshop environments, methodology that encouraged self-exploration and self-expression through writing for individuals recovering from illness or interested in recording major life events. This discussion includes a description of the organizations from which the subjects were recruited, the settings, length and duration of all three workshops, as well as data gathered and analyzed to determine the participants’ perceived benefit from the project.

Chapters Three, Four, and Five focus on case studies from The Victory Center, and St. Vincent’s Hospital, correlating observations and drawing implications to the existing body of research in the field.

Chapter Six explores the general results of the study. Because previous chapters focus on case studies based upon two single workshop participants and two couples, this chapter will examine some of the significant data associated with other workshop participants as well, in
order to demonstrate the breadth of the research conducted. This discussion of the study’s
general results focuses on the characteristics of writing that make it therapeutic, and also on the
importance of writing in enabling senior members of our community to tell their stories. Another
important aspect of Chapter Six is its acknowledgment of the project’s limitations as a pilot
study, and appeal for continued study on the topic of therapeutic writing. Finally, Chapter Seven
concludes by discussing research that bridges the gap between community and academic writing
as well as the classroom implications of this research; as such, it will address important
characteristics of therapeutic writing that would make its implementation particularly valuable
with service learning and community literacy programs.
CHAPTER TWO: THE PILOT STUDY

“The discipline of writing empowers us to creatively express who we are. By challenging ourselves to be honest and put our voices on paper, we cannot help but disrupt old patterns and beliefs . . . Writing is a portrayal of our personal experiences, a tool to enhance understanding and gain perspective.”


Introduction

The previous chapter’s survey of literature in the fledging field of writing as therapy encapsulates the innately therapeutic nature of narrative and creative writing that scholars have posited nurtures personal identity while promoting healing and self-development. Such assertions are based upon representative literature that communicates instances where this genre of writing has produced favorable physiological and psychological results. Notwithstanding, this same body of literature promulgates the dearth of discipline-specific studies on the use of writing as therapeutic intervention. Illustrative of these collective voices, Alice Brand, in Therapy in Writing: A Psycho-Educational Enterprise, praised what she referred to as “helping professions” for their facilitation of writing as a means of self-validation and self-help; however, she also admitted that, “knowledge about writing therapy in its diverse forms is still largely in its infancy. Indeed, the benefits culled from clinical data have accumulated to a point where the potentials of writing as a therapeutic tool must be more systematically researched” (26). Twenty years later, in Writing as a Way of healing: How Telling our Stories Transforms our Lives, Louise DeSalvo touts both the personal and societal benefits of sharing our writing in a community atmosphere:

Scores of . . . writers write about what they have lived through . . . to heal themselves.

But they also write to help heal a culture that, if it is to become moral, ethical, and spiritual, must recognize what these writers have observed, experienced, and witnessed.
All are writing to right a human wrong—one that affected them, surely, but one that affects others too. (216)

Hence, Chapter Two describes an ethnographic study whose purpose has been to provide such an opportunity to observe, experience, and witness others’ attempts at using and sharing written expression to examine what has significantly affected their lives.

Settings

The following information describes the setting of each writing workshop:

_The Victory Center_

For ten years, The Victory Center has, through an inviting warm, and homelike environment provided free, non-medical support to individuals who have been diagnosed with cancer and their family members. As an organization, it describes its mission as one that offers services focusing on strengthening both body and spirit through a variety of services that promote gentle exercise, relaxation, self-awareness, and spirituality. The Center’s progressive philosophy encourages participants to “think outside the box” and “break through conventional thoughts,” in addition to “[promoting] education and prevention techniques for healthy living.” Accordingly, The Victory Center provided an ideal venue for fostering a therapeutic writing program.

_St. Vincent Mercy Medical Center_

St. Vincent Mercy Medical Center, established in 1855, is a large regional hospital, offering a wide range of cancer support services at venues throughout the Northwest Ohio area. These services include educational workshops, as well as therapeutic and symptom management workshops, some of which are held jointly with the American Cancer Society. Through its on-
campus Cancer Resource Center, information regarding cancer services is disseminated to patients and their family members.

Swan Creek Retirement Village

Swan Creek Retirement Village, established in 1992, is housed on 34 neatly landscaped and wooded acres; residents are encouraged to enjoy the outdoors by using the paved walkways, benches, and personal plots within the community garden. The community offers villa homes, independent living apartments, assisted living apartments, long-term nursing care, short-term rehabilitative care, and specialized Alzheimer's/dementia care. Home health services and adult day programs are also available. The community is modeled on “The Eden Alternative” philosophy whose mission Chevremont, et al. describe as:

- to improve the quality of life for individuals who live in long-term care facilities. The core vision of this organization is to teach the concept that long-term care facilities are not institutions for the frail and elderly but rather habitats for human beings that can be both vibrant and vigorous and be inclusive of Mother Nature. (Eden Alternative Homepage 1999)

This mission and philosophy created an ideal setting for a writing workshop where vibrant personalities recounted numerous details of active and productive lives. The ten principles of The Eden Alternative emphasize banishing the loneliness and suffering of many elderly by encouraging residents’ independence and interaction with children, plants and animals as well as by de-emphasizing the role of prescription drugs in favor of more holistic approaches to handling problems, all of which served as a nurturing environment for facilitating a therapeutic writing workshop.
Research Questions

While Chapter One’s literature review revealed a lack of discipline-specific research related to writing as therapy, ample non-disciplinary scholarship guided me in developing this study. Ultimately, however, it was participant characteristics, in addition to facility and equipment availability, that affected the types of data and results obtained; nevertheless, I was reasonably successful in creating writing communities that would contribute information to the following questions:

To what extent can:

a. creative written discourse provide Senior members of our community with an opportunity for establishing their personal identity and preserving their life stories?

b. regular written discourse empower critically ill patients throughout their treatment and recovery?

c. regular written discourse provide family members of critically ill patients with a vehicle for exploring, understanding, and accepting the emotional impact of a loved one’s serious illness?

Research Methods: Writing Workshop, Case Study, Interviews and Questionnaires

Use of the Workshop Setting

Influenced by my past experience working with individuals during the more acute phases of illness, when I first conceptualized this project, I imagined carrying it out by visiting patients individually in a hospital or hospice-like setting. However, after familiarizing myself with the existing body of literature on the topic of writing therapy, I concluded that the opportunity to share one’s writing with other writers who themselves are undergoing similar experiences is one of the most therapeutic aspects of such therapy. Many researchers supported this conclusion; for
example, Alice Brand’s 1980 monograph, *Therapy in Writing: A Psycho-Educational Enterprise*, provided an important model for my own study. In her text, Brand describes research she conducted with 8th grade students; the research centered around a small journaling group focused on improvement of participants’ self-esteem and self-confidence. The format for her study comprised a workshop setting with sessions that included reading, warm-up writing, discussion, and group activity. As such, students’ interaction and voluntary sharing of their writing were integral pieces of the study’s success. In the same way, the work of Philips, Linington, and Penman also value the workshop atmosphere for therapeutic writing, “A creative writing group can be seen as therapeutic in much the same way as other forms of creative activities can be” (9). Based upon this research, I decided to conduct writing workshops, rather than attempt to work one-on-one with hospitalized individuals in acute phases of illness.

Additional research supported my decision to implement group writing workshops; this included DeSalvo’s *Writing as a Way of Healing*; here, DeSalvo asserts “When we share our writing, someone else knows what we’ve been through. Someone else cares. Someone else has heard our voice. Someone else understands. We learn that we are no longer alone and that we no longer need be alone” (213). Echoing these sentiments is Emily Nye whose study involving the use of writing as a method of healing in an HIV/AIDS community was published in Anderson and MacCurdy’s *Writing and Healing: Toward an Informed Practice*. Nye’s research methodology attracted my attention, not only because it focuses on writing that takes place among a group of seriously ill individuals, but because it provides detailed information about its effective methodology, “The writing we did involved two stages: private writing, followed by public reading . . . the group process required making the private public.” Nye’s conclusions described the effectiveness of her noted methodology, underscoring how it elicited “individuals
to unburden themselves, to make sense of experience, or to reconstruct themselves or the events in their lives” (405). Additional conclusions reached about the effectiveness of her group methodology include its evocation of “compassion, caring, and a sense of belonging” and of “being acknowledged” (405-406). As mentioned above, such earlier research justified the decision to implement a writing workshop format for this pilot study. Of relevance, however, is clarification that this decision does not imply that therapeutic writing could not or should not be implemented on an individual basis, with institutionalized patients, or in more acute healthcare settings. In fact, among others, the work of both Lynn Alexander in “Writing in Hospices” and Colin Archer in “Final Fictions? Creative Writing and Terminally Ill People” offers insightful information about their successful experiences implementing therapeutic writing in hospice settings.

The format of each workshop session was influenced by the 1999 Philips et al. publication, Writing Well: Creative Writing and Mental Health. In this text, the researchers advise:

Each session will usually consist of a short warm-up exercise, followed by a related longer task . . . . It is advisable at the beginning of a group’s life, however, to establish a formal pattern of working, and the short exercise does allow for a flexing of the imagination and of language skills before a longer task is undertaken. As a group becomes more confident with writing and with each other it becomes possible to move straight into a longer writing exercise, or to develop work from one session into another.

(33)

As such, the workshop format was consistent between The Victory Center group and the St. Vincent group (See Appendix A for the Outline of Victory Center/St. Vincent workshops).
While I created some workshop materials and activities, I based others upon composition classroom pedagogy by borrowing and modifying materials from the following works:

- **Session 1:**
  *With Pen in Hand: The Healing Power of Writing* by Henriette Anne Klauser, Ph.D.
  *The Healing Journey through Grief* by Phil Rich, Ed. D., MSW,
- **Session 2:**
  *Writing to Heal the Soul* by Susan Zimmerman.
- **Session 3:**
  *The Allyn and Bacon Guide to Writing, 3rd ed.* by Ramage, Bean, and Johnson, eds.
- **Session 4:**
- **Session 5:**
  *Remembering your Story: Creating Your Own Spiritual Autobiography* by Richard L. Morgan.
- **Session 6:**
  *Writing Well: Creative Writing and Mental Health* by Deborah Philips, et al.
- **Session 7:**
  *Writing out the Storm: Reading and Writing Your Way Through Serious Illness or Injury,* by Barbara Abercrombie.
- **Session 8:** As some participants were leaving for vacation (this session ended just prior to the Thanksgiving and Christmas holidays), session eight’s time was spent in wrap-up, distribution of post-workshop questionnaires, participants’ submission of chosen artifacts, and final interviews.

Workshop format for the Swan Creek group was similar to the others, with some overlapping material (See Appendix B for the Outline of Swan Creek workshops); as it became apparent that the participants in this group were interested in autobiographical writing, however, the focus of the materials, as well as many of the sources, changed. As with the previous group, I created many workshop materials and activities and based others upon composition classroom pedagogy, both borrowing and modifying materials from the following works:

- **Session 1:**
  *The Healing Journey through Retirement* by Phil Rich et al.
  *With Pen in Hand: The Healing Power of Writing* by Henriette Anne Klauser, Ph.D.
- **Session 2:**
  *The Healing Journey through Retirement* by Phil Rich et al.
- **Session 4:**
  *Writing Well: Creative Writing and Mental Health* by Deborah Philips, et al.
Use of Case Studies

As an ethnographic study, this research relied heavily upon triangulation of data, and the previously described literature review comprised one aspect of that triangulation. Another aspect is represented by the use of case studies, as Brand’s 1980 text also demonstrates. Accordingly, Brand’s aforementioned text influenced my decision to structure data communication as case studies. Given the volume of data generated by participants’ pre- and post-interviews, written anecdotes, and post workshop questionnaire responses, it became imperative, when considering this text’s length, to select and focus on those participants whose data most faithfully represented the average findings, while simultaneously illustrating ample examples of therapeutic writing theory. In Ethnographic Writing Research: Writing It Down, Writing It Up, and Reading It, Wendy Bishop relies on Robert E. Stake (1994) to support the appropriateness of utilizing case study methodology in writing research:

we cannot avoid generalizations in these cases but rather that we perform this generalizing to help others understand what we ourselves have seen in the data, given the limited reporting space we always have at our command ‘to encapsulate complex meanings into a finite report but to describe the case in sufficient descriptive narrative so that readers can vicariously experience these happenings, and draw their own conclusions.’ (qtd. in Bishop 143)
When conceptualizing project framework, Bishop’s work influenced my positing that case-study methodology would facilitate analysis and communication of select participants’ verbal responses to interviews.

In addition to the influence of Brand and Bishop, another successful model of writing research whose reliance upon case study methodology influenced the methodology of this research, is Sampson and colleagues’ 2004 Kingfisher Project. This ongoing project conducted in the United Kingdom uses thick description and the multiple perspectives of each researcher to relay information regarding writing in health and social care. According to the researchers, this project “was set up in response to local need and as a national model for good practice” (92), and identifies as one of its benefits writing as “celebratory and creative work which can impact on the broader health-care environment” (111).

Interview and Anonymous Questionnaire Creation

The decision to interview subjects both prior to the workshops’ beginning and after their completion, in addition to their completing an anonymous questionnaire, served as the final piece of triangulation in my ethnographic data collection. I anticipated multiple purposes for the pre-workshop interviews: First, the interviews would enable both participants and me to become familiar with each other, helping to abate anxiety or nervousness; whereas in a writing “course” instructors might have sixteen weeks to work through student writing anxieties, in a six or eight week workshop, there is much less time; therefore, the importance of facilitating participants’ comfort as early as possible was paramount in my decision-making process. Further, I determined that pre-interviews might also enable determination of prior education, expectations, motivations, and comfort levels with the anticipated workshops, knowledge that might help or hinder participants’ experience. In the case of seriously ill participants or spouse-participants, I
posited that the pre-interview would also help me to learn the current status of illness, since ongoing treatments might interfere with attendance, energy levels, motivation, or mood.

Post-workshop interviews, I rationalized, should be conducted for the purpose of “debriefing” participants to determine if their expectations had been met by the workshops, and whether their participation in the workshops had motivated them to continue writing. In the case of retirement village participants, it was important to learn whether the workshops had increased their sense of community and motivated them to continue their autobiographies to completion. With the aforementioned in mind, I also created the post-workshop questionnaire to elicit critical reflective feedback about the workshop itself. In each group, on the last day of the workshop, I handed each participant a stamped self-addressed envelope with a word-processed questionnaire inside. Participants were instructed to take the questionnaires home with them and complete them at their leisure, mailing them back to me when convenient. Questions were to be answered anonymously, and I requested that participants be detailed and honest in their responses, as their feedback would be used solely by me to improve subsequent workshop sessions. 100 percent of questionnaires were returned, and their results will be discussed in subsequent chapters.

Limitations

One of the study’s limitations regarded my original intent for individual participants to amass their choice of written texts produced through workshop writing, and compile them into a “published” collection to be used in the following ways: the Victory Center workshop participants were to contribute their compiled text to the Center’s library, where it would be available to future clients and their families. The Swan Creek workshop group was to have made their text available in the residents’ community library for the reading enjoyment of other residents. However, when individual participants were questioned during the pre-interview
sessions and again as a group during the first workshop meeting about their willingness to participate in these projects, the consensus was that written work would remain private. Ultimately, the overall mistrust of online community space, coupled with participant desire to maintain privacy and control of their written work, altered my original project plan and limited types of data collection, completely excluding both the group compilation and the online format.

Subject Selection

In the summer of 2005, after securing requisite approval from Human Subjects Review Boards, volunteer participants were solicited through the cooperation of three separate institutions located in the Northwest Ohio area, specifically, the Victory Center, St. Vincent Mercy Medical Center, and Swan Creek Retirement Villages. Although the size of each group was small, I decided that combining the groups into one would result in a group whose size would be detrimental to fostering and promoting a secure community atmosphere for all participants; as a result, all three workshops were conducted separately. Accordingly, Victory Center participants comprised four recently diagnosed or recovering cancer survivors: three females and one male whose spouse also participated; the St. Vincent workshop participants comprised two female breast cancer survivors and one spouse. The Swan Creek Retirement Village participants numbered six females who were primarily interested in autobiography and memoir writing, but who had at one time either suffered serious illness, or were current or previous caretakers of ill loved ones. While the material prepared for both The Victory Center and St. Vincent workshop groups were identical, and focused on coping or recovering from serious illness, in the case of the Swan Creek Retirement Community, workshop material was geared more toward memoir and autobiographical writing, at the request of the participants.
**Variables**

As with any research study, it is important to consider what conditions or influences might have affected the outcome. In this study, I encountered two:

- **Participation:** Such factors as participants’ vacations and other previously made plans and commitments, doctor and treatment appointments, as well as daily health greatly contributed to the number of workshop sessions participants were able to attend. One method that proved to be helpful in mitigating the effects of missed workshops was to structure each session independently of other sessions; this included the specification that carry over assignment remain “optional” to avoid creating stress for participants who missed workshops. By maintaining such session independence, participants who missed sessions were simply able to start up where they left off, without feeling embarrassment over having “missed anything.” Additionally, when participants requested the “missed” material, I provided it to them either via email or upon their return to the next workshop session.

- **Comfort level and trust of Internet and computer technology:** Comfort level with computer technology turned out to be an important variable that significantly affected the structure of workshops and data collection. Ultimately, because a large majority of participants lacked either confidence in their personal computing skills, trust in committing their written expression to Internet weblog sites, or lacked access to computer technology, the study was unable to incorporate the use of weblogs, and unable to examine the functioning of a web-based writing community.
**Data Collection and Analysis**

Data was collected from participants in the following manner: Each was required to complete a tiered consent form indicating at what level they wished to participate in the pilot study. Choice of levels enabled participants to:

- permit the researcher to digitally record a pre-workshop interview
- permit the researcher to digitally record a post-workshop interview
- participate in a between-session online journal (weblog)
- complete a post-workshop anonymous questionnaire survey
- provide the researcher with copies of written artifacts of text produced throughout the workshop sessions

The informed consent also asked participants to designate the manner in which they would like themselves and their writing to be referred: for example, on a first- and last-name basis, a first-name basis only, or by an alias. Individuals were free to choose any combination of participation levels (see appendices C and D for copies of the informed consent forms).

As a result of participants’ designated level of consent, each was interviewed prior to workshop commencement and again after all workshop sessions were completed; all interviews were digitally recorded and later transposed for use within this document. During the last workshop session, participants were provided with an anonymous post-workshop questionnaire survey and a postage-paid, addressed envelope; subsequently, all post-workshop questionnaire surveys were completed and returned to me. Individual items on The Victory Center and St. Vincent’s pre- and post-interviews were identical (see appendix E), while individual items on the Swan Creek pre- and post-interviews differed slightly (see appendix F), based upon the participants’ characteristics. All post-workshop questionnaire survey items were identical for all
three groups (see appendix G). Analysis of relevant data responses will be presented and discussed later in this document.

**Researcher Findings**

Throughout the literature and research addressing writing as therapy, various ideas about the theoretical nature of the discipline have been addressed. Within the field, however, no single source has clearly defined the scope of writing-as-therapy in terms of specifying parameters that define the practice. As outlined below, therefore, this text offers one such possible compilation of parameters through which the field might be defined. In fact, based upon case study methodology, Chapters Three, Four, and Five will analyze the pre- and post-interviews and written artifacts of four representative workshop participants from this pilot study, illustrating how their data address the following list of attributes that define writing as being therapeutic; furthermore, by using case study data to support these attributes, the following chapters intend to argue that such attributes approximate a list of best practices in writing therapy, practices that define writing as being therapeutic when:

- It engenders an intrinsic motivation to continue writing.
- It enables individuals to cope with trauma or serious illness, engendering acceptance of one’s circumstance.
- It promotes a sense of ownership or control over one’s life.
- It positively affects interpersonal relationships.
- It is both self-affirming and other-affirming.
- It is reflective and reflexive.
- Individuals are comfortable with the media used to produce it.
Additionally, given how the previous attributes define when writing takes on a therapeutic role, the case study data analysis will also address both how the data answer the study’s research questions and how these data assimilate with current discourse about writing as therapy.
CHAPTER THREE: CASE STUDY OF ELENA HUSTON

"My spirit dances in shimmering waves of rose, reds and pinks. It is a rainbow that ranges from gentle pastels to intense, vibrant hues. When I am strong of heart, my spirit radiates with the stronger spectrum of rose and red. When I am at rest, tranquil and peaceful, my spirit shimmers with a pink aura. These colors seem to be healing to me.”

Workshop participant Elena

Introduction

Chapter Three will analyze the pre- and post-interviews, as well as the written artifacts of Elena Huston (name changed) as a typical representative of the participants in this study. This analysis will focus on how Elena’s experience in The Victory Center writing group reflects the previous list of attributes that define writing as therapy. In doing so, the chapter will also address the theoretical underpinnings of Chapter One’s literature review as well as its contributions to answering the research questions outlined in Chapter Two.

Elena’s first professorship was at the University of Minnesota, where she taught children’s literature and studied creativity and language development in young children, continuing her dissertation research. She left Minnesota to become Director of Teacher Education at a small, private college in Georgia. A twenty-year-long professorship at a regional state university in the Midwest followed. There, she was primarily an administrator, starting as Director of Continuing Education and later serving as the Assistant Vice-Provost of Continuing Education, Regional and Summer Programs. Upon taking an early retirement, she entered into a full-time position with Adopt America Network, a national charity that focuses on “the effective and successful adoption of children who wait with an established pool of parents who care, with special emphasis on children who have been abused, neglected, have physical and/or emotional challenges, are of minority heritage, have siblings, or are school age or older” (http://www.adoptamericanetwork.org/2003/Corporate%20Reports.html). For four years, Elena
poured her efforts into reorganizing and assisting in that charity’s reformation, which she defines as “her life’s work.”

Concurrently, the athletically gifted Elena also engaged in training and competing with the United States Women’s Curling Team whose talents took them on tour in Scotland during 1996. In fact, both her involvement in this sport, her university work, and later her work with Adopt America Network required that Elena travel not only to Scotland, but to other countries for speaking and fundraising engagements for the charity network, all of which she accomplished despite a persistent weakness and fatigue. It was during one such trip that Elena fell ill with a severe gallbladder attack that resulted in surgery to remove the damaged organ. After the surgery, Elena, who had been feeling exhausted and weak for quite some time, anticipated a return to her “normal” high energy level. That level never returned, however; instead, Elena continued to experience severe overall body pain that limited her ability to participate in curling competition, and travel, and which finally drove her to seek a complete physical evaluation where a bone marrow test confirmed she was suffering from advanced multiple myeloma, a rare, and terminal blood cancer.

As a result of her illness, Elena had to resign her full-time position with Adopt America Network in 2004, and now volunteers as her health permits. Instead, she engages in both medical and non-medical treatments that have helped her to conserve strength and boost her immune system, focusing on personal care in a way that she claims she would never have done before her illness:

Elena: [I’ve] tried to do everything that seemed logical to me that was offered by western medicine. And then I’ve explored a lot of other realms that I thought would help me, both [in] dealing with a terminal illness, looking at my life and feeling that it was a
worthwhile kind of thing. I’ve done some things that I consider [to be] following spiritual paths. I’ve spent more time learning meditation, reiki, various massage and human touch sorts of things. I’ve had sessions with shamanic healers. I’ve done journeying myself—spiritual journeying where you work with a shaman and you go into a different type of state and you journey into a different type of realm and you find your power animal and you find out about your soul . . . I would never have done that. I would have thought that was sort of non-scientific or something that made no sense—it was certainly not something I wanted to be involved in while I was living my life the way I used to view my life.

Elena also values spending time with family and friends and, in the fall of 2005, was even able to travel to Scotland again. However, it was her pursuit of non-medical therapies that ultimately led her to the writing-as-therapy workshops offered by The Victory Center.

The Intrinsic Motivation to Continue Writing

Elena shared how writing has always been a part of her life: her career in education, focused primarily on teaching courses in children’s literature, teaching methods for language arts and secondary English teachers, language development in young children, elementary and secondary curriculum classes for teachers, and basic college classes in speech and composition; in the same way, her work with Adopt America Network required regular participation in written communication.

Elena: Writing’s always been a part of my adult life . . . but not this kind of [personal] writing. I’ve always been a communicator in written form . . . [L]etter writing, report writing, articles for magazines, whether it be in scientific journals at one point, all kinds of things. I’ve written travel articles for different groups that I’ve been involved with . . .
[I] was a national officer [for a Greek fraternity and sorority] organization . . . and I did a lot of their communications as the director of their member ed [sic] program, and in my work at Adopt America, or my work at the University, every single day. I directed publications and promotions for all the special programs of the University, so I was always involved with creating things for the writers and artists and at Adopt America I did much of the communicating in writing, whether it was the electronic newsletters to the volunteers, the publications that we did for the public, reports to foundations. I did stories a lot about the children and the families.

However, while Elena’s education and professional endeavors made her “a natural” for participation in a therapeutic writing workshop, her interest in what she called “personal” writing also impacted her decision to join the group of writers. Additionally, Elena’s tentative health status provided her with the motivation to explore “more spiritual types of healing” or non-medical therapies, fueling a more intrinsic motivation for her participation in this study’s writing activities.

Elena: I’ve always written a little bit for myself . . . So, yeah, probably very few days in my life have gone by where I haven’t been using some form of writing, and I would say . . . that there was always a great deal of personal woven into the majority of my communications.

Elena’s commitment to regular participation in writing activities can be made not only by her previous comments, but also by noting that Elena has continued and expanded her writing beyond the scope of the eight-week workshop, a fact that she attributes to her participation in the workshop itself:
**Elena:** I’m also working on other journals as well. I did a journal while I was in Scotland about what was happening. My impressions of just Scotland separate. And then I started three other journals, one for each of my children. And, so, all together, in class, I’ve worked—since class started, I have four different journals going.

Although Elena credits the workshop for stimulating her desire to continue with her more personal writing, it is important to note that self-motivation also compelled her to continue and expand her writing beyond the scope of the eight-week workshop, especially as she desires, upon her passing, to leave a collection of individualized written work for several close relations. Recent post-workshop communication with Elena has revealed that some of the journals to which she referred have since been completed, and she has also begun others, continuing toward her goal of completing separate written journals of thoughts, impressions, and memories she has shared with those to whom she is closest.

**The Ability Cope with Trauma or Serious Illness**

Much of Elena’s interview responses and writing artifacts clearly support the findings of researchers whose scholarship have contributed to recognition of the therapeutic nature of writing. The following is an artifact of Elena’s writing, composed and shared during one workshop session. Participants were asked to write in response to a quote by Victor Hugo, “Those who live are those who fight”:

I have learned to live with Pain [*bolded text is Elena’s*] as a trespasser in my body. Actually, Pain is an unwelcome resident with a lifetime lease. And this trespasser has taught me unforgettable lessons etched in its many manifestations. In fact, Pain has an entire family of relatives that live in my body and make their presence known to me as intrusively as a heavy metal rock band playing in the next room . . . . Pervasive pain is
omnipresent, an obese matron who sits in a rocking chair in the center of the family room wrapped up from head to toes in a navy blue, quilten [sic] comforter. How ironic that there is a comforter for the persona who has destroyed my comfort . . . . Oh, Pain. They are here as my foes, not as my friends, playing an intrinsic role in my life and my fight to live. I have learned to live with Pain as well as to fight Pain. It is the battle of a lifetime. My lifetime. **Oh, the Pain of it all.**

Elena’s compelling personification of Pain exemplifies what Anderson and MacCurdy, in their introduction to *Writing and Healing: Toward an Informed Practice*, describe as the use of writing to garner a sense of control and ownership of one’s life,

> By writing about traumatic experiences, we discover and rediscover them, move them out of the ephemeral flow and space of talk onto the more permanent surface of the page, where they can be considered, reconsidered, left, and taken up again. Through the dual possibilities of permanence and revision, the chief healing effect of writing is thus to recover and to exert a measure of control over that which we can never control. (7)

In that Elena ended her previous text by directly addressing Pain, a reader can perceive her anger at the trauma she is experiencing, trauma brought about through her affliction with terminal illness. Specifically, in the written artifact above, she personifies her pain, and then addresses it through vivid imagery, calling it “a family of relatives that live in my body with a lifetime lease.” Her intense delivery of this text is reflective of her overall involvement and participation in the pilot study and subsequent responses to her final interview questions, which support Anderson and MacCurdy’s claim for writing as a valuable tool in coping with the challenges presented by serious illness. In fact, in her final interview, Elena shared the following:
Elena: [T]he writing in your class has given me a wonderful channel for working through thoughts, reflections, of what’s happened to my body. What’s happening in my life. What will happen to my family. And letting me wrap things up and pass things on to others . . . and it’s been comforting. It helped me a great deal . . . When you read about people who are terminally ill, [depression] is one of the very, very difficult things that they deal with. And being able to process [those] kind of emotions and look at them and know that I can move above that and beyond that . . . [writing] has been extremely valuable. I would call it, you know, therapy. A very therapeutic method. I find yoga to be helpful. I find certain physical therapies, like swimming, to be very freeing. But [writing] is a form of therapy that both frees me and allows me to process and grow in the experience, so that I arrive at a much more mellow, comfortable place, both physically and mentally.

In the above entry, Elena claims that such writing as was facilitated through the writing workshop became a buffer for her pain and suffering, and assisted her in alleviating much of the fear she once associated with her terminal illness. Moreover, as Elena acknowledged, such writing has helped her to achieve, if not closure, then certainly an acceptance of her illness.

The Ability to Promote a Sense of Ownership and Control

Similarly to Elena’s observations that writing can foster both mental and physical respite from disease, DeSalvo’s text, Writing as a Way of Healing, embraces the perspective that writing, while it cannot abolish serious illness, can certainly mitigate its psychological impact by altering a writer’s outlook:

[Writing] can help us heal. It can enable us to accomplish that shift in perspective marked by acceptance, authenticity, depth, serenity, and wisdom that is the hallmark of genuine
healing. . . This applies, too, to those of us with serious challenges. I have taught people who are disabled, who live with chronic illness and with terminal illness . . . All have been profoundly changed by writing. Their work does not make their pain disappear, but they say they have a different relationship to it. (12)

From both the literature and my research, it appears that the “difference” to which DeSalvo refers is a greater sense of control over what is happening to one’s body. More often than not, when confronted with serious illness, the diagnosis is only the start of the mental and physical trauma to come. Soon to follow are cycles of chemotherapy or radiation that attack the body’s already depleted immunity; those afflicted often refer to such treatment as grueling and dehumanizing, a chaotic quest for survival through which they numbly proceed, as ordered by their medical professionals. Furthermore, in defense of writing’s ability to positively alter one’s point of view, Writing Well: Creative Writing and Mental Health, the work of scholar-researchers Philips, Linington, and Penman corroborates the previous assertions:

Among the functions of writing is that it requires the writer to articulate feelings, about themselves and others in a form, and that form can give shape to what might otherwise be chaotic thoughts and ideas. The shaping of ideas into a formal piece of prose or poetry can allow the writer some distance from their thoughts, and enables them to be put into a different perspective. The practice of expressing ideas and feelings in a relatively unfamiliar form can allow for the development of new insights. (16)

Like Elena, other writing-as-therapy workshop participants who presented with current or past diagnoses of terminal illness also articulated feelings of fear and loss of control upon receiving their diagnosis, a diagnosis that threatened, in many cases, to rob them of careers, relationships, and hobbies. Of note, because taking up or continuing with writing activities is relatively
uncomplicated, requiring little physical exertion, as an activity, it is highly feasible that most seriously ill individuals, who have the desire to participate can do so. According to Elena, “I didn’t realize how positive or just how wonderful the [writing workshop] experience would be both in stimulating my writing and also as a factor in letting me look at and reflect upon and get some closure and move on or grow in relationship to my illness.” Her observations, in conjunction with those of the sources previously mentioned, underscore how writing about pain and suffering has the potential to alleviate the fear and anxiety felt by many seriously ill individuals, while simultaneously bringing these individuals to an acceptance of the reality of their illness and a sense of control over that reality.

**The Ability to Positively Affect Interpersonal Relationships**

Another interesting aspect of Elena’s experience with writing is that it had, from her childhood days, been an important tool in fostering interpersonal relationships, a tool that she has relied on throughout her illness, and especially throughout the workshop. From her childhood, Elena recounts the rich usage of written discourse as a means of communication in her home:

**Elena:** We were encouraged to write a great deal, even when we were quite small . . . in our family we were encouraged—when the family was together . . . everyone offered things, whether it was songs or poems, and we were encouraged to memorize poems, and some of them were quite long . . . and I always organized the group—a group in our neighborhood—when I was young into doing plays.

Her words call to mind those of Elbow quoted on page 17 of Chapter One, words that describe the meaning-making capabilities of writing as therapy. Enhancing Elbow’s observations, Elena touts the meaning-making value of memory, especially as a tool for communicating one’s written words to others. Her past experiences with both written and oral forms of interpersonal
communication served as a natural impetus for her reliance on writing for its healing properties during her illness; in fact, not only did Elena write copiously throughout the workshop, she also shared that writing openly with other members of the group. Her sharing then had the effect of encouraging other participants to share, and often poignant discussions about the devastating effects of cancer ensued, fostering an observable bonding among participants. Researchers have referred to the powerful effect of sharing one’s writing with others, indicating that when it exists, that effect is powerful. By using experience from her own writing workshops, in “Las Madres, Upstairs/Downstairs,” Florence supports the therapeutic benefits that come from sharing one’s writing:

Amazing things began to happen for the writers in our intertextual groups [. . . ]

Something in our work together reverberated and resonated beyond the writing circle. We learned something about revision not only of our writing, but also of our lives. And as we collaborated with one another, we became both the initiators of and the witnesses to our revisions and transformations, our healings. (Writing and Healing 447)

Such affirmation regarding the importance of sharing one’s writing is extended by Weldon who claims, “That you tell you story and how you tell it are critical to understanding yourself, and will help you to keep healing and growing “ (217). Elena’s participation in The Victory Center writing workshop punctuated the findings of these important scholars who have written about writing as therapy. When questioned about whether regular journal writing had an impact upon her relationships, Elena affirmed:

I would say yes, profoundly. The journaling will help me leave a lasting legacy for each of my children, where they will understand the bonds of love we share and [. . . that] is a gift from journaling. It will be a gift for them for a long, long time. I know it will be very,
very meaningful. So, yes. I think [regular journaling] is going to be a very beautiful part of our relationships and strengthening them. A couple times when I’ve been very irritated with my husband because I think, for the most part, overall he’s been highly supportive and sensitive, but . . . those times he hasn’t been, whether I write it down or I [think through] it in a way that I would write it down, it’s been very freeing and very forgiving and allows me not to get stuck in that moment of being upset or provoked. So, yeah . . . [writing has] helped my day-to-day relationships . . . and I think it’s going to be profoundly important in both my long term relationships with the people I love and the legacy I leave behind to them.

Above, Elena touches upon another interesting aspect of the therapeutic value of writing: it is capable of positively affecting behavior. For example, Elena describes how even when she does not actually write out her feelings about something that is upsetting her, she is able to use the same thought process she would use if she were actually writing, and that thought process alone brings her comfort and helps her over a behavioral hurdle.

**Writing is Self-affirming and Other-affirming**

In addition to being therapeutic when it sheds positive light on relationships, writing is therapeutic when it is both self-affirming and other-affirming. In *Writing to Save your Life*, Weldon reasons that the act of writing itself becomes therapeutic when it is Self-Affirming. For example, he states,

The act of writing will teach you about how you think and feel and remember, what you remember and why, not because the writing is coming from some source outside of you, but precisely because the writing is coming from a place deep within you. It is perhaps
the first time you accessed your own wisdom and put into words you own interpretations or account of your history. It is the cheapest form of therapy I can imagine. (217)

An artifact of Elena’s writing supports Weldon’s remarks:

Miracles abound, and whenever I open my eyes and look at nature, I see one of them. When the heron stands in the shallow water of the lake to fish, when the osprey soars overhead, when the Canada geese swim by with their babies following (one parent in front and the other bringing up the rear), when the gold finches hang like a bunch of yellow grapes from their feeder, I see the miracles with my eyes and my heart is glad.

[emphasis Elena’s]

In another artifact, in response to a writing prompt asking her to choose a color that best describes her, Elena wrote freely,

If I concentrate by closing my eyes and focusing, I see a pink lotus blossom almost growing out of my chest. Once during meditation, the lotus blossom was aglow, almost a living entity, and it opened, unfolding its petals with a pulsating rose light that filled my mind and body with energy.

In both of these examples, Weldon’s assertion regarding the power of writing to uplift and affirm one’s life is evident. In the first writing sample, by using writing to note how nature affects her, Elena savors life and conveys her gratefulness for the beauty that fills each day she is given, claiming her resulting happiness in the end. The second example illustrates the power of contemplative writing to “energize” a woman who experiences little energy due to severe illness. Both reflect Weldon’s observation that the writing is coming from a place deep within oneself, causing the writer to access one’s own healing wisdom in making sense of life’s circumstances.
In “Writing and Healing: Toward an Informed Practice,” Nye corroborates the self-affirming characteristic of therapeutic writing, but also posits about the communal benefit that is evident when writing is therapeutic:

Indeed, every narrative told constructs a world of its own . . . . Others may read [my] story and recognize parts of their own landscape or backdrop. They may connect my Aunt Edna to their Aunt Edna, or Tia Rosa, or Cousin Hosei . . . Such narrative linkages connect people and help explain our experiences. They help us to reconstitute ourselves as part of the larger humanity and restore us to “health,” which can best be defined as both a personal and collective or communal wholeness. (Writing and Healing 391)

From these texts, one can infer that another characteristic of therapeutic writing is its ability to connect with the experiences of others when it is shared, and as a result of this sharing others who suffer similarly are affirmed, made to feel both stronger and less isolated in their experience. According to Elena, she sees writing to be therapeutic as it encourages her to be “very open to exploring and finding out more things” about herself, “about what is happening to me at this time. Making me more ready for what’s coming next.”

**Writing is Therapeutic when it is Reflective and Reflexive**

When contemplating writing as being therapeutic in nature, an important consideration is its characteristic reflective and reflexive nature. Nye explains the relationship between these dual characteristics, “It is useful for writers to become or own themselves as both the subject of their writing, as well as the object of examination” (392). Unpacking Nye’s explanation, Celia Hunt in Fiona Sampson’s edited work *Creative Writing in Health and Social Care*, adds:

Where reflection could be said to involve taking something into oneself—a topic, an event, a relationship—for the purpose of contemplation or examination,
reflexivity involves putting something out in order that something new might come into being. It involves creating an internal space, distancing oneself from oneself, as it were, so that one is both inside and outside of oneself simultaneously and able to switch back and forth fluidly and playfully from one position to the other, giving oneself up to the experience of ‘self as other’ while also retaining a grounding in one’s familiar sense of self. (156)

Thus, both Nye and Hunt affirm the reflective and reflexive characteristics of therapeutic writing, explaining how reflective writing involves a writer focusing inward for personal study, and reflexive writing allows the writer to step outside the self to examine the self from an ‘other’s’ perspective with the intent of responding in some way. Thus, when it is reflexive, writing can enable healing or change. In support of the work of these researchers was the following post-interview response from Elena:

I think [writing] has allowed me to be even more reflective and to move beyond the terrible days when I wake up and everything hurts so bad. . . I can think the thoughts I’ve written about or I can go back and read something, or I can sit down and write how I feel, and, yes; it makes it more possible for me to keep going . . . It’s given me a more long range view. It’s also helped me . . . through the moments that are not very good.

These comments address both the reflective and reflexive qualities of writing, qualities that make it therapeutic in nature. Although Elena first refers to her writing as enabling her to be more reflective, as her response continues, the reader understands that because of her experience with writing, Elena is able to take action against the debilitating aspects of her illness, action that assists her in moving through each painful day. The inference of her response then, is that by
allowing her to improve her methods of dealing with her illness, writing takes on a reflexive quality, becoming a therapeutic activity for her.

Individuals Should be Comfortable with the Media Used to Produce Writing

In its original form, this research project was conceptualized to include both a face-to-face and an online component. The plan was that participants would engage in a weekly writing workshop, and then follow-up the week’s writing in a group weblog. I theorized that the weblog would have provided a forum for additional interaction among group members as they wrote and responded to each others’ online journals. Additionally, it would have provided a mechanism through which workshop members could have continued their interaction beyond the duration of the workshops. Upon conducting initial interviews, however, most interviewees expressed negative reactions to the idea of journaling in an online setting. As might be expected, there were concerns about privacy; nevertheless, the overriding sentiment was that personal writing requires the feel of pen and paper, and Elena summarized this sentiment:

I could not have gotten along without a pen and a journal . . . but I could have gotten along without a computer. So the pen and the journal were far more important. I would never have been comfortable with bringing my laptop, for example . . . That would have been an obstacle for me. I could have done it, but I felt so much more comfortable with my journal and pen.

Similarly, in his text The Therapeutic Potential of Creative Writing Gillie Bolton describes a study conducted in England where a group of general practitioners prescribed writing to anxious and depressed patients. Bolton described one patient who needed the feel of a special pen and paper to break out of his “work writing” mode and write therapeutically, “Peter wrote that he found it enormously important to choose writing materials with meticulous care and that writing
at different times and in different places affected what he wrote. . . . So he tried writing in places like by a river . . . and with a paper and pen he really liked . . .” (159). These are authentic examples supporting the fact that, in order to be therapeutic, writers must be comfortable with the media used to explore their feelings. Therefore, since a number of participants expressed the desire to conduct their journal writing with traditional media, pen and paper, the idea of an online component was abandoned.

Overall, Elena’s interview and text add credence to the larger perspective of what characteristics make writing therapeutic. For example, her writing and observations indicate that, when it is therapeutic, writing creates in individuals the motivation to continue writing, and to cope with trauma or serious illness, accepting one’s circumstance. Further, therapeutic writing promotes a sense of ownership or control over one’s life by acting as self-affirming and other-affirming and positively affecting relationships. Finally, when individuals are comfortable with the media used to produce it, therapeutic writing is both reflective and reflexive, enabling the writer not only to learn from past experience, but to change behavior because of that learning.

While this chapter has focused on how writing can be therapeutic for those suffering from serious illness, Chapter Four expands upon this focus by addressing the case study of a participant who had recently undergone treatment for breast cancer. While the writing of each case study participant was motivated by differing exigencies, both have in common the desire to record personal written work for the purpose of creating a lasting record of their lives; it is in this common perspective that both case study participants perceived their writing experience to be therapeutic.
CHAPTER FOUR: CASE STUDY OF BARB

“As Mother Nature provides a rainbow after the storm, I offer you a legacy of love.”
Workshop participant Barb

Introduction

Chapter Four will analyze the pre- and post-interviews, as well as the written artifacts of Barb as a typical representative of the participants in this study. This analysis will focus on the value attributed by this participant to the writing workshops, and their effect on her both as an individual and on her relationships. Additionally, it will categorize aspects of that value into characteristics that mark writing as therapy, using a combination of interview responses, participant writing, and research to support the importance of these characteristics in defining writing as being therapeutic. Overall, this chapter will parallel the case study of Elena Huston in Chapter Three, addressing the same characteristics of writing as therapy in an effort to add credence to their role in defining how writing can be therapeutic. The difference between Barb and Elena’s situation, however, is that, where Elena’s circumstances required that she only care for herself, in addition to battling cancer, Barb is also a caretaker for her husband who is chronically ill. Thus, the impact of her illness was that much more stressful. Additionally, while Elena had a strong support structure in her husband and family, Barb lacked the emotional involvement of her oldest daughter who could not cope with her mother’s illness. Finally, Barb had successfully completed a mastectomy and subsequent chemotherapy at the time of the writing workshop, whereas Elena was dealing with a terminal illness.

As a former third-grade teacher, Barb had always valued writing in both her classroom and private life. Her diagnosis of breast cancer came three years into her retirement as the result of a routine mammogram. Following her diagnosis, she underwent a mastectomy and breast
reconstruction; at the time of the workshops and for two years prior, she has remained cancer-free.

In addition to teaching third-grade, Barb also assumes the role of caregiver to her husband who suffers from a heart condition and frequent bouts of pneumonia. Also afflicted with Fibromyalgia, Barb reports that her life was hectic at the time of her cancer diagnosis; consequently, she had scheduled her yearly mammogram later than usual. Nevertheless, despite her husband’s recent bout with pneumonia, and the death of her father-in-law, a nagging feeling of urgency prompted her to schedule the mammogram, and its abnormal results arrived in the midst of funeral preparations. Rapidly, a biopsy was scheduled, and the breast cancer confirmed, leaving Barb stunned and unprepared for this devastating news. Shortly afterward, she was given a blank journal book through a program called “Reach to Recovery,” and she began to routinely write in it as a means of negotiating the onslaught of surgeries, chemotherapy, and doctor visits that soon followed. Ultimately, writing in this journal set the stage for Barb’s interest in writing as a means of coping with her illness, and as a result of writing in her Reach to Recovery journal she became determined to find a way to keep up with her journaling; consequently, the writing workshops offered through this research project peaked her interest. For Barb, the benefits she perceived from writing spurred her desire to continue writing; an outcome I posit is an important characteristic of writing as therapy.

The Intrinsic Motivation to Continue Writing

When questioned about the role of writing in her life, Barb reported a lifelong commitment to it:

I’ve always loved reading and writing. I knew I wanted to be a teacher from the time I was in the second-grade, and that’s probably right there where it started. I had a teacher
who was just really supportive and really loved the reading and writing aspects, and I just took off [from] there, I guess.

Similarly to Elena, Barb describes an early affinity toward writing, an early environment conducive to the acquisition of strong language skills, and a natural tendency to use writing to record her thoughts and emotions. As a teacher, she attended writing workshops, honing her ability to teach the subject; she also employed daily journal writing with her students, “I wrote every single day. The kids had writer’s notebooks and I kept one too, and then I would share my writing with them and they would share . . . I did that all the way until I retired.”

However, it was during her bout with cancer that Barb earnestly began journaling and writing stories, “I started from the beginning, you know, wrote everything down . . . and kept up until [I was] feeling better . . . Now I’ve started on it again.” Her desire to continue journaling spurred Barb’s interest in this therapeutic writing workshop. When asked why she so strongly felt the need to continue journaling she responded:

I think validation is one of the biggest [reasons]. Because, you know, it’s hard to put [experiences] into feelings that other people can understand . . . And when you have an illness like this, and especially in my case when you have somebody else that is ill, you don’t want to . . . put all of this on them exactly.

Barb’s description of the personal validation inherent in her journaling process prompted her desire to continue writing, a characteristic supporting the assertion that writing is therapeutic when it instills a desire in the writer to continue writing. This desire to continue writing is visited in Moffet’s Coming on Center where Moffet elaborates on writing as a product of inner speech:

. . . .writing does not merely convey what one thinks, it shows what one is thinking and
helps to discover what, further, one *might be* thinking . . . writing discovers as much as it communicates . . . Sustained attention to inner speech reveals ideas one did not know one thought, unsuspected connections that illuminate both oneself and the outside objects of one’s thought. No better motivation exists . . . . (104)

Here, Moffet reveals that, in its potential to elicit both self-discovery and discovery of new meaning in our present and past experiences, writing produces in the writer an intellectual fascination that fuels the drive to continue writing. Barb argues that such discovery creates in her a sense of validation, not only as it relates to her experience with illness, but also as it relates to her role as caregiver. In light of her desire to protect her spouse from additional trauma, she withholds stressful communication from their communication, “I would compare the essence of my life to that of Mother Nature. She coddles, nourishes and rejuvenates . . . Such has been the purpose of my life . . . As Mother Nature protects her delicate blossoms, I have protected my beloved family.” Instead, writing about her emotional reactions to her illness provides her the needed outlet for her emotions. Furthermore, Barb describes how her lifelong attraction to writing routinely calls for her return to this combined method of discovery and validation of the trauma associated with her illness

. . . . writing down my thoughts, my frustrations, my angry feelings helped to minimize my stress and gave me great comfort . . . . Taking this class has made me realize how much I missed my journal. It has also made me realize what an invaluable tool writing can be when you are recovering from any kind of trauma, be it physical or emotional. To this day, whenever I have an off, down period I seek out [this] proven comforter. [It] still helps me to stay emotionally up when I am physically down.
In acknowledgment of this therapeutic characteristic of writing, Bolton, in his introduction to 
*The Therapeutic Potential of Creative Writing*, emphasizes Moffet’s assessment of how writing 
itself can motivate a writer to continue writing, “Writing in this way can become compulsive; it 
is a way of life, not just something to try” (11). Indeed, like Elena and Barb’s sentiments, 
Bolton’s words clearly convey the self-generating therapeutic characteristic of writing. Along the 
same lines, another characteristic of writing as therapy is its ability to enable individuals to cope 
with the trauma of serious illness, assisting in their acceptance of the illness’s reality in their 
lives.

**The Ability Cope with Trauma or Serious Illness**

Throughout Barb’s post interview, her insistence in writing as a valuable coping 
mechanism for confronting serious illness reveals that one characteristic of therapeutic writing is 
its ability to help seriously ill individuals accept their circumstances. Toward this end, Barb 
reminisces:

> it’s been a big coping mechanism for me because it helped me deal with all aspects [of 
my illness]. For me, it was like an in-your-face thing. Once you’ve written it down, then 
you can go back and say, okay, this is where I was at two months ago. Now look where 
I’m at now. Because . . . a lot of times with cancer, you don’t realize how far you’ve 
come.

As Barb acknowledges, once something has been recorded on paper, it becomes a permanent 
record that provides a benchmark by which one can measure progress. By acting as a benchmark, 
writing allows seriously ill individuals to return to a record again and again, deriving comfort 
from its proof of progress along the treatment pathway. In addition to providing comfort, 
however, this written record also engenders acceptance of illness by providing afflicted
individuals with a method of “fighting back.” For example, in “The More I Tell My Story” Nye emphasizes how writing assists in this important coping characteristic:

Several conclusions regarding writing and healing among people with HIV/AIDS can be drawn from my study. First, people found it healing to make sense of their lives. Writing their life stories, particularly key moments and events, helped them to become more aware of their lives and to reckon with their pasts. They developed a sense of the whole of their lives by marking points along the time line of their existence . . . . The writers found it healing to “fight back” by sharing their stories.” (Writing and Healing 405)

Nye’s work with HIV/AIDS sufferers points to the fact that many who become seriously ill require assistance in coming to terms with their illness. In 1994 Nye conducted a writing group whose aim was to help individuals cope with their AIDS/HIV diagnoses; to this end, reflective and autobiographical writing provided the necessary means for writers in her study to examine key points in their lives, examination that would subsequently help them make sense of the broader picture, and how their illness fit in to that picture. Likewise, Barb’s writing reflects a similar critical analysis, one that enables her to grasp the reality of her illness and then begin to fight back,

I am fully aware now that this is not a bad dream that will dissipate with time. However, my real world is no longer the nightmare it used to be. Once you face reality, you can begin to turn those bad dreams into good ones. To sum it all up, I would put it this way: When faced with a catastrophic nightmare, such as a flood, you have three choices in my opinion. One, you let yourself be pulled under the swirling waters without a fight. Two, you keep your head up and tread water until you are either rescued or the waters subside. Three, you grab onto a rowboat called courage, and row with all your might until you
reach safe, dry land. Cancer is a catastrophic nightmare. I choose to row away from its devastating effects with every ounce of energy I have left.

No reader of Barb’s writing can fail to see her courageous spirit, and that there is no room for self-pity in her outlook. What is most interesting in the above text is its similarity in both content and tone to Elena’s words in Chapter Three, “[T]he writing in your class has given me a wonderful channel for working through thoughts, reflections of what’s happened to my body, what’s happening in my life.” Both Elena’s post interview and Barb’s written text reflect the empowerment that writing has afforded these women in confronting the reality of their illness. To further illustrate this empowerment, Barb relates, “[Writing] helped my emotional state; I mean it’s not going to cure cancer. But it definitely played a role in keeping me emotionally stable, and I still say that cancer is more than 50% emotional. I mean, you can treat the physical and whatever, but the emotional part stays there forever.” Both Barb and Elena lend support to the theory that one characteristic of therapeutic writing is that it provides writers with strong coping skills with which to face their illness. These coping skills, it may be argued, translate into a positive attitude that, in spite of illness, suggests an overall better outlook on life.

DeSalvo underscores the sentiments of both Barb and Elena by discussing Alice Walker’s metaphor illustrating “writing as a sturdy ladder.” DeSalvo posits that Walker’s metaphor alludes to a pit, and “that though there’s a pit, there’s a way out that’s safe and strong and dependable. That all you have to do when you’re in the pit is to remember that writing’s there. And use it as a way to reach freedom and safety” (qtd. in Writing as a Way of Healing 8). Clearly, whether examining Barb’s metaphor of survival as rowboat or Walker’s metaphor of survival as sturdy ladder, the participants in this study reach the same conclusion as many researchers and professional writers: they advocate writing as a vital, necessary part of developing strong coping
skills. Akin to strong coping skills, writing also nourishes a sense of ownership and control where catastrophe has threatened to tear it away.

The Ability to Promote a Sense of Ownership and Control

When serious illness strikes, many individuals are swept into survival mode; catapulting from doctors’ appointments, to surgery, and chemotherapy in a frenzied bid for survival. According to Barb, “one of the biggest things that cancer does is take away your control of everything.” Often, this loss of control has a dehumanizing effect, where individuals who are already ill now become an insurance identification number or a case number, ultimately losing all sense of control over what once was their life. Barbara Ambercrombie, in her book *Writing Out the Storm* addresses this dehumanizing loss of control:

> And then I think—this is such a joke. Here I am trying to control things. Thinking that buying books and clothes will somehow contain my feelings, make everything okay. It’s like planning and making a list while strapped to the railroad tracks with the train coming right at you. The design for my future is on slides in the pathology department at the hospital. I have no control over any of this, and that’s what really makes me crazy. (65-66)

As a result of this loss of control, it’s likely that depression sets in, and it is precisely at this point that writing can play an invaluable role because both the physical act of writing and the intellectual process that make writing possible help writers regain a measure of control over events that seem uncontrollable. Here, Barb recounts an experience with using a journal early in her treatment schedule,

> . . . I took that journal everywhere. I wrote—before I went to the doctor’s—I wrote down all the questions I had. When I came home from the doctor’s I sat down and I wrote down
everything that I could remember that he said and my feelings about . . . what he said and what my options were . . . I used it daily.

The ability to write down specific questions and concerns before a doctor’s appointment and to record conversations that ask one to make choices are certainly ways that writing assists individuals in gaining back some control during dire circumstances. However, during such times, more personal and self-revealing writing, where individuals relate their reactions and responses toward the changes that illness has brought to their life, can also reinstate a lost sense of control. In *Creative Writing in Health and Social Care*, Sampson’s edited text, Maureen Freely’s chapter extends Barb’s description of how writing can be used therapeutically to regain control of one’s life. Freely depicts how the writing of Fiona Shaw carried Shaw through post-partum depression, “Her story is the best advertisement I can imagine for writing-as-therapy. Writing like this can release you from the position of a patient who is healed by others. No longer are you the object of study, with observable symptoms but no inner life worth mentioning. You can take charge of your life” (85). This idea of “taking charge” can be a powerful motivator for healing in that it liberates a patient from the traditional doctor-patient hierarchy by enabling the patient’s voice to emerge. Whether by recording questions and answers, or through written revelation of deeply troubling fear and pain, writing out the significance of one’s experience with illness clears the mind and validate one’s sense of self, boosting confidence for the doctor-patient relationship. The opportunity to regain control during illness is a gift of the therapeutic writing experience, and a strong indicator of the therapeutic value of writing. Another such indicator is writing’s ability to positively affect interpersonal relationships.
The Ability to Positively Affect Interpersonal Relationships

Like Elena who explained how writing about her thoughts helped her to express negative feelings before sharing them with her husband, Barb discussed similar experiences, “[Writing] is a great stress reliever. It’s a way to get all those feeling out on paper without hurting anybody else’s feelings. And still have your feelings validated.” Barb, however, had always been a caregiver, and the one to be in charge of family affairs. Thus, when she became ill, it created much upheaval within her family structure, and was difficult for Barb, herself, who was unaccustomed to playing the “patient” role. Regarding this dichotomy, Barb expressed in her writing, “It really upsets me when friends or family treat me like I am different or pity me.” Barb also expressed how there are family members who simply can’t deal with the diagnosis, and these individuals react by distancing themselves. Abercrombie discusses this in a pragmatic fashion, “Of course some people don’t call or write, don’t know what to say or do. Or are afraid of disturbing you . . . Or simply can’t be around cancer for whatever reason” (22).

Unfortunately for Barb, one of these people was her daughter, and in her post-interview, she relates how painful her daughter’s withdrawal was, and how she dealt with the situation by writing out her feelings,

That was a real traumatic experience for me, during my cancer time not to have my own daughter supporting me whatsoever . . . that was very hurtful and I had a hard time dealing with it, so it’s all written down. I mean, I would just sit and get it all out because I couldn’t understand . . . You have to learn to accept, but there again, I think writing has helped me do that. Because I write down all of the things and then I go back and read over it, and it helped me understand it . . .
Both Barb’s commentary and Abercrombie’s example suggest that writing can be used to record both positive and negative feelings; this observation is important because it indicates that individuals can use writing as a medium to help understand interpersonal relationships, and by doing so demonstrate something important: another feature of writing as therapy lies in its ability to act as a medium for self-study and for modulating reactions and behavior. This fact makes writing a powerful tool for developing the self-awareness needed for successful interpersonal relationships, and its benefits should be more widely recognized by healthcare personnel as well as educators. Similarly, just as therapeutic writing mirrors feelings and attitudes about relationships, its therapeutic characteristics include the ability to be both self-affirming and other-affirming.

**Writing is Self-affirming and Other-affirming**

Before beginning this project, one of my fears was that no one would sign up to write in a group. Indeed, I could tell from individual opening interviews that participants were hesitant and wary of exactly what would be taking place in our group. Therefore, from the first meeting, I introduced a completely voluntary system where participants could join in activities at the level they preferred. For example, they could respond to the writing prompts, write freely on a topic of their choice, or not write at all. When it came time for sharing, it was acknowledged that participants might or might not wish to share; if they chose to share, they were free to either read verbatim from their writing or paraphrase only that information they wished others to know. At no time was participants’ writing ever in the hands of another participant. While participants were somewhat reserved the first time sharing came up, their reservation didn’t last long. Soon all participants were eager both to write and engage in discussions; they had discovered first-hand that among the characteristics of therapeutic writing is its ability to be both self-affirming
and other-affirming. I am reminded of Nye’s similar experience arising from a writing group set-up along the same parameters as the group in this study. Her conclusions touted the value of healing through group writing:

The writing we did involved two stages: private writing, followed by public reading . . . I contend that this shift of private to public constitutes a healing process for three reasons. First, writing is a vehicle to record “untold stories.” As many scholars agree, such storytelling helps individuals to unburden themselves, to make sense of experience, or to reconstruct themselves or the events in their lives. Second, in a writing group, the group dynamic of sharing with one another evokes compassion, caring, and a sense of belonging. These lead to growth and transformation on both individual and social levels. Finally, being acknowledged is part of the healing process. Being heard, or acknowledged, is being cared for . . . I would argue that telling stories is also a way of preparing for life, and decreasing distance between ourselves and others. (405-06)

Here, Nye is describing a threefold purpose for sharing private writing in a small and safe public setting. She claims that when individuals tell their stories, they unburden themselves and make sense of their experiences. She also posits that when individuals share writing with others in groups, it elicits compassionate caring from group members. Finally, Nye believes that sharing writing with others aids in life preparation by breaking down the prejudices that separate them, and drawing people closer together. Nye’s ideas embellish how, when writing is therapeutic, it reflects the characteristic of being both self-affirming and other-affirming. That is, by sharing our writing among a small group of trusted individuals, the opportunity is available to bring out the best in all.
Reacting to our group writing and sharing sessions in our final interview, Elena stated,
“[The writing] that we did was so incredibly different and creative and liberating, and growing!”
Her statement melded with Barb’s:

I would have to say it was like a revelation. Each session that we had our group, I got a new insight from somebody, or, you know, listening to other people share what they wrote was just as meaningful as writing itself. It was an extension of writing. I can’t explain it. It was like a validation, a validation of who you are and what you’re going through and other people are going through the same thing, and hearing them say these things was a real, real booster.

The words of both women extend those of Nye, explaining how by sharing writing in a supportive environment the healing effect of the writing can actually be maximized because the sharing enables the text to benefit both the writer and the listener. Sandra Florence, author of “Las Madres, Upstairs/Downstairs” envelopes the sentiments of all three women by considering, “I’ve been in many writing groups myself and have seen that sitting in a room and simply writing with others can have a very powerful effect on people, transformative, even life-changing” (Anderson and MacCurdy 416). Perhaps Florence means that when people know they aren’t alone in the experience of serious circumstances, then they don’t feel so isolated, and this makes words that have been both written and heard all the more meaningful, both self-affirming and other-affirming.

Writing is also self-affirming because it bolsters a patient’s confidence to undergo what is necessary from the standpoint of a cure. Barb’s writing illustrates how her illness altered her physique, something that can impact both self-image and self-confidence. Among the written
work Barb chose to share was an entry where she addressed the physical changes that confronted her:

Admittedly, at first I was repulsed and saddened by what I saw in the mirror, but as time went by, I learned to look at myself with “new eyes.” What I see in the mirror now is not pathetic or disgusting. Every scar is a reminder of where the enemy, Cancer, was removed from my body. What I have now may not be what I had before, but it is cancer-free and that’s what’s important. The battle may not be over, but I am fighting for all I am worth, and I have the battle scars to prove it.

Again, Barb’s courage is evident in her writing. But, in addition to courage, there is also something else this time. This time Barb is looking at her body with “new eyes;” viewing her scars with respect, personifying Cancer as the enemy, and using the metaphor of “Battle” to describe what it has done to her body. Such awareness, such acceptance can only result from the repeated affirmation that writing and sharing one’s story can enable. Barb offers another perspective,

this was so much more than I anticipated, because this was a sharing group. I gained, I think, new friends, you know. New relationships with people that I think are in the same situation I am . . . Everybody accepts you where you are. You may not be a poet; you may not even be a writer, but putting down your feelings and sharing those feelings is a gift.

It’s important to let those who are healing from emotional or physical illness know that this gift exists because doing so will further them along on their journey. Forming a writing group where writers share their stories in a non-threatening environment helps to create an atmosphere where the self- and other-affirming qualities of writing as therapy can thrive. Of equal importance in
recognizing the qualities of writing that render it therapeutic is that writers are comfortable with the media used to produce it.

**Individuals Should be Comfortable with the Media Used to Produce Writing**

Just as Elena expressed a strong preference for writing with her pen and paper, so too did Barb. Because workshop participants generally expressed this preference overall, it struck me that in order for writing to be therapeutic, individuals must be comfortable with the media used to produce it. In fact, both Elena and Barb reported being comfortable with computers, just not with using them for the task of writing about personal experiences. Specifically, according to Barb,

> I’m okay with the computer, and of course I did a lot with it when I taught school. I did a lot of writing on it. But I’m more comfortable with my little journal rather than—I mean supposedly the computers are safe, but then you hear of all these viruses and all this stuff, you know. And I just feel much safer and have more confidence in putting [my thoughts] in my little book where I know nobody else is going to come in and look at my [writing]; it’s just for me . . . It’s more meaningful. It’s more personal than a computer is to me.

Speculation suggests that this preference for pen and paper might have something to do with the creative process. For example, in Chapter Eleven of *The Therapeutic Potential of Creative Writing*, Bolton declares that “to concentrate directly on the therapeutic would be detrimental to the writing and its beneficial effects” (165). Rather, he describes the work of one poet who interacted with hospital writing groups and deliberately downplayed writers’ attention to the written word by having them focus, instead, on their other senses. To this end, she brought an array of fragrances, fabrics, textures, postcards, and jars of spices, then designed her sessions around timed writing snippets orchestrated between participants’ exploration of the items. In this
way, she was able to keep their focus more on the creative process and less on the words they were writing (166). All of which lends credence to the fact that writers should be comfortable with the media they use to produce writing, since it is likely that this comfort will result in the beneficial aspects of writing, rather than in a focus on the words they are writing. Additional support for this notion calls to mind some of my own students who, when confronted with a new writing assignment, cannot focus on any other details besides, “How many pages does it have to be?”

Overall, Barb’s case study and writing artifacts offered much insight into the ways that writing as therapy positively affects a writer’s motivation to continue writing, acceptance of one’s circumstances, and one’s coping skills. Additionally, it provided excellent information on the value of writing groups on the therapeutic writing process, offering strong support in favor of writing groups, support that parallels the work of scholars and researchers in the field.

There were several reasons that made Barb’s situation different from Elena’s. First of all, the fact that Barb had been her husband’s caregiver for thirteen years at the time she was diagnosed with breast cancer made her diagnosis much more difficult for Barb. Furthermore, Barb, who has a caregiver’s personality, was always the strong, caring person in her family, and her illness was a wake-up call to other family members; it also meant that Barb needed to submit to being the patient, a difficult task for her. Another differing factor was that, while Elena had her family’s involvement and support, Barb did not have the support of her entire family, as her oldest daughter withdrew from her after her diagnosis and during the time of her surgery and chemotherapy. Her inability to cope with Barb’s illness, and her subsequent emotional and physical withdrawal, meant that Barb was struggling with this emotional stress at the same time
she was undergoing treatment for her cancer. Finally, while Barb had successfully completed her treatment for breast cancer, Elena was suffering from multiple myeloma, and incurable disease.

The format of Chapter Five differs from that of the previous two chapters in that it focuses on the experiences of two married couples. Additionally, each woman was participating in the writing workshop at her husband’s insistence because of both men’s strong belief in writing as a coping skill and positive means of self-expression that could benefit their wives. The couples did not participate in the writing workshops through the same organization; one couple, where the male spouse had recently learned of his terminal illness, participated through The Victory Center, whereas the second couple, where the female spouse was recovering from a successful bout with breast cancer, was a part of the St. Vincent’s writing workshop. One factor that makes the participation of these two couples particularly interesting is the extent to which the male spouses, having engaged in writing activities most of their lives, touted the benefits of writing, while their wives had little to no interest in the activity. As the only two men in the study, it impresses that they were much more open to the emotional dimension of writing, and, ultimately, extremely supportive of its therapeutic potential.
CHAPTER FIVE: CASE STUDIES OF TWO COUPLES

“The things that I’ve considered as fun, a lot of deep stuff that I’ve written, even though there’s some funny stories, they have some deep reflections in them . . . Not just because I have thought of them as fun, or sharing a thought, but, by God! It really does make me feel good to put that stuff on a piece of paper . . . almost a necessity.”

Workshop participant, Dale

The structure of Chapter Five diverges from those presented in Chapters Three and Four; rather than discuss a single participant, Chapter Five will examine the writing experiences of two married couples. One couple, Dale and Carol, participated in The Victory Center writing group. The other couple, Duane and Karen, participated through the St. Vincent’s group. In both cases, it was the husbands who loved to write, both having done so regularly for work and pleasure. As a result, after Dale became ill with Myelodysplastic Syndromes (MDS), an incurable blood cancer, and Karen was diagnosed with breast cancer, both Dale and Duane wanted their wives to experience the same benefits of writing that the men had always valued; as revealed through interviews, both believed that their wives often repressed their emotions and needed a voice, especially to help them cope with this bout of serious illness.

Interestingly enough, neither Carol nor Karen believed that she could write, and both came into the workshop at the request of their husbands. While in their post-interviews, both women claimed they gained some value from attending the workshop; both also admitted that it was not the writing itself that had produced the gains, and that they probably would not even continue writing after the workshop was over. For both couples, the emphasis of their writing was on capturing memories and recalling experiences they might have forgotten. All noted that the most important aspect of the experience rested in completing the workshop together, both for the companionship and motivation it provided, and also because the presence of both spouses naturally led to follow-up discussion of content and ideas after each session.
The experiences these two couples had in the workshop, where husbands wanted wives to write, and wives wrote because their husbands wanted them to, led to some interesting results on two levels. This chapter will illustrate how first of all, their experience supports the value of a group writing workshop and of sharing one’s writing. Secondly, their experience addresses one of the research questions advanced in Chapter 2, specifically, whether regular written discourse can provide family members of critically ill patients with a vehicle for exploring, understanding, and accepting the emotional impact of a loved one’s serious illness.

Dale and Carol

Dale and Carol joined the Victory Center writing workshop in an unconventional way. During Dale’s interview, while he openly discussed his diagnosis of MDS, he also confided that he had one real hope associated with his participation in the writing workshops, and that was that his wife might also join because, he explained “I’m a person that wears all my emotions on my sleeve . . . My wife will keep emotions buried in her heart.” At the time of Dale’s pre-interview, Carol would not participate; in fact, she never completed a pre-interview. However, it was after Dale so enthusiastically discussed the pre-interview process and workshop plans with her that she reluctantly agreed to participate for his sake, with the understanding that she probably would not write, and certainly would not speak to share her writing.

Dale is a large man, with an open, gregarious personality; he was diagnosed with MDS in June 2005, and the diagnosis came as a shock. As Dale recalls, “I had walked in the house from a three-and-one-half mile walk, and there was a message from the doctor’s office to call and the doctor said, ‘You have MDS and there’s no cure for it.’” Describing his disease as being “in the early stages,” Dale is the picture of good health. In fact, he cannot understand how he can be terminally ill when he looks and feels so good. Yet, routine blood work says otherwise.
Having grown up on a farm, in a small farming community, Dale describes himself as a retired 35-year veteran of the railroad who prefers to learn through life experiences rather than through formal schooling, “I did not like school. I didn’t dislike school; I [just] didn’t like school.” However, he confesses that he has always loved to write, “I just kind of experience an experience, whether it’s humorous or whatever it is and I’ll say, Damn! That would be cute to sit down and write my thoughts on that. About my wife and my family—I mean, these are usually pretty short little stories and that’s what they are. They’re just very . . . reality stories.”

Carol, on the other hand, is quiet and reserved. A retired schoolteacher, whom Dale calls a “perfectionist,” she explained her reluctance to participate in a writing workshop, “I think I’m quite a private person, and to write down something is to take the chance that someone’s going to read that and think whatever of me. I don’t know what.” In fact, Carol plainly stated, “I do not enjoy writing, and it’s not a release for me. I really don’t know that it does anything for me. I can think through things, but to write it is more of a chore for me, and I just haven’t done a whole lot, to tell the truth. A subsequent journal writing expressed, “Two things that are interfering with my adjustment [to Dale’s illness] is that I am a very private person, who is slow to share my thoughts with other not-so-familiar people. Dale has always been my best friend and person to share my thoughts with.” Familiar with his wife’s reticence, but concerned about her struggle to accept the reality of his illness, Dale’s hope was that the writing workshops would provide an outlet and a coping experience for Carol. Dale’s sentiments about Carol’s inner wall of silence bring to mind the silenced feminine voice discussed in Marlene Schiwy’s, A Voice of Her Own:

Nowhere are we taught the value of our emotional life. Instead, we learn to stifle and suppress our feelings because they are illogical, inconvenient, and often messy. But just because we force them underground doesn’t mean they no longer exist. It merely ensures
that they will surface in other ways—generally destructive ways . . . Your journal allows you to explore your inner truth without embarrassment. (43-44)

Thus, originally, Carol’s lost voice seemed to be a limiting factor in her desire to participate in the writing workshop. However, because she wanted to please Dale, she ultimately joined the group, challenging her beliefs and expectations. Eventually, Dale’s hope was partially realized in that soon after she entered our writing group, Carol began to write when the group wrote, and to our amazement, she soon began to share her writing and her tears along with it:

This has to be all a bad dream. My husband has color in his face and seems to have more energy than a few weeks ago. This is because of weekly shots of Procrit that stimulate his red blood cells to grow and grow healthier cells. I look at him and see how handsome he is. For just brief moments, I feel that maybe the doctors will find results of the next tests will show the absence of any of the disease. But back in reality again, I know that is not possible.

I was further surprised at the end of the workshop sessions when Carol handed me 10 pages of original writing. When I told her I’d make copies and return the originals, she declined my offer saying, “I won’t need them.” So, I wondered to myself, did Carol gain anything from the writing workshop experience? But it wasn’t until her post-interview that I discovered how Carol described her gains.

During her post-interview, I asked Carol what she thought she had gained from the writing workshop experience, and, unexpectedly, she replied:

I think that I have gained . . . probably more than I anticipated . . . [Dale’s] illness has been such a terrible experience that I think any tiny little comment that someone makes is of value to me, and help to me. I don’t enjoy [writing], and I have never been a writer,
and when I’ve had to write things, as a teacher, as a student, I think it would take me three times as long to sit and think it through and I think it has been something that has really limited the experience of going through [this] writing class.

While Carol’s comments touch upon an uncomfortable past writing experience that may be to blame for both her avoidance of writing and her disinclination to find therapeutic value in it, interestingly, she refers to her interaction with others in the workshop as a meaningful part of the experience. When I asked her if the writing she had done for the workshop had in any way helped her cope with Dale’s illness, she again measured her gains against her interaction with others:

Hearing other people’s writings and experiences, that I think has been one of the things that’s helped me cope. My writing, I don’t think has helped a whole lot. It has meant a lot to my husband to be here and I think just to have me be here. You know, he’s the one that’s dealing with the physical illness and he—he just has been really motivated by the [writing workshop]. And there aren’t a lot of things, since he’s been diagnosed, that he’s been motivated to do . . . seeing him really enjoy the writing has helped me.

Carol’s words demonstrate that, while writing was not an activity that she, personally, enjoyed, by participating in the writing workshop, she was able to better cope with her husband’s illness through hearing the stories of others who shared similar experiences; she also found value in supporting her husband and his enjoyment of the workshop. Thus, Carol’s experience validates the work of researchers who claim that, beyond the writing in a writing group, there is value in the interactivity generated by the group’s writing and sharing; that while writing alone can be therapeutic, sharing one’s writing with others can enhance its therapeutic value. DeSalvo’s comments on the sharing of writing in groups underscores Carol’s experience, “Sharing our work
removes us from a solitary brooding on our personal hurts as we listen to other people’s
difficulties, learn of other people’s triumphs. For those of us who find intimacy difficult, sharing
work becomes a bridge to sharing ourselves” (208). Florence shares similar observations about
the power of writing in a group environment, “I’ve been in many writing groups myself and have
seen that sitting in a room and simply writing with others can have a very powerful effect on
people, transformative, even life-changing” (Writing and Healing 416). Florence and DeSalvo’s
words accurately support Carol’s experience: when she and Dale first joined the writing group,
Carol was an observer who curled up close to Dale, not wanting to be noticed, struggling to cope
with his terminal diagnosis, and feeling very much isolated in that struggle. Slowly, things
changed, and she began to write, and then to share her writing. She attributes that change to
hearing the stories of others in the group, stories that mimicked that of hers and Dale’s, and
despite the fact that she dislikes writing, this interaction with others enabled her to gain
something from the experience, and in this sense, the experience was therapeutic to her.

Nye extends DeSalvo’s view by also emphasizing how community-based writing can be
therapeutic. To explain herself, she offers three reasons why “the shift of private to public
writing] constitutes a healing process.” The first reason is the storytelling benefit that leads to
the “unburdening” of untold experiences or events; the second reason why group writing is
therapeutic, according to Nye, is because it “evokes compassion, caring, and a sense of
belonging.” Finally, group writing is therapeutic because it enables the writers in the group to
feel acknowledged. It is this acknowledgement, when an individual becomes part of a “whole”
community, to which Nye attributes the therapeutic properties of writing (405-406).

Nye’s explanation also connects well to Carol’s experience, in that, initially, Dale
confided his concern that, while he was able to express the myriad emotions that resulted from
his cancer diagnosis, Carol was not; instead, as Dale described, she maintained her quiet, pleasant demeanor throughout, trying to be a support to him, and he worried that this bottling up of emotions might eventually take its toll on her. However, soon after Carol joined our writing group, she immediately witnessed the “unburdening” of emotions addressed by Nye: others in the group were willing to share, and after a while, she, too, was able to share in this unburdening by reading small snippets of text that she wrote about her reactions to Dale’s illness. Nye also attributes the therapeutic value of sharing one’s writing to the fact that doing so “evokes compassion, caring, and a sense of belonging.” In Carol’s post-interview, she illustrates how her experience exemplified Nye’s findings of the camaraderie that develops among a group of writers,

I have enjoyed talking with Elena and listening to her, with Barb, with you . . . you are all people who are to me, you are good people. You have good ideas, and . . . all have had experiences that haven’t been so pleasant, and I’m glad to have known you . . . we don’t know each other real well, but we know some of the problems, physical health, and so forth, that we’ve had.

Carol’s accounting of her reactions to being part of a writing group, while guarded, are certainly more positive than they were on the day of her husband’s pre-interview, when she refused to join the group. She specifically references the sharing, and the merging of ideas that takes place among those who have undergone similar experiences. While sharing one’s writing in the proper setting can have therapeutic effects, it’s imperative that a writer feels comfortable in a writing group before sharing can be effective. With respect to this fact, DeSalvo cautions:

To be sure, we must care for ourselves as we make our work public. We must choose our witnesses carefully. Whomever we share our work with, while it’s in process, we expect
to be empathic. We share only when we’re ready and only when we’re prepared to share. But making our story accessible to others (through writing groups, writing partners, and eventually through publication, perhaps) can evoke a healing moment that’s a logical outgrowth of the writing process . . . I believe that it is our responsibility to ourselves and to our work to control the conditions whereby we share our work so that we do not foreclose our need to tell our story. (210-211)

Carol’s experience in the writing workshop demonstrates the veracity of DeSalvo’s words; it was not immediately that she began to write and share her writing in the group setting. Over time, however, she came to feel trust in the group dynamics, and this encouraged her to move forward with her own thoughts and perspectives.

In his post-interview, Dale corroborates the unexpected benefits of sharing one’s writing in a group setting. He observes,

I think when you’re going through the kind of thing [these] folks are going through, you develop an openness to be able to share, really, and again, I’m not an inhibited person. I can share with a hitchhiker! But I think I’ve probably seen in the class some other folks that maybe aren’t quite as open that have become more open.

Here, both Dale and Carol reinforce DeSalvo and Nye’s conviction that writing groups foster a sense of belonging by making participants feel included and cared for. In turn, these feelings assist in helping workshop writers to sense acknowledgment of their ideas and experiences, and herein rests the therapeutic nature of sharing one’s writing in a small, intimate, trustworthy setting.

Dale and Carol’s joint experience also supports how regular written discourse can provide family members of critically ill patients with a vehicle for exploring, understanding, and
accepting the emotional impact of a loved one’s serious illness. When Dale and Carol joined the writing workshop, one of the key issues, from Dale’s perspective, was to find a way of helping Carol cope with her emotions over his illness. Carol’s first written entry supports and illustrates Dale’s concerns:

The biggest change I’ve faced in my life since Dale’s illness began is seeing him as someone who has a weak or vulnerable characteristic. Up until now, he was the very strong person who was unaffected by any problem. This change has greatly affected me because previously I was a weaker and dependent person, and now, it is difficult for me to think of myself as an independent, strong person, and I’m frightened I’m not the strong person I need to be.

The above text clearly shows how Dale’s illness forces Carol to realize that she has always been the “weaker” person in their relationship; it also shows her assuming how, now that Dale is ill, she must be “the independent, strong” one. Along with these observations, however, Carol acknowledges the sense of fear and conflict that this change in roles has created in her. To assuage these emotions, reported Dale and Carol, after each writing workshop the two of them were able to share their feelings on the lengthy ride home, and in doing so, help Carol to release some of her fear and anxiety over Dale’s illness and prognosis. The topics that the two of them discussed were generated through the writing produced during each workshop session, and the communication that followed supports how written discourse is able to assist critically ill patients with the means to confront the emotional impact of a loved one’s serious illness. Hence, Dale was subsequently able to claim, “Carol keeps a lot of her thoughts to herself, and I’ve seen even her, as the class went on, open up a little bit more to people that, my God, she never knew them at all, much less [as] family or close friends.”
Dale and Carol’s writing workshop experience also helped them describe to friends and extended family what they were going through, both with regard to his illness and to their experience in the writing workshop. Dale explains that he comes from a large, extended family, having grown up as one of seven children. Because all siblings contact him regularly to inquire on his condition, and since Dale is open about his emotions and experiences with his illness, he enjoys sharing with his family the anecdotes and reflections he has written in the workshop. To this end Dale claims:

I found it enjoyable [to discuss] with some of our friends and family that have been interested in this class also, that they want to know what goes on; so there’s an exchange there that’s happening. It’s not writing, but it’s an exchange, and that’s beneficial: ‘Here’s what we’ve talked about.’ ‘Here’s what we did.’ ‘God! I hadn’t even thought about that and I wrote it down.’ ‘I’m kind of glad I remembered that.’ So those end up being [only] conversations, but beneficial.

What is notable in Dale’s account is how he is able to use writing as a springboard that prompts discussions, and he sees this as a benefit of the writing itself. He also notes that writing helps him to remember experiences that he had otherwise forgotten, and to share those memories with others. DeSalvo refers to the importance of the sharing that results from writing, “When we share our writing, someone else knows what we’ve been through. Someone else cares. Someone else has heard our voice. Someone else understands. We learn that we are no longer alone and that we no longer need be alone” (213).

Duane and Karen

Duane and Karen were participants in the St. Vincent writing workshop. Their similarity to Dale and Carol is remarkable in that, once again, it was the male spouse who had always
viewed writing as a positive experience, and one that he wished his wife to experience as well.

To illustrate, when asked about his reasons for participating in the writing workshop Duane replied, “[To] see my wife learn how to do it. She’s the one that doesn’t like to write. She doesn’t like to do that kind of stuff. I do it and I think I have a lot of fun with it. I want to see her do the same thing.” The impetus for Duane’s desire that Karen begin to explore writing was Karen’s diagnosis of breast cancer in 2003. Like other participants in the study, Karen’s illness was unexpected,

“I had my mamm in January 2003,” Karen explains, “Then I had to come back for a spot compression, and then I didn’t have the biopsy until March. And the doctors tell you 80/20% it’s nothing, and the tech tells you 80/20% it’s nothing. Then a week later, [the doctor] called the house and told me I had cancer. And I asked her, I said, ‘What happened to that 80/20%?’ And March 31st I had my surgery.

In his workshop writing, Duane’s description of the sequence of events that led up to Karen’s diagnosis is similar to Karen’s: unexpected, but unequivocally real,

March 18th of 2003, Karen received a phone call during our supper with our daughter and grandchildren. When she began talking on the phone, she went to the living room. As the conversation continued, she moved to the stairway. I went in to find out what was going on, and she motioned me to return to the dining room. When she came back to the table, she didn’t say anything at first. She sat there and started to eat. We asked what the phone call was about. She said that it was the doctor and that the biopsy came back positive. I said, ‘You’re kidding. Right?’ She assured me that what she was telling us was the truth. She sat there and started laughing.
Karen’s biopsy and subsequent lumpectomy was followed by 33 treatments of radiation therapy. Then lymph edema set in, and Karen had to receive therapy for that. Lymph edema is a condition where fluid backs up into the arm and chest due to removal of lymph nodes on the side of the affected breast. The condition is chronic and requires lifetime precautions to manage; these precautions include the inability to lift objects on the affected side. As an x-ray technician, who lifts x-rays all day, Karen was restricted at work by the lymph edema precautions she needed to follow, and was required to take six weeks leave.

Like the other participants in the study who also described a supportive family structure, Karen affirms that her relationship with Duane negated any feelings of isolation she may have otherwise experienced during her bout with cancer. Both she and Duane reported functioning as a team in attending doctor appointments, coping classes, and other support groups; so their attending the writing workshop together was not unexpected. Nonetheless, when asked about her previous writing experience, Karen responded that she had none, but that she wanted to learn to record important aspects of her life, just as Duane did, describing the enjoyment she experienced from reading his writing that recorded many of their family experiences, “I only came because Duane signed up. I would never have come by myself. And then . . . I really enjoyed it. Otherwise I never wrote. And he always kept a journal.” Additionally, Karen’s goals for the workshop included memory recording for her children and grandchildren because she asserts that, since losing her mother, she realizes how once a loved one is no longer around, there are no more questions that can be asked of that person. As such, Karen recorded some twenty pages of treasured memories and daily activities with her children and grandchildren. She also reflected on her experience with breast cancer, and some of the ways her life will be forever altered, “[I have] to be careful of my arm. The cancer is not there anymore, but you can never forget you had
it. You do things differently because of your arm and the breast. Your everyday things you do have an effect on the arm and you can feel it in your breast by lifting.”

Overall, however, Karen’s writing differs from that of other workshop participants in that its focus was not on her illness, but on the satisfaction she derives from her family life. For example, she writes, “Every other weekend we watch Nathaniel while the kids go bowling. We have a lot of fun playing. Kyle and Katie just got over being sick. But now Kyle has hives from the medicines, they think. The kids took us on the Sandpiper downtown for my birthday and we had a very nice time.” Karen was also able to record some anecdotes of memories shared by her adult children:

The kids asked if we remembered when Dad climbed on the dining room table to change the light bulb and broke the table. They said he did not break the table; the boys did. The boys were chasing each other in the house and one of them ran across the table and broke it. They put it back together and kept it from us . . . We had some good laughs that day.

There were other things too, and I always thought I had perfect kids! At least they didn’t burst my bubble until they were older and had kids of their own.

She also reflected upon her regrets of the past and on changing things for the future, “I wish we lived like our parents did. Where the mothers stay home with the kids and only fathers worked. I missed a lot of things with my kids, and want to do more with my grandkids.”

As expected, Duane himself was a positive force in supporting his wife’s writing goals: It’s not so much that Karen needs [writing]. It’s just that I think that she needs to be able to write down events and this type of thing that she would want to keep for herself. Like she said, she likes reading my journal, because it brings everything back to her. Well, if
she can write some of her [thoughts] down that she has gone through or any of her experiences, it will be something that she can go back to and read later and enjoy again. Similarly, in Duane’s post-interview, when asked what he felt he had gained from participating in the writing workshops, he stated, “Seeing Karen do the writing.” Given that communication is inherent in the writing and sharing process, as with Dale and Carol, Duane’s observations suggested that Karen could benefit from communicating the emotions she experienced as a result of her recent illness. Shiwy affirms the connection generated between writing and the interaction that can follow, “Realizing that someone else has thought as we do—has felt the same emotion, drawn the same conclusion—affirms the solidarity of shared experience. . . ” (267). Similarly to what Dale and Carol communicated during their interviews, for Duane and Karen the writing itself was not the only benefit of the workshop, especially since Carol, like Karen did not consider herself to be a writer or to enjoy writing.

When asked in her post interview how often she was able to write throughout the weeks between workshop sessions, Karen admitted that she only wrote during workshop sessions. In addition, when discussing the factors that limited her ability to write more, she claimed, “Because I’m not that good at it. I have to think and think and think what I’m going to write.” Again, Karen, like Carol, claimed to have a weak writer’s voice; a factor that limited the amount of writing she accomplished throughout the workshop sessions. Nevertheless, Karen described how her search for topics opened up new dialogue with her younger sister,

I even talked to my sister and I said I had to have something to write about . . . She gave me ideas . . . she said ‘Write about how you used to buy us Christmas presents and we found them and opened them up.’ And then they used to wrap them back up and I finally found out they did that and I had to keep [their presents] at somebody else’s house!
Karen also communicated how she preferred writing about her family because, like Dale, doing so helped her to remember things long forgotten. She also shared how she surprised herself by contributing unexpectedly during the sessions:

This [workshop] has made me remember a lot . . . remembering the good times, ‘cause I think you forget a lot of things. I have brought out thoughts that I even surprised myself on. One day, I made a comment in class, I thought, ‘Did I say that’? It was when we were talking about my family, about being from a big family and people look down on you. And that week, I thought about that [comment] all the time, and I thought, ‘Why did I say that?’

Karen’s commentary lends further support to the notion that not all the benefits of a writing workshop come from the writing itself; they also result from generating ideas and then sharing those ideas with others. In addition to the writing then, the group interaction generated by the communication of feelings on paper, engenders a bond that enables individuals undergoing similar experiences to relate to each other and accept what previously seemed unacceptable. When that communication extended beyond the workshop session to involve spouses, friends, and other family members, participants still recognized communication as a memorable result, even for those who lacked a passion for writing.

Duane’s previously mentioned idea of an individual’s ability to return to past experiences by having recorded them in writing is similar to Dale’s belief that writing can be a vehicle for recording and prompting future memories and discussions. In other words, writing in workshops can be therapeutic beyond the act of writing. As these two couples demonstrate, the ability to return to a written text to prompt a sharing of experience, or trigger a forgotten memory, can be equally therapeutic as the writing act itself. Bolton, in The Therapeutic Potential of Creative
Writing refers to a characteristic of writing that makes it different from other communication media, “One of these [characteristics] is that the act of writing creates an object to which the writer can relate tangibly, visually, and aurally. The writing is seen, it can be heard, it can be touched on the page —framed, filed with care, screwed up in a ball, or burnt. And this tangibility lasts over time, to be re-experienced in different frames of mind, different stages of life” (214). Bolton’s position illustrates that after recording a thought in writing, a writer “owns” that writing, and the page upon which it has been written becomes a tangible artifact that can be revisited at the writer’s will. Shiwy and Bolton’s comments collectively reflect how writing can help writers to know themselves through its reflexive and reflective qualities, as discussed in Chapter Three: writing is reflective in that it permits the writer to re-evaluate the past by re-experiencing it, and it is reflexive because it enables the writer to modify future behavior in response to what has been learned about the self as a result of the re-experience.

For both couples, even though the female spouses were driven to participate in the workshop in order to satisfy their partners, both Carol and Karen ultimately had similarly positive experiences: Carol was able to come closer to accepting her husband’s illness, not so much by writing, but by the interaction that followed the writing experience. She valued this interaction, both with other group members and with her spouse, because by listening to the accounts of their struggles with illness, she was able to open up and express her emotions regarding her husband’s rare blood cancer. Following the workshops, she and her husband were also able to communicate further on the writing topics they had explored, and doing so elicited positive memories they had forgotten. Recording these memories in anecdotal form helped Dale to revive these positive experiences.
In addition, Duane and Karen’s writing workshop participation also began at Duane’s insistence, given that Karen did not engage in writing activities as Duane did. After participating in the workshops both by writing and sharing, however, Karen also expressed enjoyment in the experience, although, like Carol, Karen doubted that she would continue writing without the motivation provided by the weekly workshops. Thus, as workshop participants, both Carol and Karen tend to contradict more typical research suggesting that mostly women are prone to recording their feelings through writing and participation in writing workshops. For example, Ruth Ray, in her text *Beyond Nostalgia: Aging and Life-story Writing*, explains:

> Current research on gender and emotion indicates that, while men and women experience the same emotions, they express them quite differently. Women typically internalize and contemplate their feelings, while men externalize and act out their feelings, divert their attention through physical activity, or suppress feelings altogether. Women are more verbally expressive of feelings and receive more social support for these expressions.

(184)

Despite such research, in this study, male participants were equally engaged in writing activities and similarly vocal about sharing their writing and writing experiences as were female participants, if not more so.

Chapter Six will examine some general data provided by the workshop participants as a whole; these data revisit earlier findings about the characteristics of writing that make it both therapeutic and instrumental in assisting senior members of our community to tell their stories. First of all, Chapter Six will reiterate, using support from additional participants and research, how writing, once begun, motivates a writer to continue writing. Next, by examining additional pertinent data, a discussion ensues regarding how writing enables individuals to cope with
trauma or serious illness, experience relief from stress that can often impede healing, accept their illness and limitations, and help their loved ones to do so. This chapter also asserts how writing can benefit interpersonal relationships that are often strained during the stress of serious illness. Additionally, writing can assist in retrieving memories and experiences that have been forgotten, thereby further motivating many participants to write; the data also illustrate how autobiographical writing emerges as an important writing goal for many participants in this study. Furthermore, the chapter will illustrate some differences between group and individual writing, as well as the important role of a workshop facilitator. Finally, limitations of the study will be considered.
CHAPTER SIX: GENERAL DATA SYNTHESIS

General Results

This chapter will explore the general results of the study. While overall, the text has foregrounded case studies based upon two single workshop participants and two couples, this chapter will examine some of the significant data associated with other workshop participants as well, in order to demonstrate the breadth of the research conducted. The general results of the study focus on the characteristics of writing that make it therapeutic, and also on the importance of writing in enabling senior members of our community to tell their stories. First of all, Chapter Six will discuss how writing, once begun, can motivate a writer to continue writing. Next, the data will demonstrate that writing enables individuals to cope with trauma or serious illness by fostering a relief from the stress that can often impede healing; writing also encourages personal acceptance of illness and its limitations, along with helping loved ones to do so. Furthermore, this chapter will address how writing can positively affect interpersonal relationships. Data also supports that writing can trigger remembrance of memories and experiences that have been forgotten, and that this type of memory recording is a strong motivator for many participants to write, some for the pleasure of being able to retrace events in their lifetime, and others because they want to leave behind a written record of their lives and sentiments for their loved ones; nevertheless, autobiographical writing emerged as an important writing goal for many participants in this study. Additionally, this chapter will illustrate important dynamics in group writing versus individual writing. The important role of a workshop facilitator will also be explored. Finally, this chapter will also examine limitations in the study, including how, given the seriousness of many participants’ illnesses, one might question whether it is somewhat natural that writing would be therapeutic.
The Intrinsic Motivation to Continue Writing

One of the significant findings of this study is that most of the writers who had already written routinely throughout their lives, either as a condition of employment, or through self-motivated autobiographical or anecdotal records were more likely to be spurred by the writing done as a part of the workshop environment, and the suggestion of topics to write upon between workshop sessions. For example, Ruth, a resident of Swan Creek Retirement Community, was one of the first residents to sign up as a participant in the Swan Creek writing workshop. At eighty-five years of age, Ruth writes every day. A graduate of both Otterbein College and Ohio State University, she had often held jobs where writing was required. In addition, she has written a biography of the Titgemeiers, the family store, and donated the text to the public library, then published it in a local magazine. In The Therapeutic Potential of Creative Writing, Gillie Bolton reveres writerly activities like Ruth’s, commenting on the importance of supporting the reminiscing efforts of society’s senior members:

Older people often tend to reminisce naturally. Encouraging it . . . deepens its therapeutic value. From the relatively cut off position of old age, reviewing life in this way can offer a greater sense of consistency and coherence of life, control over it and a greater understanding of their relationships to others . . . Older adults can think of themselves as offering material to our society’s bank of social history, increasing self-confidence and self-respect. (189-191)

Bolton suggests a need for society to place value on the lives of its senior members, and providing encouragement and opportunity for written expression and autobiographical work is one way of assigning such value, as doing so allows for the fostering of self-esteem among this
population. Accordingly, Ruth also keeps a daily journal of activities, and has been working on her autobiography for several years.

Ruth was excited at the prospect of a writing workshop at Swan Creek because of her desire to complete her autobiography and to meet new people within her small community. Although she admits that writing is sometimes difficult for her because her age makes her take “twice as long to do things,” she enjoyed the writing workshop because it “was encouraging me to do more [writing].”

Another resident, Mary H., had tried several times to record her autobiography, but over the previous seven years had been waylaid by her husband’s illnesses. As a caregiver for someone with dementia and a tendency to wander and fall, Mary had been homebound in recent years, unable to leave her husband alone for any amount of time. Several months prior to the start of this workshop, Mary’s husband passed on; so, Mary was once again hopeful that she might continue with her autobiography.

Years earlier, after earning a two-year degree at a commercial college, Mary’s youth was challenging and full with a civil service secretarial career that placed her in Washington, D.C. as an administrative assistant for then Presidential Chief of Staff General Curtis LeMay. Always interested in literature and English, Mary also enrolled in post-graduate literature and writing courses at the University of Maryland, an experience that she maintains has helped her throughout the workshop:

I would say my past writing experiences helped. I had taken courses at the University of Maryland that were also writing before I married . . . I discovered . . . that I was very surprised that I could write. They would give us a ridiculous topic . . . I’d take class on Tuesday night and Thursday night and some of it was done in class and then we’d have a
long one to turn in on Thursday night, so Wednesday I’d have to stay up nearly all night . . . . And as I say, absolutely ridiculous topics and I would be amazed that I could get a story written about something that I just never even thought till you write about it.

Additionally, Mary reports that regular letter writing to friends and family, recently replaced by email writing, keeps her writing skills sharp. When asked if the workshop writing had any impact on her present writing experience, like Ruth, Mary H. responded, “Definitely . . . it stimulates a desire to write more . . . You can make [your writing] more complete, inclusive,” although she also admits that, “sometimes it’s not a cheerful memory . . . it also brings back some unpleasant memories.”

Ruth and Mary H.’s observations have been previously addressed by writing researchers. Schiwy, for example claims, “Journal writing creates its own momentum and provides its own justification. The longer you continue to write, the stronger your sense of identity and entitlement” (48). Bolton adds, “Writing creates something positive out of suffering. The very act of creativity itself is life-enhancing: a piece is created out of the writer her/himself” (165). The fact that both Ruth and Mary H., whose writing sometimes brought back painful memories, note that the experience of participating in writing workshop session stimulates their desire to write more is significant in supporting that writing workshops can benefit not only those who are suffering from serious illness, have loved ones who are ill, or have written throughout life, but also those who write seldom, because usually, once a participant begins writing, he or she is likely to gain the momentum to continue. For example, Alice, eighty-two years old and another resident of the Swan Creek community, never considered herself to be a writer, although she graduated from Bowling Green State University with music and English majors. After teaching vocal music in the public schools for 15 years, and directing church choir for 20, macular
degeneration threatens her sight, and she fears that she won’t have the time to complete her autobiography. For that reason she joined the writing workshop. Because of time constraints and vision problems, Alice admitted to only working on her autobiography during workshop time, and not on the days between, although she did spend time revising what she had written by working on a word processor. In spite of her limited time, like Ruth and Mary H. she claims:

I’ve enjoyed it and I have a hard time stopping once I get into it . . . and now I will complete [my autobiography] . . . before Thanksgiving. I’m going to complete it . . . and possibly some vignettes that come to me later to add to it . . . I’ve gained more different things [sic] by participating than I ever thought I would. It’s been a surprise. I wanted to get this on paper, and chronologically do it, but I find that I’ve gained the motivation to improve my writing, and I’ve kind of learned how to do it.

As previously mentioned, Alice’s work on her autobiography also included re-writing her work on the word processor, something that she felt was necessary so that her writing could be more easily read. In addition to limited sight, Alice was also limited by her inability to attend all of the workshop sessions because of prior commitments. However, when she was able, she worked diligently on re-writing her work, and such motivation left her close to reaching her goal of completing her autobiography by the time the workshop sessions ended. Although her participation in workshop sessions was limited, her testimony, above, credits her participation to increasing her desire to, not only complete her work, but also to improve her writing, lending credence to the theory that once an individual begins writing, it is likely that the writing itself will motivate them to continue.
The Ability to Cope with Trauma or Serious Illness

Much research points to the fact that one of the therapeutic characteristics of writing is that it helps writers in coping with trauma or serious illness; it also reputedly assists writers in the acceptance of their fate and in stress relief. For example, Smyth, et al. in “Effects of Writing about Stressful Experiences of Symptom Reduction in Patients with Asthma or Rheumatoid Arthritis,” an article that appeared in the Journal of the American Medical Association, conducted a four-month-long experiment with chronically ill patients suffering from asthma and rheumatoid arthritis. This study, which built upon earlier work by Pennebaker, was the first study to demonstrate that writing about stressful life experiences improves physician ratings of disease severity and objective indices of disease severity in chronically ill patients . . . Although it may be difficult to believe that a brief writing exercise can meaningfully affect health, this study replicates in a chronically ill sample what a burgeoning literature indicates in healthy individuals. (1308)

The importance of this research lies in the fact that, while other research was conducted with healthy individuals, this study included individuals who were chronically ill. Stressors for this population included the death of loved ones, car accidents, and relationship difficulties. Its favorable results claiming that writing is effective at reducing the effects of these stressors were based upon findings that this chronically ill population experienced a decrease in symptoms up to four months after the experiment.

As discussed previously through case studies in this project, results of this study favorably underscore this research. Additional examples of workshop participants whose experiences are relevant to the existing body of research follow. For example, Alma, a Victory
Center workshop participant who has a long history of battling cancer, expresses strong sentiments about writing’s ability to help individuals cope. She shares her experiences readily: “I think [writing] helps to put [your thoughts] down and clears [them] up and you can see possibilities of treatment options or thought options . . . it just gives you some choices, I guess.” Alma’s experience began with a brain tumor in the late 1990s; after a year of observation by doctors, the tumor was ruled benign. Nevertheless, a diagnosis of breast cancer came in February 2004, followed by news of a mutant gene that also carried a high risk of ovarian cancer. After a double mastectomy and reconstructive surgery, Alma now faces surgery for removal of her ovaries. Like Elena, Alma’s experiences with cancer encouraged her to try many alternative therapies. As an individual who always made writing a part of her life, both through owning her own business and as a member of the Fireland’s Writing Center, writing about her experience with cancer was something she pursued on her own until she learned of the writing workshop at the Victory Center; then, she became anxious to share her experience with others who were undergoing similar situations.

Angeline, a participant in the St. Vincent’s writing workshop, commented on the value of writing in her life. Having much cancer and many mentally handicapped individuals in her immediate family, Angeline is a long-time caregiver; in spite of her own diagnosis with breast cancer, she continues to care for others. In her workshop writing she explains,

My days are usually completely filled with some type of activity involving family and friends. I need more hours in a day . . . I live each day one day at a time, and today’s the first day of the rest of my life. Most all my waking hours are filled with something to do, and I don’t dwell on myself . . . I’m a fighter and a survivor and I keep going day by day.
Unfortunately, because of her hectic schedule, Angeline was another participant who was only able to write during the workshop sessions. When asked if she perceived her writing to be a method of coping with the stress in her life, she responded, “You know what? I think it could help me. I think it could. I’m not sure that it has, but I think it could if I continued it. But the kind of writing I did do I kind of enjoyed it, ‘cause I just—kind of like a review of my life.” Clearly, scheduling conflicts limited Angeline’s ability to do more writing. She differed from other workshop participants in that, in spite of being ill herself, she continued to focus her energy on others who needed her. However, she relates that she realizes if she were able to devote more time to writing, it could be of benefit to her in helping to cope with her illness and other stressors in her life.

Ruth also commented on how naturally writing could become a more important activity in her life. Currently, she walks two miles every day as a mechanism for relieving stress, but reports that writing could also be a stress-relieving activity, “I think I should [do more writing], because sometimes even walking—I usually do my walking—my two-mile walking to get rid of [stress] or whatever. But I think as I’m getting more limited, I think I should use the writing as a tool. I do think that’s something I should do.”

The observations of these participants, in conjunction to the existing body of research, testify to the ability of writing to act as a coping mechanism for those who are chronically ill or undergoing stressful life events. Abercrombie describes the relationship between writing and coping, “Writing can help organize chaos and conflicting feelings, can give you a sense of control and meaning. Writing down the details of an experience can sometimes reveal the shape and meaning of what you’ve been through and give it clarity” (128). This information is significant in that it validates writing as more than just a pleasant, creative experience. Rather, it
demonstrates how writing also has therapeutic value, especially as it empowers individuals to cope with difficulties in their lives.

The Ability to Positively Affect Interpersonal Relationships

One of the significant outcomes of this project has been the number of anecdotal responses that favor writing and writing in groups as positively affecting interpersonal relationships. Previous chapters illustrated how this positive effect played out in the relationships of both Dale and Carol and Duane and Karen. Elena and Barb also affirmed the importance of sharing within the writing workshop. It is also possible to look to research as supportive of this therapeutic characteristic of writing. For example, DeSalvo touts the value of sharing one’s writing, “Sharing with empathic witnesses our work about the shocks we’ve survived is, for me, an essential part of the process of using writing as a way of healing.” In his definition of therapeutic writing groups, Bolton adds to DeSalvo’s observation by describing therapeutic writing groups as existing “to support the writers in their own personal explorations and expressions. A group can gently lead a writer to understand the import of their own writing more clearly; to think of fresh writing avenues to try; enable them to discuss issues with involved and caring others who are on similar voyages themselves” (128). When discussing her reasons for participating in the Victory Center’s therapeutic writing workshop, Alma exemplifies Bolton’s message in her response:

I want to tell other people what has been going on, but I don’t want to be boring . . . so I was really looking forward to this [writing workshop] because I wanted to see what everybody else was writing . . . and we can feed off of each other, encourage each other, and feel for each other . . . I’ll know more how people feel about what’s going on in their
minds and lives because I don’t—I don’t have anybody to talk to. I mean . . . you still
need someone else that’s going through it [serious illness] at the same time you do.
Alma’s words describe the isolation that can afflict victims of serious illness who may feel as if
they don’t have a strong support structure. Or, as Alma explains, “After you’re sick for so long,
people go . . . she should be well by now . . . they don’t want to hear about it.” Clearly, a writing
workshop group that spends session time both in writing about similar experiences with illness
and in sharing that writing can fill a void in the lives of participants.

From the Swan Creek writing workshop, Ruth shared similar sentiments when explaining
one of her goals for participating in the workshop,

One thing I wanted to do is –living in a villa and not eating over here, you really don’t get
to know people very well. And I wanted to use [the writing workshop] as a tool to learn
people a little better—learn and understand people. . . I want to get acquainted with
people and then I want to improve my skills and my writing by sharing . . . .

Ruth echoes the conclusions of Molly Travers who, in her article “Older Women and the
Community Writing Group” asserts, “The writing groups offer much more than an occupation to
fill retirement, as those who stay in them discover about themselves and others in the group.”

Ruth’s reasons for participating in the Swan Creek writing workshop suggest aspirations of
lifelong learning as their underpinning; nonetheless, from the standpoint of writing as therapy for
older adults, her observations indicate that, in addition to working on her autobiography, as was
discussed earlier, Ruth also saw the writing workshop as a way of meeting new people and
continuing to learn about others in general. Specifically, in her post interview, Ruth declared,
“I’ve really learned so much—I had no idea—some of these people’s experiences. I was
awestruck at how different we are and what experiences we shared . . . it was most interesting.”
These sentiments strongly suggest that, even at eighty-five, Ruth seeks out opportunities to further her interpersonal relationships, and she sees a writing workshop as an avenue that provides that opportunity.

Like others who have written about the benefits of writing and writing workshops, Abercrombie also communicates how valuable writing workshops can be, “In the workshop we soon realized that the written word read aloud also offered a deeper connection between people than simply talking.” Part of this deeper connection might lie in how reading one’s writing aloud can influence the writing of others. As Alice describes:

I’ve heard people share and I’ve heard how they put it together and I realize . . . my shortcomings or my assets in doing it [writing] or ability in doing it . . . [people of the older age] all have experiences to share that might be interesting . . . but some people don’t talk much, but you find that sharing, [for] them, is important and the more you hear others, then you feel you can do it also. So I think [the workshop] has increased the comfort level of sharing. I think I’ve gained a lot of insight by sharing . . .

Mary H. concurs, “I’m realizing that everybody has things to talk about and share, and they aren’t always perfect . . . I feel more comfortable expressing things about my past. It’s more than I expected, really.” Both Mary H. and Alice discuss dual benefits of sharing one’s writing in a writing workshop: first of all, Alice suggests that by listening to others read their writing, one is able to reflect upon one’s own writing and how to improve or revise it; this is a helpful result of a writing workshop, as feedback and criticism are not appropriate in this setting. Therefore, hearing another’s writing is an important way for a writer to find a model for his or her own writing.
Secondly, and Mary H. agrees, by sharing their writing, those who are often too reserved to interact in other ways are able to find a voice that helps others get to know them, improving their interpersonal relationships with others in the community. Thus, the writing act takes on a therapeutic quality when it is assisting the writer in developing meaningful relationships based upon the experience of sharing that writing. Just as writing and the sharing of that writing positively impact relationships, another important finding of the study is that therapeutic writing tends to help people remember past ideas and experiences.

**Therapeutic Writing Triggers Memories that Have Otherwise been Forgotten**

From seniors to those suffering from unexpected illness, an observation reiterated by most of the study’s participants is the extent to which their private writing produced memories they had otherwise forgotten, and the significance of these autobiographical events. For some participants, the memories served as reconfirmation that life has been good; for others, the memories posed difficult reminders of unpleasant events; for still others, the memories became anecdotal records of a lifetime, records that would eventually be shared with loved ones. Regardless of how writers labeled these memories, however, all welcomed them as treasured autobiographical anecdotes that had been prompted by writing. Yet many expressed surprise that the act of writing had elicited memories so long forgotten, and wondered how they could have forgotten things so important in the first place. Also interested in this question is Marian MacCurdy, who in her chapter “From Trauma to Writing: A Theoretical Model for Practical Use” posits,

happy times do not need to be processed. They can recede into the general soup of life to add to our sense of well-being . . . As [writers] jiggle their memories . . . they begin to
MacCurdy suggests, then, that the pragmatic business of living is sufficient to bury memories that the subconscious may deem nonessential to that purpose. Once the writing act begins, however, the subconscious allows a re-visioning of these past events, and their memory is triggered.

Mary C’s writing vividly describes her life with family and friends in the late 1920’s and 1930’s. Another Swan Creek senior, she surprised herself during one afternoon workshop by writing, “My mother always sang when she was working. One day I remember her washing windows and singing, ‘Take Your Burdens to the Lord and Leave them There.’ I couldn’t understand why you would take a bird to the Lord and leave it there.” After sharing this charming childhood perception with the rest of the group, she exclaimed,

I was surprised at how—writing about something and thinking about the past—it brought up ideas that I hadn’t thought about for years; things that had happened that I hadn’t thought about for years! And I’ve always been a ‘now’ person . . . never thought much about the past. Maybe some of it I wanted to forget, I don’t know. But [writing] brought to mind a few things that I had forgotten entirely.

Mary C. attributed a focused writing activity to prompting the memory of her mother, who had died when Mary was 14. Her auditory recollection of her mother’s singing while working illustrates MacCurdy’s explanation that, “Sensory details from our lives are significant contributors to our humanity” (165). Alice, too, supports how remembrances of the past can be perceived as integral to our perception of ourselves, “It’s kind of fun to realize some of those things that we didn’t realize were important to us —it brings it home. Brings it out to our
understanding of ourselves.” Encouraged by her initial writing, Mary C. was subsequently able to record many more pages of memories, some painful, such as the death of both parents when she was only 14. Nevertheless, each recollection became a treasured addition to her autobiographical writing, writing that she was eventually able to share, both with other workshop participants as well as with her daughter and grandchildren.

In congruence with MacCurdy’s theorizing and Mary C.’s discovery, Ruth also communicated how the writing workshop experience resurrected events lost in time. “[The writing] triggered experiences that I hadn’t thought of forever,” Ruth declared, “which I think was very refreshing.” Undoubtedly, similar observations pervaded the commentary of most workshop participants who uniformly expressed pleasure at recalling parts of the past they no longer associated with themselves. Abercrombie also offers some explanation for this memory retrieval by asserting that “everything we need to tell our story, and to be creative—our memories and fantasies and ideas—is in us, available, waiting to be drawn out. You don’t need to measure the water or the depth, just trust that it’s all down there” (77). Schiwy adds to Abercrombie’s explanation by illuminating the mechanism behind such unexpected personal revelations, “We draw on memory as we write. The more we write, the more we remember. And the more we re-member and integrate forgotten and abandoned bits of ourselves into our present lives, the greater our self-awareness, and the more whole we become” (100). The message here is that writing places individuals on a quest for a more unified sense of self where they are able to connect with displaced memories that complete them. It is in this retrieval of the completed self, through eliciting forgotten memories, that writing is therapeutic.
Group vs. Individual Dynamics in Therapeutic Writing

Marlene Schiwy claims, “Reading journals connects us intimately with other women’s lives and stories. It requires us to put our own egos aside and identify with a different perspective. We share the writer’s experience of the turning points and inevitable losses by which we all measure our lives” (268). While in this project participants did not read each others’ journals, Schiwy’s message can be connected to oral group sharing of writing as well. Since writing privately fosters a different focus than group writing and eventual sharing of that writing, it is important to understand how such sharing necessitates “putting aside our own egos.” Specifically, when I spoke with participants individually in the pre-workshop interviews, they were centered upon relating their own experiences with illness and how it had completely altered their lives. In contrast, during post interviews, after having shared their experiences through writing, participants were much more likely to comment on others’ experiences and to view their own situation from a less dire perspective; or, as Schiwy puts it, after having engaged in group sharing of their writing, participants appeared to “measure their lives” according to what they learned about the experiences of others in the group.

This tendency for group writing and sharing to shift participants’ perspectives away from the self is another interesting result of this study. The difference in dynamics between individual writing and group writing and sharing correlates to Jack Leedy’s suggestion that “the essence of therapy in groups is the activity of the patients themselves” (Poetry Therapy 163). His observation translates to this study because, when participants wrote, their writing tended to be introspective and autobiographical, focused on the onset, progression, and treatment of their illness. However, when participants shared their writing, they became more focused on the experiences of others, and their post-interview responses addressed this new awareness of others
and of no longer feeling alone. Thus, according to Leedy’s statement, the writing “activity” in which the participants engaged became the “essence” of the sharing activity that followed. Elena, for example, praised the benefits of sharing writing with the group, “I feel really comfortable with the kind of positive responses in our little group and how warmly I feel toward everybody in that group. And that was not the case before I walked in to the room on that first day . . . I’ve never shared that kind of writing with anybody.” In this example, Elena addresses the importance of sharing one’s writing in a trusted environment and receiving positive feedback when writing about sensitive topics. But she is also expressing the important bond that is formed among participants in a writing group, a bond that benefits both the writer and the listener, and is something that cannot be formed from individual writing alone. Abercrombie explores the intricacies of this bond:

I also realize how lucky I am to have these women in my life. These are the women who teach me courage. These are the women who understand how I feel, who will stick with me no matter how deep I sink into feeling sorry for myself about this, who listen and don’t offer glib words to make themselves comfortable. (120)

Abercrombie’s words suggest the socially inadequate responses that often confront those who are struggling with life and death experiences. It also suggests that many who are not ill find it uncomfortable to relate to someone who is. As a result, a writing group, made up of others who are experiencing similar trials can offer an empathic alternative, and can play an important role in the therapeutic writing process.

The group dynamic also impacted the senior writing group who, although not afflicted with illness, nonetheless benefited from the companionship offered by such a group. For many participants, like Marge K., the writing group offered a chance to feel community, “It was nice to
be considered part of a writing community. When we worked in the group, it was nice to be considered part of that group.” Mary H. augments Marge’s comments by adding, “I think we’re more acquainted with people that we have never talked with before.” Again, Marge and Mary’s experiences would have been different if the writing had been done outside of a group environment, and to this extent the group dynamic was valuable.

Of course, that is not to say that working with writers individually would not bring about therapeutic effects. In fact, there may be times when the individual dynamic is preferable to that of the group, as supported by John Killic, a professional writer, whose chapter in *Creative Writing in Health and Social Care* describes a ten-year venture working in nursing homes with people suffering from dementia. His work entailed listening to them, writing down and recording what they had to say, and then transcribing the material to present to the patient or family members because, as he notes, “My work appears to confirm that many of the things people with dementia say are not nonsense” (58). More importantly, he describes why his work should only be done with individual writers and not in group situations:

All the work I have done with people with dementia over the years has been one-to-one. This seems to me to be essential: not only is every person different in terms of personal characteristics and life history; but the illnesses that make up the dementia family affect each one uniquely and they display individual language features which must be respected and embodied in the resulting writing. (58)

Killic’s work would indicate, then, that there are occasions when individually working with people to compile their stories or record their emotional reactions are not only justified, but preferable. In fact, if one is facilitating writing as therapy in hospitals or nursing homes, there may be times when patients are too ill to leave their rooms and meet with others in a group
situation. In these cases, taking therapeutic writing techniques to them would still provide benefits despite the fact that there would be no group interaction to follow the writing.

**Importance of a Facilitator**

Research, along with this study’s post-interviews and post-program questionnaire surveys point to the important role of a facilitator in successful writing workshops. Overall, it appears that the presence of a facilitator creates group cohesiveness. For example, Leedy looks to the facilitator to create an appropriate emotional climate, claiming that he or she, “must encourage a positive transference and group cohesion through shared experiences” (165). In her foreword to *Creative Writing in Health and Social Care*, Christina Patterson echoes Leedy’s advice explaining, “Much of the value of such projects lies in the skills and sensitivity of the poet-facilitator who leads the process of opening up and of creative engagement. If this is not done with due sensitivity and care, then it may be of no value at all. It’s a process of trust” (11).

While both Leedy and Patterson’s experiences are based upon workshops using poetry for therapy, there is no reason to suggest that their observations regarding the important role of facilitator would be any less pertinent to groups using writing for therapy. Both researchers agree that the role of facilitator is a delicate, but indispensable, part of successful literary-based workshops.

Additionally, while the importance of a facilitator was clearly a solid result of this study, so were some specific characteristics that a facilitator should possess. Some of these characteristics included: caring, empathy, and a non-judgmental attitude; flexibility, and skill in creating a safe, non-threatening environment were also characteristics that emerged as important. For instance, in her post-workshop interview Barb’s observations illustrate the importance of these facilitator characteristics, “Being in this group helped a lot because you [facilitator] made it
a very safe environment. I think everybody felt the freedom.” The notion of “freedom” pertains not only to the degree to which participants felt they could share writing, but also to a facilitator’s ability to offer choices of topics or prompts for participants to write about. Participants generally liked having several topics from which to choose, as this feature appeared to decreased the stress of being asked to write “on the spot.” The importance of having freedom in writing was reiterated by Alice in her post interview, “I think you’ve had a wonderful format of presenting it [writing] to us—a little at a time and just gradual [sic] and so much freedom. It isn’t that you were saying ‘now you do this.’ You said ‘you can do this or this or this,’ and that’s a wonderful ability as a teacher . . . because that’s really inspiring and motivating.” Similarly, in The Therapeutic Potential of Creative Writing: Writing Myself, Bolton relates to the importance of “inspiring and motivating” participants to write by cautioning, “Remember, always, how easy it is to demolish confidence and how difficult it is to build. Encouragement is the key word. Find the good in the writing and help the writers see for themselves where they can go from there” (135). Thus, if the facilitator can avoid rigidity in planning and presenting workshop material, allowing writers to have the freedom to choose the direction in which they want their writing to go, it’s much more likely that participants will produce something not only that they will want to share with other participants, but also something with which they can be satisfied and that will be of some significance to them.

A notable inference that one may draw from the above discussion is a necessity for the facilitator to relinquish absolute “control” of the workshop group. Thus emerges another important characteristic of the writing workshop facilitator: the need to be a flexible leader, not a dictator. Gina Levete, in The Creative Tree, appropriately describes the writing workshop facilitator:
Runners of workshops will help themselves and their workshops, I believe, if they constantly remind themselves that although their position in the group is that of expert and initiator, they should not in other respects be leader. We are not doctors, teachers, scoutmasters, dictators or other wielders of power, we are facilitators. And although we should accept our responsibility for the overall running of the workshop, we should avoid as much as possible the leadership roles adhering to our position. (54-55)

Levete’s words underscore the purpose for the workshop’s existence: to enable participants to ease their burdens of illness, stress, advanced age and other afflictions through the act of writing. The facilitator’s job, then, should be restricted to “clearing the path” for that to happen and the best way to clear the path is by listening to the goals of the participants. Molly Travers delineates how the facilitator must respect the goals of workshop participants. In her article, “What Writing Workshop Tutors Do,” Travers explains, “the tutor needs to understand the context in which the group exists, the intentions of individuals in the group, and the reasons for the group’s existence” (6). Again, while Travers’ comments pertain to the tutoring of writing, they bear strong implications for writing therapy workshops because both environments have similar goals of making writers as comfortable as possible with their “writerly” selves.

In terms of this project, I can relate to Travers’ emphasis on the importance of deciphering group context and intentions; originally, I had planned to conduct The Victory Center, St.Vincent, and Swan Creek writing workshops using much the same methodology and materials for all three groups. However, once I actually met with the Swan Creek seniors, it became clear to me that they wanted to focus only on autobiographical writing; in fact, many of them had started autobiographies that they wished to complete through participation in this workshop. Rather than continue with my original plans and materials, by altering those plans in
favor of materials and choices that could be adapted to autobiographical writing, I adapted the plans and materials to fit the goals of this writing group. At the end of the workshop, this anonymous feedback was received as part of the post-program questionnaire survey; it spoke to some important characteristics of a writing workshop facilitator, “[The] leadership and direction kept the class on track . . . Direction was unobtrusive, [the facilitator] related to what we wrote, never criticized or corrected anything we had written. Her acceptance provided the encouragement any writer needs.” As mentioned earlier in this chapter, many of the seniors in this group were able to remember events they had long ago forgotten, and to record stories about themselves or their significant others, all of which brought with it the satisfaction of knowing that their goal had been realized. Of equal importance, however, is the feedback received about other important characteristics a writing workshop facilitator should display: leadership and direction to keep the group “on track,” providing unobtrusive direction, relating to what participants wrote while not criticizing or correcting anything, and providing the encouragement that comes from acceptance.

Other valuable knowledge that the writing facilitator should be able to draw upon is not to expect “too much.” Specifically, no one in the group will be cured of cancer because of writing therapy, and it’s unlikely that anyone will walk out the door forever changed as a result of writing therapy. Nevertheless, there are gains from the experience; as Dale explains it,

When you’re dealing with illnesses that are this serious, little things mean a hell of a lot.

So I hope as an instructor or a prompter or a coordinator or whatever you consider yourself, whatever that role is, you have to be very, very satisfied with tiny moments of gratitude. ‘Cause it’s not like painting a black room white. It’s making little tiny inroads in people’s lives and those are significant.
Dale is communicating how, when people are seriously ill, they are often grateful for small joys in their lives; for instance, noticing a flower when out walking and writing about that experience; marveling in the beauty of an autumn day, and writing about that. For those who are seriously ill, such small events that represent the beauty of life and the world around them become so important because of the uncertainty of ever again having the opportunity to experience those things. As a result, having the opportunity to record these small but important events where they can be re-read and thus re-experienced, is worthwhile, or as Dale says, “a gift.” The facilitator, then, must be aware that a participant can write about how a seemingly small experience can be of value, and even in this case the writing activity will have still been successful.

**Study Limitations**

Some limitations inherent to the study included: the lack of a control group against which to measure the study’s findings, and an insufficient sample size from which to generalize results. Additionally, a social desirability bias that applied to the Swan Creek results specifically and the Victory Center and St. Vincent’s outcome reporting in general, given that the seriousness of these individuals’ illnesses, might have led to a natural tendency for the workshop writing to have been perceived as therapeutic by the participants.

First of all, it was not possible to develop a control group as there were individuals at each of the three venues who wanted to take part in the writing portion of the study; thus, barring a certain group from participation would have made it unlikely to secure that group’s participation in the study. Furthermore, while there were three separate workshop groups, the total number of participants among all three groups remained between 13 and 15 at all times. Since this number is significantly less than a sufficient sample size, the data of this study, while
engaging, cannot be applied to the general population; it does, however, suggest that further study is warranted, and should be pursued at a later date with a larger sample size.

Another limitation was a social desirability bias; “social desirability” was codified by Douglas Crowne and David Marlowe in their 1960 publication, “A New Scale of Social Desirability Independent of Psychopathology” and defined as the need for subjects to gain approval by responding in socially appropriate ways (354). In the field of Psychology, the term social desirability bias resulted from Crowne and Marlowe’s definition, referring to the tendency of certain members of a group to uphold opinions that are consistent with the social standards of others within the group. Such a tendency, when exhibited, is believed to skew study results. In this study, this bias applied in two ways, both in the withholding of pertinent feedback within the Swan Creek group, as well as through the self-reporting of therapeutic results by participants as a whole.

Social desirability bias among Swan Creek participants can be attributed to the fact that, unlike participants in the other two writing groups, this group of seniors were all members of the same community and thus would continue to interact with each other beyond the termination of the writing workshop. Therefore, it is likely that members of this writing group found it important to uphold a mindset consistent with that of the group as a whole. An example follows: during the portion of each session when individuals would share writing, there were always one or two participants who held the floor much longer than the others. Not wanting to interrupt, I generally allowed each to speak as long as they chose. Throughout the duration of the workshops, no one ever expressed displeasure at the pacing of the sessions. However, during Ruth’s post-interview, she almost apologetically suggested that, during future workshop sessions, I find a way to curb such verbosity,
My suggestion would be that you have a nice little bell—a sweet one—just a sweet one, a nice one . . . because some go on and on and on, and it’s not a fault. I don’t mean it that way . . . I mean, you have to—in a class like this, you can be—as a teacher—of course. . . you can say, ‘Now we have a limited time . . . and the little bell is going to ding when the time is up,’ whatever you decide that [time] should be. It should be so that every person has an equal opportunity to share. And a teacher can handle that very nicely.

While this information was important, clearly, Ruth waited until we were away from the group, and until all sessions were over to broach the subject. However, it would have been much more valuable to the group as a whole had she relayed this information sooner. Additionally, Ruth’s observation raises the questions of whether others shared her sentiments. Nevertheless, Ruth avoided a situation where she might have been the only one to negatively express herself; thus, her social desirability bias led her to self-censor her true views. Even when she did express herself, she did so in a halting manner, conscious of maintaining her socially conscious demeanor, content to transfer the burden of censorship to the “teacher” rather than accept it herself.

Another indicator of social desirability bias pertained to the seriousness of participants’ illnesses with relation to the overall favorable results of the study; specifically, given the seriousness of the illnesses, one might question whether there existed a natural tendency for the writers to have communicated their experiences as therapeutic. Since the post-interview responses were self-reported and delivered directly to the interviewer, an argument could be raised as to the likelihood that interviewees wanted to maintain a favorable rapport with the researcher by praising the effects of the writing workshop. While this may be the case, the anonymous post-workshop questionnaire should have mitigated the problem. Unfortunately,
because the groups were so small, and many participants also submitted handwritten samples of their writing, they may have concluded that handwritten questionnaires could be matched to writing samples, thereby jeopardizing the anonymity factor and transferring the social desirability bias onto the questionnaires as well.

Nevertheless, James Pennebaker’s later work, “Confession, Inhibition, and Disease,” argued that:

An important dimension to coping with stressors . . . concerns the degree to which people discuss or psychologically confront traumas after their occurrence . . . Whereas talking about trauma with others can strengthen social bonds, provide coping information and emotional support, and hasten an understanding of the event, the inability to talk with others can be unhealthy for a number of reasons . . . (213)

Here, Pennebaker describes how the ability for individuals to confront trauma leads to a healthier state of mind; writing, as he suggests in this and other work, is one of those methods of confronting trauma. Talking about distressing events is another method of coping; hence, despite the limitations of this study, past research leans toward the supposition that a writing workshop, where people are engaged in both writing and talking about serious illness, should have therapeutic qualities.

Cameron and Nicholls, who extended Pennebaker’s earlier experiments on the positive effects of writing on stress levels of college students, took his work to a new level. These researchers investigated how study participants, for whom self-disclosing alone did not succeed, could benefit from adding a “self-regulatory” writing piece to the experiment. In addition to self-disclosing then, this self-regulatory writing asked participants to write about methods they might employ to cope with their problems, “it instructs participants to write about their thoughts and
feelings concerning current problems and then to identify specific strategies for resolving these problems” (85). These combined techniques demonstrated increased efficacy at prompting participants to not merely focus on trauma, but also to brainstorm possible resolutions to that trauma. Again, material within this writing workshop also asked participants to discover ways they might take control of their illness by considering specific ways to combat the stress caused by their diagnosis. Therefore, while it is possible that the desire for social approval may have biased participants toward believing the writing workshop experience was therapeutic, still, there is an abundance of research that has previously demonstrated the therapeutic value of writing to be so.

Chapter Seven will conclude this study by discussing research that bridges the gap between community and academic writing as well as the classroom implications of this research; as such, it will address important characteristics of therapeutic writing that would make its implementation particularly valuable with service learning and community literacy programs.
CHAPTER SEVEN: CONCLUSIONS AND RECOMMENDATIONS FOR FURTHER STUDY

“With sensitive prompting, imaginative ideas for creative work and individualised [sic] approaches, people can be enabled to extend themselves and succeed in a wide range of personal goals through their reminiscences.”


Classroom Implications and Service Learning Initiatives

This project has examined how therapeutic writing was implemented in three different groups recruited through The Victory Center, St. Vincent’s Hospital, and Swan Creek Retirement Village. Chapter Seven concludes the project by addressing how such a workshop structure can bridge the gap between community and academic writing through initiatives such as service-learning and community literacy projects that can better prepare both first-year composition instructors and writing instructors in general, to expect and respond to emotion in student writing.

In Writing Partnerships: Service Learning and Composition, Thomas Deans defines service-learning as, “not volunteerism or community service; nor is it simply an academic internship or field placement. While service-learning may draw on these practices, it is at heart a pedagogy of action and reflection, one that centers on a dialectic between community outreach and academic inquiry” (2). Deans is pointing out that service-learning should not be confused with community service, but rather, viewed as a method of instruction, whereby the traditional goals for a college course exist in tandem with meeting the needs of a given community. In addition, both students and academy should benefit from the service-learning arrangement; hence, its dual but equal purposes.
Jeffrey Grabill, in his current publication *Writing Community Change*, asserts some important stipulations on Deans’ definition:

I do not believe in clear classroom-community or university-real world distinctions. The people in our classrooms are citizens as well as students. We don’t need to invent that identity for them . . . I don’t believe that we need to take composition into public space in the way that typically means because our schools and classrooms are always already part of that network of civic institutions. The much trickier issue is providing students with meaningful opportunities to do the work of citizenship and to learn how to be powerful at that work. (121)

Grabill refers to providing students with opportunities for engaging in meaningful writing by positioning the service-learning experience at the core of the composition course. While many researchers and students tout service-learning initiatives as examples of stellar learning, Ellen Cushman, in her article, “Sustainable Service Learning Programs,” cautions that, in order to make these experiences truly exceptional, the teacher must function as a researcher alongside his or her students in the community learning field, emphasizing the difference between academic and non-academic writing, and assisting students in learning the research process by actively participating in it (44).

It is through such active participation that both students and writing workshop participants could benefit from using therapeutic workshop sessions as one such community venue for a service-learning composition program. For example, if the participant group size were to grow, then it would be feasible to divide it into smaller groups with students facilitating individual groups and the course instructor monitoring sessions. Students could use a tape recorder to record sessions so that they could later transcribe them into a log. Students’ logs
could be subsequently used in class as companion texts for regular course readings, and to spark class discussion. Later in the semester, when students were preparing their final project, this log would function as a journal in triggering memory recall. Such a service-learning project would revolve around community, and the experiences generated for both the composition students and workshop participants would provide topics for course writing. As DeSalvo reminds us, “We are using our writing to help build community. And this reinforces our ability to do our work well and to use our work to heal” (208). Thus, such a service-learning project would create the opportunity both for students to find value in their writing, and seriously ill individuals to cope with their illness. For example, in his post-interview, Dale recommended that information about similar therapeutic writing workshops be disseminated where it would travel furthest in the community:

We all deal with doctors—really sophisticated, bright, intelligent doctors—people you really, really like. But they still have a professional life that they’re dealing with you on. And the situation that you’re [facilitator] dealing with is just as critical as that doctor’s profession. I mean, he’s prescribing this medication and various operations or something, but there’s a whole lot more than just the physical well-being of the body. There’s also the really, really, huge need to work the mind and when a doctor’s got 20 patients out in the waiting room, you’re [only] going to have a little bit of time . . . And it would be really good if classes like this somehow were introduced to these doctors where they would encourage patients to come to things like this to meet needs that the doctor doesn’t really and can’t really meet.

Dale communicates an indisputable concern in today’s health care profession: the baby-boomer generation is aging and falling ill at a faster rate than current medical professionals can care for
them. Consequently, many of these professions are understaffed, the employees overworked; they may not have time even to acknowledge many patients’ need for emotional support in coping with illness, let alone provide that support. Hence, Dale’s observations clearly indicate a community need that could be mitigated by creating a viable service-learning composition course for undergraduate students. Not only could such a course lead involved students to an appreciation for good health and its preservation, it also could provide some seriously ill community members with a therapeutic means of coming to terms with their illness.

Another area where service-learning pedagogy could be applied is with senior members of our communities, similar to those with whom I worked at Swan Creek. These individuals, brimming with a lifetime worth of experiences, are often just waiting for someone or something to trigger their memories to be recorded on paper. Molly Travers describes their personalities so well:

What impresses is . . . that they are so skilled in language and in the manipulation of words to express emotion, that they come across as they want to: thoughtful, articulate, passionate and often gently humorous. They have strong views on language and literature, and on the value of the written word to clarify, document and preserve their experiences, often painful, of life . . . they use writing—and the opportunity to read to the group, and for some to publish—as a way of achieving some satisfaction in their present lives. (8)

Surely this senior community of writers presents another venue for a service-learning composition course. As Travers indicates, these writers place value upon the written word’s ability to create a permanent record of their lives, and without exception, this preservation, through the genre of autobiography, was the goal of the participants in the Swan Creek writing
workshop. In fact, once, when Alice and I were conversing, I mentioned how I would like to bring such a writing workshop to other communities of seniors; in response, she shared these thoughts, “I think [sharing experiences] has been vital, and that’s why going to other facilities like ours, as you would like to do, is very helpful and very, very thoughtful for people of the older age because they all have experiences to share that might be interesting.” Again, Alice reiterates the important desire of most elderly individuals to capture their experiences through autobiography, and one can imagine the service-learning potential that working with such individuals could provide for both undergraduate students and their senior counterparts.

Pennebaker, in a journal article “Telling Stories: The Health Benefits of Narrative” that appeared in a 2000 issue of Literature and Medicine, discusses at length his research that supports how the specific genre of autobiography supports health and immune function:

It is critical for the client to confront anxieties and problems by creating a story to explain and understand past and current life concerns. The story can be in the form of an autobiography or even a third-person narrative . . . the act of constructing stories is associated with mental and physical health improvement. A constructed story, then, is a type of knowledge that helps to organize the emotional effects of an experience as well as the experience itself . . . writing about emotional topics has an immediate positive impact upon the subsequent social interactions of those who write with others in their community. (11, 15)

Pennebaker, who admits that he is “not an expert in literature,” (3) nonetheless has conducted some twenty years of research about the effects of writing on general health, most of which suggests a strong correlation between the two. Here, he is arguing, specifically, for the benefits of autobiography, and his final words can even support the practice of service-learning activities
that expand beyond the mere idea of an individual writer sitting in a room writing alone. Rather, Pennebaker is describing how writing about emotional material in a social setting can lead to a more positive social connection between those who write and share their writing with others, and those who keep it to themselves.

With regard to service learning, specifically, undergraduate students working with seniors might not only learn about the genre of autobiography, but, when taking into account failing eyesight, hearing, and even general health, perhaps may also learn what it’s like to act as a scribe; additionally, in helping senior writers to prepare their documents, students might also act as tutors, word processing instructors, or even publishers. By the course’s end, both the students and seniors should have a completed text that the senior writer could share with friends and family and the students could add to an ongoing electronic portfolio of undergraduate projects.

Classroom Implications and Community Literacy Initiatives

Alice Brand, in her 1985 Journal of Advanced Composition article, “Hot Cognition: Emotions and Writing Behavior,” argues that writing teachers must acknowledge the importance of emotion during the writing process and encourage student writers to be conscious of both emotion and cognition when composing. Critical of the degree to which writing instruction enables affective processes to be overshadowed by cognitive ones, she advocates the need for further research on this issue. Almost a decade later, Wendy Bishop espouses the same dilemma in “Writing Is/And Therapy?”

First-year writing teachers . . . are hesitant to explore the strong personal relationships and undercurrents that develop in the workshop due to the very power of writing to become for some students, at some junctures, a therapeutic process . . . first-year writing teachers have not been trained or encouraged to view writing in this manner. Instead,
more simply, more safely, but equally problematic, many first-year writing programs have internalized a university perception that our job is primarily one of socialization, thereby constructing composition as a service course without content. (6)

Brand and Bishop both realize that, although writing is an intellectually taxing activity, it is not merely intellectual, as once was argued. Instead, the integration of intellect and emotion is key to eliciting meaningful writing from students. Yet, most first-year writing programs are concerned with teaching “traditional” academic writing, emotionless and objective. This section of the chapter argues that through community literacy initiatives, first-year composition instructors, and writing instructors in general, can be better prepared to expect and respond to emotion in students’ writing; certainly, these instructors can avoid consciously or subconsciously encouraging the opposite: student disengagement from their own writing.

Jerome Bump in “Teaching Emotional Literacy” attributes part of this lack of preparedness to an educational system that stunts emotional literacy in educators themselves by favoring objectivity over “emotional literacy, a requirement of personal growth, healthy relationships, and effective teaching . . .” (316). Bump’s claim is based upon the tenet that, because educators spend so much time in the system as students themselves, they are “programmed” not to reason any other way but objectively. Such programming leads them to shy away from addressing any lack of objectivity in students’ writing.

I first noticed the difference between student writing and workshop participants’ writing during one of our early workshop sharing sessions. Afterward, one of the participants asked me if it was difficult for me to listen to their writing, since I was used to teaching in a community college. “Not difficult,” I responded. “Just different.” What I meant by different is how surprising it was for me to hear writing laced with emotion, not restricted by a forced “academic
voice.” Yet, at the same time I also realized that, had I received such emotion-laden writing from my students, I would have felt compelled to let them know that it did not function within their assignment parameters. Brand, in “The Why of Cognition,” reminds me of what is lacking in my students’ writing by asserting, “Examining the impact of the emotions on writing may also help us understand why some problems occur during writing and how we can solve them” (441). Clearly, the lack of spontaneity and even personality in first-year composition students’ writing poses one such problem, and teachers need to be able to reconnect their students’ writing to emotion in a way that can infuse it with enthusiasm. Given how this therapeutic writing project illustrated the rich experience that writing becomes when the topic is of value to the writer, one way to enable composition instructors to replicate such enthusiasm with their own students is through service-learning and community literacy pedagogy, as these pedagogies increase the likelihood of students discovering topics of value. Since service-learning was addressed earlier in this chapter, a discussion of community literacy projects and their implications for the composition classroom will follow.

In their article, “Community Literacy,” Peck et al. define the term as:

A search for an alternative discourse for dealing with difference; it supports social change, genuine intercultural conversation that operates from a strategic approach to this conversation; it supports people in developing new strategies for decision-making, and inquiry/research—to openly acknowledge not only the difficulty of empathy and the history of failed conversations, but to purposefully examine the genuine conflicts, assumptions, and practices we bring to these new partnerships. (205-206)

Peck and his colleagues created this definition from their experience in building Pittsburgh’s Community Literacy Center (CLC), a joint venture with Carnegie Mellon University (CMU). As
a venue where individuals with varied backgrounds meet to exchange ideas, discuss community concerns, write about them, and hold “community conversations” with authentic audiences likely to be in decision-making positions, the CLC has brought about such positive community change for twelve years. Undergraduate students from CMU participate as “mentors,” after first enrolling in CMU’s Community Literacy Seminar where they train to be supporters, collaborative planners, and writing mentors in a program where “the aim of community literacy is to build a discourse in which people not only acknowledge difference, but in which people do productive work together” (207). This productive work has included a co-authored, practical and readable housing handbook for city residents; it has also included the efforts of a group of teens at a local high school as they lobbied for change in a suspension policy that unjustly targeted African American males. Eventually, students assisted in rewriting the policy that has subsequently been enforced in their school, but only after much deliberation with school officials and community residents “who saw them as the problem.” In such negotiations, “intercultural collaboration is a strategy for making something new—a new understanding, a document, a public, literate act” (210). Such initiatives as the CLC bring the power of literacy out into communities where the dominant discourse is not usually the one in practice. The strength of such a program lies in its ability to merge dominant and marginalized discourses where attitudes of respect chip away at the resentment caused by long-standing disenfranchisement.

Similarly, consider the disenfranchisement among today’s elderly. Where once individuals in their upper years were esteemed and revered, many are now tucked away in nursing home facilities where they have little voice and even less respect. This population offers an ideal demographic for community literacy initiatives as evidenced in McKee and Blair’s recent publication, “Older Adults and Community-based Technological Literacy Programs:
Barriers and Benefits to Learning.” Here, the authors share their individual experiences working with older adults through community centers in the Midwest and New England. While their work addresses the barriers and benefits of helping older adults learn to navigate new technology, the authors also communicate how their own roles as teachers and researchers shifted and broadened as a result of working with individuals outside of the academy. They affirmed this shift as a focal aspect of their five-year experiences, emphasizing the importance of “seeing literacy as a series of cultural processes and practices in which university teachers, students, and researchers have as much to learn from the community populations they serve as they do from us” (par. 62). Like McKee and Blair, Ray also advocates the recognition and acceptance of the reciprocal growth and development fostered by acknowledging and engaging different populations, such as those within and outside the academy:

> difference need not mean deficit, the struggle with differences is inevitable in any relationship, and the conflict that arises from difference can be positive. When managed with developmental goals in mind, conflict expands awareness and initiates change. Such conflict management also includes understanding on the part of more powerful groups that their privileged status blinds them to the need for change and makes them more resistant to it. (239)

The underlying commonalities, therefore, between the works of McKee and Blair and Ray underscore the growth potential for both community members and academics when they unite on behalf of the mutual value inherent in community literacy and service learning projects.

But how can such engagement between these diverse communities occur? One suggestion might be that, in conjunction with local senior centers, students in first-year writing courses could mentor a group of seniors, assisting them in preparing autobiographical anecdotes
or family vignettes that could ultimately be edited into a collection and donated to community libraries. Not only would such a project provide an opportunity for today’s youth to interact with community members of another generation, acquiring fascinating information about a cohort who lived through World War II and the Great Depression, it would also lend a voice to many within that cohort who have come to believe they have nothing to say, bolstering their sense of self-respect, individual self-worth, and healing.

Another worthwhile community literacy project in which to involve undergraduate writers could benefit The Victory Center. As a non-profit organization, all of their pamphlets and materials are funded through their low budget. Since the center already has a strong mentoring program, where cancer survivors are paired with someone newly diagnosed, a publication created through this “Buddies” group could have a positive impact on the center. More specifically, first-year composition students could be paired with a client, and together could create a “What to Expect” brochure for other newly diagnosed individuals and their families; these publications would be placed in the family reading room and serve multiple functions. First of all, these publications would welcome newcomers to The Victory Center, providing them with basic information and recommendations from others who have been through the same experience. Through my experience conducting the writing workshops, I learned that individuals involved with The Victory Center are deeply caring and committed to sharing information that will help newly diagnosed clients feel less alone. Furthermore, the undergraduate writers, in developing empathy for those who are less fortunate than they, simultaneously would have the experience of producing an authentic publication of value to the community. Since the publication could also include a schedule of all the programs offered at the site, as well as other
materials decided upon by the “Buddies” group, this project could also be implemented in a Technical Communication course.

As indicated, service-learning and community literacy programs are capable of a variety of functions in communities, and can involve individuals with eclectic backgrounds and interests. Their tendency to bridge gaps between academy and community establishes them as a natural course of action for instructors who wish to create thought-provoking courses for students.

Of course, there are those who point to the downsides of service-learning and community literacy initiatives. For example, Deans cites brevity as a common concern in service-learning projects; that is, one semester is just too brief for students to familiarize themselves with an off-campus site and the type of writing expected of them. As a result, students could feel overwhelmed by such a project, rather than stimulated by it (62). Another problem occurs if the goals of student mentors do not correlate with those of the course instructor or other leadership. If not addressed in a timely manner, the evolution of such discord could lead to ill effects for students who would pay the price if the project did not come to fruition. One such example references the CLC initiative. In this instance, a student mentor expressed frustration over what felt like a product-oriented writing approach rather than an expressivist, process-oriented one. Eventually, the situation was resolved by the mentor relinquishing her views for the benefit of the project (129-130).

Other problems could initiate due to the degree to which a supervising instructor does or does not wish to be an active researcher on the project. For example, some departments have standard lists of community organizations to whom they assign students; students are placed at these sites, and may be responsible for completing regular journal activities and producing a final project at the end of the semester. Such experiences are generally not favorable for either the
student or the site, resulting in much confusion and frustration. As instructor involvement in the project increases, however, the experience becomes much more beneficial for both the student and the facility. Specifically, when the instructor himself or herself is also on-site conducting research and available both to the student and facility, the project becomes much more successful. Unfortunately, many instructors do not have the time to become invested to this degree in a service-learning course, and so many courses do become sub-par. Overall, the three greatest challenges to service-learning/community literacy projects are institutional support, matching a student’s ability level to project requirements, and assessment of the student’s work once the project has begun (81). Of note, one problem that can quickly curtail the success of a service-learning or community literacy program is if the instructor’s institution is not committed to seeing it flourish. This lack of commitment can be evident in many different ways; lack of funding and time to adequately develop the program are obvious ways, but so are the refusal of personnel and materials. Moreover, it can often be difficult to find a “good fit” for both the student and the community service site, and doing so is quite important as it is not fair to ask a student to take on, and be assessed on a project for which he or she has no skill or training. Simultaneously, it is unfair to request that a site accept a student for whom too much training must be given for the short period of time he or she will remain. Finally, assessing a student’s work while he or she is participating in a service-learning or community literacy project is difficult. Should an instructor require a daily log? An end-of-term project? Favorable evaluation from the site coordinator? In answering these questions, fairness to the student should be kept in mind. Some instructors opt for a hybrid form of assessment in which both formal assessment and informal conversation are a part. To be sure, optimal assessment techniques in service-learning
and community literacy are still under development, reflective of the relative fledgling status of the field.

For first-year writing instructors, some incorporation of service-learning or community literacy initiatives can be a meaningful way to create student interest and self-investment in writing, and with these results is likely to come an increase in affect. To some, this increase may be reason enough to avoid such pedagogy; yet, Laura Micciche, in her article “Writing through Trauma: The Emotional Dimensions of Teaching Writing” affords a pragmatic view about the role of emotion in our students’ writing:

however pervasive charges against personal writing may be, the fact remains that students have and will continue to write personal narratives about trauma whether we ask them to or not. Thus, teachers need to have a repertoire of skills for responding to such writing and an approach to pedagogical theory that takes this reality into account. (132)

Micciche is asserting that, in the end, there is little that instructors will be able to do to curtail the emotion that students are bound to employ in meaningful writing. In fact, since the amount of emotion students use is closely related to the types of writing that teachers assign, ultimately, teachers impact the amount to which students engage emotion in their writing. However, Micciche’s admonition to develop the skills with which to respond to more emotional writing is well taken.

This being said, the argument doesn’t advocate that teachers adopt the role of therapist or counselor. In “Language, Power, and Consciousness” Guy Allen markedly delineates the teacher’s role from that of the therapist, “The teacher is not, and must not be, a therapist. However, the teacher sets the frame, a ‘facilitating environment,’ which becomes a safe place for students to carry on their work . . . Students decide how to use the space and time within this
frame” (284). Allen’s description of a “facilitating environment” is reminiscent of the therapeutic writing workshop environment and the notion of safety to which participants attributed their creativity. It also describes the type of environment that can be replicated in a composition course structured around service-learning and community literacy, since the underlying premise of both these environments is one of respect and the safety that a writer draws from that sense of respect. In firm agreement with Allen, Mary Rose O’Reilley also addresses the same notion of safety in The Peaceable Classroom, “Most of the healing that goes on in English class is self-healing. The teacher’s job is not so much to counsel as to provide an atmosphere of safety and to keep out of the way of the process” (47). Thus, O’Reilley reiterates the idea that, in order for students to incorporate emotion in their writing, a teacher need not worry about counseling so much as about providing an environment where students feel safe enough to express themselves without fear of ridicule or retribution. Allen and O’Reilley stand in agreement that allowing students to incorporate emotion into their writing should not cause fear in the minds of composition instructors because it is through the expression of emotion that students and individuals can heal. In reflecting upon the memory of writing workshop participants’ honest and often emotional writing, it becomes clear what so many of them tried to communicate: their writing was filled with such honesty and emotion because the environment facilitated feelings of safety, which in turn promoted the therapeutic effects of their writing. How much more successful could the writing of composition students become were they to experience a similarly safe and nurturing writing environment in the classroom!
Works Cited


--------------. “All writing is autobiography.” College Composition and Communication, 42.1 (1991): 66-74.


--------------------------. “Confession, Inhibition, and Disease.” Advance in Experimental Social Psychology 22 (1989): 211-244.


APPENDIX A: VICTORY CENTER/ST. VINCENT’S WORKSHOP SESSION OUTLINES

Session #1

Some Rules for Our Writing Community

1. Do your best to arrive on time.
2. During workshop time, try to stay within the time parameters of each writing exercise. If you would like to continue working on something, or would like more individual feedback on something you’ve written, I will be happy meet you before class for additional writing consultation.
3. Be respectful of everyone’s comments, opinions, and of any writing they choose to share.
4. Be accepting when someone chooses not to share something they have written. (Just say “pass.”)
5. Try to remain silent during writing time; it’s important to allow people to concentrate.
6. Respect the privacy of our writing community. Please do not share what people write about or discuss outside of our writing community, unless you have their express permission.
7. Any other comments?

I. Warm-up activity: Getting to Know Each Other

True or False?

Directions: Write down three facts about yourself that are true and one that is not true (use one index card per each “fact”). Now, swap with the person to your left and see if you can both identify the untrue fact in each others’ lists.

II. Writing Exercises:

Barriers

In your journal, respond to the following questions:

A. The biggest change I’ve faced in my life since my illness began is . . . .
B. The thing I’m having the most trouble adjusting to is . . . .
C. Two or three things that are interfering with my ability to adjust are . . . .
D. Some things I can do to help me get over these hurdles are . . . .

Discussion, if you choose . . . .

Magic Moments

A. Spend the next few minutes writing about a color that is your spirit. What about that color attracts you? Why does it best describe you?
B. Fall is a colorful season! But I’ve always spent so much of it just mourning the loss of summer and dreading the coming winter that I’ve seldom appreciated autumn for all its glory. This autumn, because I’ve tried to keep a commitment to keep up with yoga and to walk to and from class four nights a week, something special and unexpected has resulted. Along my pathway I’ve noticed the splendid colors around me—the other day I even noticed a white pumpkin that seemed particularly startling in the way it was set among the other orange ones and framed by the cloudless blue sky!

During this same walk, an interesting metaphor came to my mind: Might this be a pattern in my life? Do I do the same thing with people in my life: focus only on what I think is lacking instead of paying attention to the colorful personality before me?

C. Ten magic moments a day.

Discussion, if you choose . . . .

III. Something to work on

A. Over the next few days, can you find 10 magic moments a day to list in your journal?
B. Color your journal with your spirit: Find what moves you when you write. Paste in photos and quotes from others; if something colorful attracts you, tape it in too! Be creative in your journal writing, whatever that process is. Your journal doesn’t have to be perfect; it just has to be you!

Some ideas borrowed/modified from:
Session #2

I. How did you do with:
   A. Listing 10 magic moments a day (a couple days)?
   B. “Coloring” your journal with your spirit?
   C. Would anyone like to share or tell about their attempts at either?
   D. Did anyone work on something different than either A or B that they might like to
      share or tell about?

II. Warm-up activity: Responding to Special Quotations
   Choose one or more of the following quotations and respond. Is there one in particular
   that has special meaning to your life? Can you identify that meaning and expand upon it?

   "It is never too late to be what you might have been." ~George Eliot

   “There are only two ways to live your life. One is as if nothing is a miracle, and the other is as if
   everything is a miracle.” ~Albert Einstein

   “Whatever you can do, or dream you can, begin it. Boldness has genius and power and magic in
   it.” ~Goethe

III: Writing Activity

   Thought passage: Sometimes bad is good

   Directions: Can you remember a time when everything went wrong? A time when you were
   overcome with heartache and thought that things simply couldn’t get any worse, only somehow
   you not only make it through, but did so better than you’d ever imagined?

   Begin a journal entry with, “It was one of the worst times of my life . . .” and keep writing until
   you can end with “. . . and so it became one of the best times of my life.”

   Thought passage: Trusting in Magic

   Discussion, if you choose . . .

IV. Something to work on: Synchronicity

   Write about a coincidence that you can’t forget. Include the details. Where were you? How did
   it happen? Why was it so amazing? How did you feel when you realized what had happened (or
   was happening)? What does a reflection on this experience make you think about the way life
   works? Appreciate the moments of grace in your life.

------------------------------------------
From: Writing to Heal the Soul by Susan Zimmerman, 2002.
Session #3

I. Voluntary Share/Response: Did anyone write about a coincidence that they would like to share?

II. Pivotal Moments
   a. Warm-up activity: Pivotal Moments Handout
   b. Use one or more of the above pivotal-moment categories as an aid to brainstorming ideas for an autobiographical moment about which you might like to write.
   c. Freewrite about possible answers to the following questions:
      i. How might you begin your story?
      ii. What events and scenes might you include in your story?
      iii. What would the pivotal moment of your narrative be?
      iv. What insights or meaning might you want your story to suggest?

Share your ideas, if you wish . . . .

III: Writing Activity

1. If you currently have ideas for narrating a pivotal moment in your life, think about the memorable people in your life and decide which one(s) you wish to focus on in this particular moment:
   a. Why was this person (or people) significant to you?
   b. What role did this person (or people) play in supporting or hindering this pivotal moment of your life?
   c. Given that role, which of their traits, mannerisms, and actions might you include in your account?
   d. Could you develop this person or people through dialogue? If so, where might you use dialogue in your account?
   e. Could you develop this person or people through a collage of representative scenes? If so, what scenes will you choose to emphasize?

2. Picture in your mind the person or people you thought of above. Now, imagine this person in a setting that reveals his or her significance—in a kitchen baking a pie, on the front steps of a porch laughing with neighbors, in an open field running barefoot, in the back yard working on an old engine, in a crowded office standing by the water cooler. Picture a photograph of this person in that setting. Freewrite about your description of that photograph.

Share your descriptive freewriting, if you choose . . . you might discuss how this text could be used in a larger autobiographical narrative, or in an expanded version of the pivotal moment you’ve been considering during this session.
IV: Something to work on, if you wish . . .

Write a narrative essay about the pivotal moment you’ve been considering during this session. Try to get at the larger significance of this moment. Use dialogue and specific details about setting and people to create a memorable recollection.

Session #4

When I write down my thoughts, they do not escape me. This action makes me remember my strength. ~ Isidore Ducasse

Time. This week we’re going to focus our thoughts and writing on time — past, present, and future. With the holidays on the way and all the pressures they can sometimes bring, let’s set our minds on the joyous opportunity we have to spend our time in the most meaningful ways possible: begin kind to ourselves and being with those we love.

I. Voluntary Share/Response: Did anyone write (more) about the pivotal moment you considered during last week’s session? If so, would you be willing to share that moment and its larger significance? As a future writing project, you might want to revisit this entry at some point to add dialogue and more specific details about the setting and people who were involved.

II. Warm-up Activity: “Spend My Time”

After listening to the song, spend a few moments responding to one or more or the following:

d. I hope to be able to spend my time doing more of these activities . . .
e. Because of my illness/accident, I hope to be able to help others in these ways . . .
f. I hope to spend more time with these people . . .
g. I hope to be able to do these things with the people I love . . .
h. I have found myself drastically redefining what I must do in my lifetime . . .
i. These are the places that I’ve thought about going that I hope to visit . . .

Share your ideas, if you wish . . .

III: Writing Activity: Writing about the Most Traumatic Event in Your Life

Although you should never feel pressured to share your writing in this workshop, because of the sensitive content the following exercise may explore, I want to reiterate that your writing should only be shared when and if you feel comfortable doing so. Because of this, I will not solicit the sharing of thoughts after this exercise; instead, after writing, we will share a few moments of meditative silence during which anyone who feels like sharing should simply speak up.


Prompt: “The most traumatic experience I’ve had occurred when I was ______ years old. And this is what happened . . .
• The people involved included . . .
• I reacted by . . .
• I have vivid memories of how I felt at the time . . .
• What I felt most powerless about was . . .
• What I learned from the experience was . . .
• As the years have gone by, I’ve made peace with what happened by . . .
• My illness or injury brought back some of the same feelings that I experienced at the time of this past event, including . . .
• Having survived this earlier trauma, I feel that I can cope with my current situation by . . .

IV: “Live Like You Were Dying” (Recording)

V: Something to work on, if you wish . . .

Throughout the week, meditate upon one or more of the following thoughts; then, compose a written response to it:

“I’ll tell you a great secret, my friend. Don’t wait for the Last Judgment. It happens every day.” ~Albert Camus

“Those who live are those who fight.” ~Victor Hugo

“Recovery of soul and recovery of the health of the body may occur together or not; healing may occur, and the body may not survive.” ~Jean Shinoda Bolen

Session #5
Recall the cycles of your life story in seven-year periods, each representing a month of the year.

<table>
<thead>
<tr>
<th>Season</th>
<th>Significant Event/Theme/Metaphor</th>
</tr>
</thead>
<tbody>
<tr>
<td>January</td>
<td>0-7 years</td>
</tr>
<tr>
<td>February</td>
<td>8-14 years</td>
</tr>
<tr>
<td>March</td>
<td>15-21 years</td>
</tr>
<tr>
<td>April</td>
<td>22-28 years</td>
</tr>
<tr>
<td>May</td>
<td>29-35 years</td>
</tr>
<tr>
<td>June</td>
<td>36-42 years</td>
</tr>
<tr>
<td>July</td>
<td>43-49 years</td>
</tr>
<tr>
<td>August</td>
<td>50-56 years</td>
</tr>
<tr>
<td>Sept.</td>
<td>57-63 years</td>
</tr>
<tr>
<td>October</td>
<td>64-70 years</td>
</tr>
<tr>
<td>November</td>
<td>71-77 years</td>
</tr>
<tr>
<td>December</td>
<td>78- X years</td>
</tr>
</tbody>
</table>
I. Voluntary Share/Response: Did anyone choose one or more of the thoughts below and compose a written response to it:

“I’ll tell you a great secret, my friend. Don’t wait for the Last Judgment. It happens every day.”
~Albert Camus

“Those who live are those who fight.” ~Victor Hugo

“Recovery of soul and recovery of the health of the body may occur together or not; healing may occur, and the body may not survive.” ~Jean Shinoda Bolen

II. Warm-up: Think through your life and see if you can perceive the pattern that ties it together. As you look at the pattern of your life story, write down your thoughts to the following questions:

- If you could relive one event in the story of your life, what would it be?
- Which year would you choose as the best year of your life? Why?
- If you could change any part of your life story, what would you change?

Share your ideas, if you wish . . .

III. Writing Activity: What I’d like to do over again
Another way to gain insight into your life story is to return in your memory to one special year, a very good year. Revisit its bright moments, pull it from your memory bank, and renew its joy:

- What was that year? ______________
- Why was it special?
- Suppose you had one last message to leave to the handful of people who are most important to you. What would it be in twenty-five words or less?
- Of all the things you have done in your life, which is the one you would be most likely to undo?
- Which is the one that makes you happiest to remember?

Share your ideas, if you wish . . .

III: Writing Reflection

- Story theologian John Shea has said, “whenever our biographies are deeply probed, a root metaphor appears which gives unity and meaning to our lives.” How would you describe the root metaphor “which gives unity and meaning” to your life?
- As you try to define the “root metaphor” of your life, how would you write your own epitaph? Try it in your journal right now.

IV: Something to work on, if you wish . . .

If I hadn’t been born . . .

Ideas borrowed from Remembering your Story: Creating Your Own Spiritual Autobiography by Richard L. Morgan. Nashville: Upper Room Books, 2002 (pp. 32-33; 144-146)
Session #6

“I have sometimes been wildly, despairingly, acutely miserable . . . but through it all I knew quite certainly that just to be alive is a grand thing.” ~Agatha Christie

I. How did you do with your response to the topic: “If I hadn’t been born . . .”?  

Would anyone like to read or share what you wrote?

II. Warm-up activity: Is there a song, verse, or melody that seems to pop up (or that you have chosen for different occasions) at different times in your life?

Several weeks ago, we selected a certain color that “best” described us; last week, we attempted to write a metaphor that defined our lives. Now, think of a song, verse, or melody that you have heard (or perhaps have chosen to hear or have performed) at key times in your life. What, specifically, is it about that song, verse, or melody that has inspired, defined, or moved you, or somehow caught your attention? In what way does it reflect who you are and what “you’re about”?

III: Writing Activity

Directions: Think of three qualities that you value in yourself or in other people, and in a journal entry, briefly explain why you think that they are important. Next, think of a situation when you had to make use of one of those qualities.

1. What was the situation, and where did it take place?
2. Describe the setting. Who was there and what was happening?
3. How were you involved, and what did you do?
4. How did other people react to the situation?
5. How did you feel immediately afterwards.

Finally: Looking back on the situation, how do you feel now about what you did?

Discussion and sharing, if you choose . . .

IV. Something to work on, if you choose: When mental strength surpasses physical strength

Directions: There are some days when our illness, treatment, physical or emotional limitations make it difficult for us to just get out of bed or do the simplest of activities. Consider such a day in your past (perhaps you’ve had one recently), and respond in your journal to any or all of the following:

- I sought solace in doing these things . . .
- These books or music provided solace and inspiration to me . . .
- I have found the will to get through difficult periods with these routines . . .
- When I need inspiration to get through a day, I . . .

Session #7

I. How did you do with your response to the topic “When mental strength surpasses physical strength”?  

Last week we ended our session by discussing how there are some days when our illness, treatment, physical or emotional limitations make it difficult for us to just get out of bed or do the simplest of activities. Were you able to consider such a day in your recent past and respond in your journal to any or all of the following?

I sought solace in doing these things . . .
These books or music provided solace and inspiration to me . . .
I have found the will to get through difficult periods with these routines . . .
When I need inspiration to get through a day, I . . .

II. Warm-up activity: Making lists

1. Make a list of what you have control over. Another list of what you can’t control.
2. Make a list of what you need—more clothes; more love, or whatever. Make a list of what you have.
3. Make a list of things you can’t do. Make another list of things you can do.

III: Writing Activity

Readings to reflect on (p. 71) . . .

Directions: Start with the words: “This is all a bad dream . . . .” and write for 5-7 minutes. Write about the ways in which you deny what’s happening with your body. Or your loved one’s body.”

Another reading to reflect on (p. 72) . . .

Directions: Write about the brick wall in your life. Write about a visit you’ve had recently with the doctor. Try writing in the third person. Sometimes when you write about he or she instead of I there’s more distance, a slightly different view.

Write about the strangest, weirdest theory you’ve had about you or your loved one’s illness or accident. Start with the words “There’s been a mistake . . . ,” and write a journal entry

Discussion and sharing, if you choose . . .

IV. Something to work on, if you choose:

Directions: Read the following poem written by Lucille Clifton; then, write a journal entry reflecting on its relationship to your illness or to your loved one’s illness.

\[
\text{I was leaving my fifty-eighth year} \\
\text{when a thumb of ice} \\
\text{stamped itself hard near my heart} \\
\text{you have your own story} \\
\text{you know about the fear the tears} \\
\text{the scar of disbelief}
\]
you know that the saddest lies
are the ones we tell ourselves
you know how dangerous it is
to be born with breasts
you know how dangerous it is
to wear dark skin

I was leaving my fifty-eighth year
when I woke into the winter
of a cold and mortal body

think icicles hanging off
the one mad nipple weeping
have we not been good children
did we not inherit the earth

but you must know all about this
from your own shivering life

Lucille Clifton “1994”
Session #1

Some Rules for Our Writing Community

1. Do your best to arrive on time.
2. During workshop time, try to stay within the time parameters of each writing exercise. If you would like to continue working on something, or would like more individual feedback on something you’ve written, I will be happy to stay for additional writing consultation after our workshop time.
3. Be respectful of everyone’s comments, opinions, and of any writing they choose to share.
4. Be accepting when someone chooses not to share something they have written. (Just say “pass.”)
5. Try to remain silent during writing time; it’s important to allow people to concentrate.
6. Respect the privacy of our writing community. Please do not share what people write about or discuss outside of our writing community, unless you have their express permission.
7. Any other comments?
I. Warm-up activities

a. True or False?

Directions: Write down three facts about yourself that are true and one that is not true (use one index card per each “fact”). Now, swap with the person to your left and see if you can both identify the untrue fact in each others’ lists.

b. I am and I like

Directions:
1. Write one sentence that begins “I am . . .” and that describes something about who you are.
2. Now write one sentence that begins “I like . . .”
3. Now write four lines that use all the words you have used in any order that you like.
4. Now repeat the first two lines (“I am . . . and I like . . .”)

II. Getting Started

Special Place

Think of a place that you were particularly fond of and that was important to you in the past (could be a town, village, home, etc.). Pretend you are there . . .

   a. Describe this place. What year was it?
   b. How long has it been since you were there?
   c. What kind of landscape is this place in?
   d. Can you remember any special aromas or smells that you always associate with this place?
   e. How do you feel when you are there?
   f. What kind of weather do you associate with this place?
   g. Are there any buildings that you should describe?
   h. Are there any special people that you associate with this place?
   i. What were the circumstances surrounding how you came to this place (summer vacation, family home, etc.)?
   j. Can you think of any special words or conversations that were spoken at this place?
   k. What made this place special?

III. Something to work on . . . if you choose:

A Perfect Day

Warm-up: Write down your favorite place, your favorite mind of music, your favorite company, your favorite food, and your favorite drink.
Directions: Pick out one perfect day in your life. You can incorporate your responses to the above if you chose, but don’t have to. Try to remember . . .

1. Where were you?
2. What could you hear?
3. Was anyone with you?
4. What did you eat and drink?
5. What about the day made it special?
6. Can you remember any conversations or any words that were said?
7. How did the day end?

Session #2

I. Warm-up activity:

   a. “Road Not Taken,” Robert Frost
   b. Response/Reaction: Does your life have a “road not taken”?

II: Gentle journey through the past

Directions: Choose one or more of these idea starters* and freewrite for 15 minutes. If you reach a writer’s block, choose another topic, skip to the next page and begin again with the new topic. You may approach this list sequentially or pick and choose the ones you prefer.

   a. I was born on [insert month, day, year] in [insert location, city/town, etc.]
   b. About my birth, my mother always told this story . . .
   c. My earliest memory is . . .
   d. My past set the stage for my present life by . . .
   e. My past taught me . . .
   f. My past gave me . . .
   g. When I think about my past, I . . .
   h. About myself, my past has taught me . . .

*Or, simply begin writing about a topic of your choice.

III: Voluntary share and response, if you choose.

IV. Looping: Look back over something you’ve written, either today, last week, or much earlier. Find a sentence or phrase that stands out for you. Write it down and use it as the starting point for a new entry.** Consider responding to any questions/feedback you may have received.

** Or, continue at your own pace with the last section you were writing.

V. Some things to think about:

   Is there a theme in anything you’ve written? Do you see your past as a powerful tool or something to get away from?
Was it difficult to find answers to these questions or to complete the sentences? Were all your answers meaningful to you? What have you learned about yourself as a result of what you’ve written today?

VI. Something to work on, if you choose:

If you have the time/desire during this next week:
1. Choose another sentence or phrase that stands out to you and use it as a starting point for a new section.
2. Continue with what you were writing, or choose a new idea starter and respond.

Ideas borrowed/modified from The Healing Journey through Retirement by Phil Rich et al. 2000.

Session #3

I. Did anyone use the “looping” technique to write anything this past week that they’d like to share? Even if you didn’t use looping, have you written anything you’d like to share? Did anyone use another idea starter from last week’s list of idea starters?

II. Warm-up activity: Pastimes

c. On a slip of paper, write about the most unusual thing that ever happened to you in the past; or about an unusual interest that you have now, or have had in the past. [Be aware that we’ll be sharing these aloud.]

d. Fold the slip of paper, and place it in the middle of the table.

e. Choose a folded sheet of paper, read its contents aloud.

f. As a group, let’s try to figure out which scenario belongs to whom!

III. Writing Activity

Directions: Choose one of the following,* and freewrite for 15 minutes.

i. Think of a pastime that was important to you as a young child or teenager:
   a. How old were you?
   b. How did you first become interested in this pastime?
   c. Describe what it involved, and how you spent your time.
   d. Did this pastime involve any specialist equipment, magazines or books?
   e. If so, were you given them as presents, or did you have to buy things to support your interest?
   f. Did this pastime involve anyone else? Or did you pursue it on your own?
   g. What was your greatest achievement or most enjoyable moment pursuing this pastime?

j. Think of someone from your childhood or teenage years who was a very good friend to you.
   a. How old were you?
   b. Describe this person. What did he or she look like? What did they sound like?
   c. How did it happen that they became your friend?
   d. How did they make you feel?
e. What were some of the activities that the two of you did together?
*Or, simply begin writing about a topic of your choice.

IV: Voluntary share and response, if you choose.

V: Development: Look back over either topic you wrote about today.**
a. If you chose topic #1, respond to the following:
   i. Looking back, do you think that this pastime was the start of any life-long interest or pursuit? Did it pave the way for you to meet anyone special in your life?
   ii. Looking back on it, why do you think that this was an activity you particularly enjoyed at the young age you first engaged in it?
b. If you chose topic #2, respond to the following:
   i. When was the last time you saw this person?
   ii. Do you know what became of this person? Or, if not, what do you imagine became of them?
   iii. What would you like to say to this person now if you met them?

____________________________________
Ideas borrowed/modified from Writing Well: Creative Writing and Mental Health by Debra Philips et al. 1999.
Session #4

I. Voluntary share and response of last week’s entries, if you choose. Reminder of the topics:
   c. If you chose topic #1, respond to the following:
      iii. Looking back, do you think that this pastime was the start of any life-long interest or pursuit? Did it pave the way for you to meet anyone special in your life?
      iv. Looking back on it, why do you think that this was an activity you particularly enjoyed at the young age you first engaged in it?
   d. If you chose topic #2, respond to the following:
      i. When was the last time you saw this person?
      ii. Do you know what became of this person? Or, if not, what do you imagine became of them?
      iii. What would you like to say to this person if you encountered him or her today?

II. Warm-up activity: Pastimes

   g. On the sheet of paper provided, respond in one or two sentences to the prompt at the top of the page.
   h. Next, pass the sheet of paper to the person to your left. That person should add one or two more sentences.
   i. We will continue this for two rounds and then share our (disastrous? unique? hilarious?) narratives aloud!

III: Writing Activity

   Directions: Choose another one of the following, or continue with one of the topics you began either last week or during week two.

   1. Think of a pastime that was important to you as a young child or teenager:
      f. How old were you?
   g. How did you first become interested in this pastime?
   h. Describe what it involved, and how you spent your time.
   i. Did this pastime involve any specialist equipment, magazines or books?
   j. If so, were you given them as presents, or did you have to buy things to support your interest?
   k. Did this pastime involve anyone else? Or did you pursue it on your own?
   l. What was your greatest achievement or most enjoyable moment pursuing this pastime?
   k. Think of someone from your childhood or teenage years who was a very good friend to you.
      a. How old were you?
       b. Describe this person. What did he or she look like? What did they sound like?
       c. How did it happen that they became your friend?
       d. How did they make you feel?
       e. What were some of the activities that the two of you did together?

l. I was born on [insert month, day, year] in [insert location, city/town, etc.]
m. About my birth, my mother always told this story . . .

n. My earliest memory is . . .

o. My past set the stage for my present life by . . .

p. My past taught me . . .

q. My past gave me . . .

r. When I think about my past, I . . .

s. About myself, my past has taught me . . .

IV: Voluntary share and response, if you choose.

V. Discussion: Is anyone interested in focusing on one of their stories to expand it and work to compile a collaborative booklet of stories representative of our workshop. We could make this book available for the Swan Creek community or just provide each workshop member with a commemorative copy. Feedback/thoughts on this?

Writing Warm-up #1:

One day I was thinking . . . .

Writing Warm-up #2:

It was an empty street, but then . . .

Writing Warm-up #3:

That day I made a decision . . .
Session #5

I. **Voluntary Share/Response** of any writing you’ve accomplished and haven’t yet shared.

II. **Warm-up activity: Special Quotations**

"It is never too late to be what you might have been." ~George Eliot

“There are only two ways to live your life. One is as if nothing is a miracle, and the other is as if everything is a miracle.” ~Albert Einstein

“Whatever you can do, or dream you can, begin it. Boldness has genius and power and magic in it.” ~Goethe

III. **Writing Activity**

**Directions:** Choose another one of the following, or continue with one of the topics you began either last week or during week two.

- t. Write a timeline of your life
- u. Create a memory list
- v. Create a list of “themes” of your life.

Now, select from one of the topics that came to mind, and immediately start writing a short passage that “colors in” some aspect of this part of your life. Make the colors vivid by describing the situation, the people present, adding some dialogue, etc. per our handout! *If you have time, continue to develop this passage throughout the following week, or choose another memory or theme and begin writing again!*
_________________________’s List of Special Memories

1. __________________________________________________

2. __________________________________________________

3. __________________________________________________

4. __________________________________________________

5. __________________________________________________

6. __________________________________________________

7. __________________________________________________

8. __________________________________________________

9. __________________________________________________

10. _________________________________________________
Session #6

I. Voluntary Share/Response: Did anyone try a narrative essay about the pivotal moment you considered during our writing time last week? What dialogue and specific details have you worked on? Even if you haven’t, would anyone like to share something they’ve written since last time we met?

II. Over the past couple weeks we have focused on writing down details of our lives. This is called autobiography. You may have started writing about a particular event or time period in your life. Now, look at your past through a different lens. Pick a different day or time period. Describe your life in any way you want. You can describe your whole life, an interval in your life, or a single incident. You can shape your autobiography on a theme or you can try a free-flowing autobiography; however, be sure to pick none of the same material described in your previous autobiographical entries.

Share your ideas, if you wish . . . .

III: Writing Activity

2. If you currently have ideas for a narrating a pivotal moment in your life, think about the memorable people in your life and decide which one(s) you wish to focus on in this particular moment:
   f. Why was/were this person or people significant to you?
   g. What role did they play in supporting or hindering this pivotal moment of your life?
   h. Given that role, which of their traits, mannerisms, and actions might you include in your account?
   i. Could you develop this person or people through dialogue? If so, where might you use dialogue in your account?
   j. Could you develop this person or people through a collage of representative scenes? If so, what scenes will you choose to emphasize?

2. Picture in your mind (or look at an actual picture) of the person or people you thought of above. Now, imagine this person in a setting that reveals his or her significance—in a kitchen baking a pie, on the front steps of a porch laughing with neighbors, in an open field running barefoot, in the back yard working on an old engine, in a crowded office standing by the water cooler. Picture a photograph (or look at a photograph) of this person in that setting. Freewrite about your description of that photograph.

Share your descriptive freewriting, if you choose . . . you might discuss how this text could be used in a larger autobiographical narrative, or in an expanded version of the pivotal moment you’ve been considering during this session.

IV: Something to work on, if you wish . . . .

Write a narrative essay about the pivotal moment you’ve been considering during this session. Try to get at the larger significance of this moment. Use dialogue and specific details about setting and people to create a memorable recollection.
Pivotal Moments in Life

To help you recognize events in your life that you might be interested in recording, consider the following list of “pivotal moments”:

- **Moments of enlightenment or coming to knowledge:**
  Consider the first time you
  - understood a complex idea
  - understood what is meant by love or jealousy or justice
  - mastered a complex skill
  - saw some truth about yourself or your family that you previously hadn’t seen

- **Passages from one realm to the next:**
  From
  - innocence to experience
  - outsider to insider or vice versa
  - child to adult
  - novice to expert
  - what you once were to what you now are

- **Confrontations**
  - with the unknown (OR)
  - with people or situations that challenged or threatened your old identity and values

- **Moments of crisis or critical choice** that tested your character or your system of values

- **Problems accepting limitations and necessities**
  Such as the
  - loss of dreams
  - death of intimates
  - failure to live up to ideals
  - difficulty of living with a chronic illness or disability

- **Contrasts between conventional wisdom and your own unique knowledge or experience:**
  - doing what people said couldn’t be done
  - failing at something others said was easy
  - finding value in something rejected by society
  - finding bad consequences of something widely valued

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This information was adapted from *The Allyn and Bacon Guide to Writing, 3rd ed.* By Ramage, Bean, and Johnson. Pearson/Longman 2003.
Session #7
When I write down my thoughts, they do not escape me. This action makes me remember my strength. ~ Isidore Ducasse

I. Voluntary Share/Response: Did anyone try a narrative essay about the pivotal moment you considered during our writing time last week? What dialogue and specific details have you worked on? Even if you haven’t, would anyone like to share something they’ve written since last time we met?

II. Warm-up: Use 10 minutes to respond in writing to one or all of the following questions. To encourage honest self-reflection, we will not be sharing our responses to the following:

- Look back at the autobiographical pivotal moment you have written about so far. What does it say about you? Does it offer an optimistic, upbeat view of who you are? Does it reflect a sense of high self-esteem, low self-esteem, indifference or detachment?
- Did you discover anything important about yourself? Does your pivotal moment autobiographical information somehow reflect how you feel about yourself in general?
- Was the mood reflected in your writing determined or shaped by events in your present life?

III. Writing Activity: Another 15-minute Autobiography
Over the past couple weeks, we have focused on writing down “pivotal moments” or significant details of our lives. This type of writing is called autobiography. You may have started writing about a particular event or time period in your life. Now, look at your past through a different lens:

- Pick a different day or time period.
- Describe your life in any way you want. You can describe your whole life, an interval in your life, or a single incident. You can shape your autobiographical narrative on a theme, or you can try a free-flowing story.
- For an idea about which to write, feel free to consult your pivotal-moments, timeline, special memories, or life-themes worksheets; however, be sure to pick none of the same material described in your previous autobiographical entries.
- Take five minutes to think/plan and ten minutes to write.

Share your ideas, if you wish . . . .

III: Writing Reflection

- How is this second pivotal moment/autobiographical narrative different from the first one?
- Why is this pivotal moment/autobiographical narrative different?
- Would people reading the two narratives realize they were reading about the same person? How?
- What influenced your choice of material or style for this piece of writing?
IV: Something to work on, if you wish . . . .

- How are your two pivotal moments/autobiographical narratives related? Together, taken as a whole, what do they say about you as a person?
- Was it difficult or simple to write this second pivotal moment/autobiographical narrative?
- Did you discover anything different about yourself?
- Have you learned anything about yourself by writing these pivotal moments/autobiographical narratives? During the next week, could you write another 15-minute pivotal moment/autobiographical narrative?

Ideas borrowed/modified from The Healing Journey through Retirement by Phil Rich et al. 2000 (pp. 235-42).

Session #8

When I write down my thoughts, they do not escape me. This action makes me remember my strength.

~ Isidore Ducasse

I. Voluntary Share/Response: Did anyone work any further on a story about a second pivotal moment you considered during our writing time last week? How are your two pivotal moments/autobiographical narratives related? Together, taken as a whole, what do they say about you as a person? Was it difficult or simple to write this second pivotal moment/autobiographical narrative? From writing this second narrative, did you discover anything different about yourself? Have you learned anything about yourself by writing these about these two pivotal moments?

II. Warm-up: Think through your life and see if you can perceive the pattern that ties it together. As you look at the pattern of your life story, write down your thoughts to the following questions:

- If you could relive one event in the story of your life, what would it be?
- Which year would you choose as the best year of your life? Why?
- If you could change any part of your life story, what would you change?

Share your ideas, if you wish . . . .

III. Writing Activity: What I’d Like To Do Over Again

Another way to gain insight into your life story is to return in your memory to one special year, a very good year. Revisit its bright moments, pull it from your memory bank, and renew its joy:

- What was that year? ___________
- Why was it special?
- Suppose you had one last message to leave to the handful of people who are most important to you. What would it be in twenty-five words or less?
- Of all the things you have done in your life, which is the one you would be most likely to undo?
- Which is the one that makes you happiest to remember?

Share your ideas, if you wish . . . .
IV: Writing Reflection

- Story theologian John Shea has said that “whenever our biographies are deeply probed, a root metaphor appears which gives unity and meaning to our lives.” How would you describe the root metaphor “which gives unity and meaning” to your life?
- As you try to define the “root metaphor” of your life, how would you write your own epitaph? Try it in your journal right now.

V: Something to work on, if you wish . . .

If I hadn’t been born . . .

CONFRONTING SERIOUS ILLNESS AND INJURY THROUGH JOURNALING: A STUDY OF WRITING AS THERAPY

Protocol:
SVMMC IRB No.: 0705103

Research Personnel
Debra Ross, BSN, RN, OCN 419-251-5897
Lucie Shetzer 419-308-3454

Purposes of an Informed Consent Form
- To tell you what this research is trying to find out
- To tell you what your part in this research will be
- To tell you if the research is different from your normal medical care
- To tell you about the risks and/or discomforts that could happen to you during this research
- To tell you if you might benefit from taking part and what the benefit might be
- To tell you of other choices you have and if they are better or worse than being in this research
- To tell you that you can ask questions about this research before saying yes to take part
- To tell you that you ask questions during this research
- To tell you that you can say no and not take part in the research
- To tell you that you can change your mind and stop taking part in the research after it starts
- To tell you what medical treatment is on hand if any problems happen

1. Purpose of the Research

You have been asked to take part in a research project. The purpose of the research is to find out if patients and/or families feel better when they write about their experience with illness or injury. There will be 20 persons in this research from St. Vincent Mercy Medical Center and 50 nationally.
2. Procedures of the Research

The following details will help you decide whether to participate in this research project. **You must be at least 18 years old to participate in this project.** Participation is voluntary and will in no way affect any of the medical care you are receiving. The research will take place during the fall of 2005. Before the journaling workshops and online journaling activities begin, we will be privately interviewing those who agree to participate in the research portion of the project about the impact of their illness (or their family member’s illness); We will also ask questions about the ways participants cope with their illness and treatment. Once our workshops and online journaling activities are completed, we will re-interview participants about these issues to learn what specific affects (if any) the journaling workshop may have had. These interviews will be conducted under your alias and audio-taped so that we can refer to them as we study the information; once the project is complete, I will retain the audiotapes, which may be used in future research; however, we will at all times maintain your privacy and anonymity. We would also like to study the specific writing samples that are produced by individual group members. Specifically, we will be asking for participation in:

- a pre-workshop interview
- a post-workshop interview
- a six- to eight-week workshop
- follow-up weekly postings to a private online journaling site
- use of journal writing and/or posts within our private online journaling (online journal)
- use of compilation of anecdotes that may be produced by a group
- a post-program anonymous questionnaire requesting general retrospective feedback about the overall value of the therapeutic writing program, interest in its continuation, and suggestions for improvements.

Although you do not need to participate in the online journaling activities of the project, should you decide to use the online journaling, you will not need any special software or hardware other than Internet access. If you do not have Internet access, or do not wish to use an online journaling site, you are still encouraged to participate in the workshops, follow-up weekly journaling, interviews, and questionnaire. In this case, you can use traditional pen and paper to complete the journaling.

During the fall, we anticipate that each participant will spend approximately:

- 30 minutes in a one-time private pre-interview
- 30 minutes in a one-time private post-interview
- 45 minutes to 1 hour in the 6-8 weekly workshops
Time spent on follow-up (between-workshop) online journaling or pen and paper journaling activities will be at the discretion of each participant, but an ideal weekly writing commitment would be 15-20 minutes 4-5 days per week.

We will request your permission to look at your journal writing, online journal postings and/or group anecdotal compilations. You will be asked to complete and return, by email or via a postage-paid envelope, an anonymous, post-program questionnaire survey to assist me in summative evaluation of this program. We plan to give each participant in this research study an alias to protect privacy, and any reference to an individual’s writing or interview responses will be cited under the individual’s alias, unless that person notifies me in writing that he or she wishes to be identified by his or her real name.

3. **Risks of the Research.**

Please understand that although there are few, if any, risks associated with this research project, writing about painful experiences may emotionally upset you. There may also be unexpected risks that are currently not known.

Please tell the person explaining this research about any medical problems or concerns you have.

4. **Benefits of the Research**

*You may feel better after writing about stressful events. After you write about these events, you may learn things about how you deal with illness and stress that will help you with future situations.*

5. **Confidentiality**

Deb Ross, Lucie Shetzer, and St. Vincent Mercy Medical Center will treat your personal information with professional standards of confidentiality. Information that identifies you by name will be confidential, to the extent permitted by Federal, State, and Local law. Authorized representatives of regulatory and oversight agencies (St. Vincent IRB) may be granted access to and copy records containing your personal information when necessary for them to perform their official duties. The results of the research may be published, but you will not be mentioned by name.
6. Information about the Research

This research has been explained to you by ______________________ (name of person obtaining informed consent). She has offered to answer all of your questions. You may contact Lucie Shetzer at 419-308-3454 if you have more questions or concerns.

7. Stopping the Research

You can stop being in this research at any time. If you choose to stop, this decision will not change your current or future medical care with St. Vincent Mercy Medical Center or its affiliates. If you would decide to stop participating, you would need to inform one of the investigators. You will be told of any new findings that may change your willingness to continue taking part in this research.

8. Alternative to Participation

Alternatives to participation include continuing to write about your experience with illness in a journal. You may have the same benefit as those who participate in the research portion of the project.

9. Voluntary Participation

You do not have to be in this research. If you refuse, this decision will not change your current or future medical care by the investigator(s) or St. Vincent Mercy Medical Center or its affiliates.

10. Costs to You

There will be no additional costs to you or your insurance company for participating in this research.
11. Payments to You
There will be no payment for participating in this research.

12. Payments to Investigators
There is no payment to the investigators for conducting this research.

13. Research-Related Injuries
If an injury happens because of your taking part in this research, medical treatment is available. If you or the investigator see that the research is causing excessive emotional upset, you will be offered a referral to “Families Coping with Cancer” support services. Neither St. Vincent Mercy Medical Center, nor the investigators, has set aside any money for payment of medical costs, lost wages, and/or direct or indirect losses.

14. Research Subject’s Rights
If you have any questions about your rights as a research subject, you may contact Ellen W. Bernal, Ph.D., Chair of the St. Vincent Mercy Medical Center Institutional Review Board through the Research Oversight & Education Department at (419) 251-3585.

15. Authorization for Release of Protected Health Information
Federal law requires that you must specifically authorize release of protected health information for research purposes.

I hereby authorize St. Vincent Mercy Medical Center, the principal investigator, the research sponsor and others affiliated with the Research Protocol to have access to use and disclose protected health information about me. I understand that the information to be disclosed may include information normally not subject to disclosure, including information concerning sexually transmitted disease, acquired immunodeficiency syndrome (AIDS), or human immunodeficiency virus (HIV). It may also include information about behavioral or mental health services, and treatment for alcohol and drug abuse. I’m authorizing this disclosure for the purpose of clinical research.
I understand that I have the right to revoke this authorization, in writing, at any time by presenting my written revocation to any representative connected with the Research Protocol. I understand that the revocation will not apply to information that has already been released under this authorization. I understand that the revocation will not apply to my insurance company when the law gives my insurer the right to contest a claim under my policy. Unless otherwise revoked, or unless I give the research sponsor greater access to my protected health information, this authorization will expire at the end of the research.

I understand that authorizing the disclosure of this health information is voluntary, I can refuse to sign this authorization, however, I understand that I will not be allowed to participate in the research unless I authorize the use and disclosure of the above information for such research. I understand that I may inspect or copy the information to be used or disclosed, as provided in CFR 164.524. I understand that any disclosure of information carries with it the potential for an unauthorized re-disclosure and the information may not be protected by federal confidentiality rules. If I have questions about the disclosure of my health information, I can contact Heather Doll-Hinton, Mercy Health Partners’ Privacy Officer at (419) 251-3375.

I also understand that the research sponsor may require me to sign a separate authorization to use my protected health information. Separate research sponsor authorizations are neither reviewed nor approved by the St. Vincent Mercy Medical Center or its Institutional Review Board, a committee set up to safeguard the rights of patients. I understand that if I sign a separate authorization with the research sponsor and it gives the research sponsor different access to use my protected health information than I have agreed to here, whichever authorization gives greater access to use my protected health information will be followed.

16. Permission to Participate
- By signing this form, I do not give up any of my legal rights.
- My participation in this research is voluntary.
- I may stop being in this research at any time.
- A copy of this consent form will be given to me.
- I agree to be in this research.
Please place an “X” in the box next to each level of this research in which you are willing to participate:

- **Private, individual pre-interview**

If you agree to this section of the research study, you will be interviewed prior to the first workshop during the fall of 2005. This interview will be audiotaped to assist me in follow-up transcription and accurate representation of your comments. Once this project is complete, I will retain the audiotapes, which may be used in future research; however, at all times your privacy and anonymity will be maintained.

- **Private, individual post-interview**

If you agree to this section of the research study, you will be interviewed during the week following our final workshop during the fall of 2005. This interview will be audiotaped to assist in follow-up transcription and accurate representation of your comments. Once the project is complete, the audiotapes will be retained, which may be used in future research; however, at all times your privacy and anonymity will be maintained.

- **Participation in six to eight 45 minutes to 1 hour weekly writing workshops.** At these workshops, we will use first names or aliases only to protect participants’ anonymity and privacy.

- **Online journal postings**

If you agree to this section of the research study, an online journaling account will be created for you through “blogger.com” where you can complete your between-workshop journal entries. Although you are encouraged to use first names or aliases only to protect your anonymity and privacy, because online journals are automatically indexed by search engines, they may be accessible to anyone using a search engine.

**Please check one:**

- Please create an alias when referring to my online journaling samples.
- Please use my first name only when referring to my online journaling samples.
- You may use my actual first and last name when referring to my online journaling samples.
- **Journal Writing Samples**
  If you agree to this section of the research study, I will ask to copy (at my expense) your journal writing, and/or your online journaling entries at the end of our 6-8 week session.

  *Please check one:*
  - Please create an alias when referring to my writing samples.
  - Please use my first name only when referring to my writing samples.
  - You may use my actual first and last name when referring to my writing samples.

- **Post-program questionnaire survey (anonymous)**
  If you agree to this section of the research study, this questionnaire will be handed out to you after our final workshop meeting with a stamped, addressed envelope to return it to me.

**Signatures**

---

Name of Subject: (Print Name)

__________________________  ____________________________
Signature of Subject  Date  Time

__________________________  ____________________________
Name of Person Obtaining/Explaining Consent: (Print Name)  am /pm
Signature of Person Obtaining/Explaining Consent  Date  Time
(If not the principal investigator.)

__________________________  ____________________________
Signature of Principal Investigator  Date  Time
{Legally Authorized Representative – In the event that the subject is unable to consent for himself or herself, use the following.

45 CFR §46.102(c) and 21 CFR §50.3(l) define legally authorized representative as an individual or judicial or other body authorized under applicable law to consent on behalf of a prospective subject to the subject’s participation in the procedure(s) involved in the research.

If the subject is unable to make their own decision due to their current medical condition or an underlying condition that prevents them from expressing their understanding of and approval or disapproval of their participation in this research, then the Institutional Review Board, in its discretion, may allow a legally authorized representative to give permission for the subject to participate. Department of Health and Human Services and U. S. Food and Drug Administration’s definition of legally authorized representative defers to state law with respect to who is able to consent for an individual to participate in a research when they are unable to consent for themselves. However, Ohio law does not specifically address consent in the research context.

Therefore, it is recommended that when a subject is unable to consent for themselves AND the Institutional Review Board has determined that it is appropriate to enroll such subjects in a research trial, the principal investigator should follow the hierarchy of individuals listed below when determining the legally authorized representative.

1. An attorney-in-fact, if the subject has executed a durable power of attorney for health care decisions.
2. A guardian, if the subject is a minor (under age 18) or has been adjudged incompetent.
3. Subject’s spouse.
4. Adult child of the subject, or if there is more than one adult child, a majority of the subject’s adult children who are available within a reasonable period of time for consultation with the subject’s attending physician.
5. The subject’s parents.
6. An adult sibling of the subject, or if there is more than one adult sibling, a majority of the subject’s adult siblings who are available within a reasonable period of time for such consultation.

Legally Authorized Representative

I am legally authorized to, and do, give my permission for:

_______________________________________________

Name of Subject  (Print Name) to participate in this research.

______________________________________________

Name of Legally Authorized Representative  (Print Name)

_______________________________________________

Relationship to Subject  
(Parent, Guardian, Spouse, Durable Power of Attorney)

_______________________________________________

Signature of Legally Authorized Representative  _____________ am /pm

Date  Time

Witness  {Use only if required by the IRB.}

_______________________________________________

Name of Witness:  (Print Name)

_______________________________________________

Signature of Witness  _____________ am /pm

Date  Time
My name is Lucie Shetzer, and I am a third year graduate student in the English Department at Bowling Green State University. I am currently working on the dissertation project for my Ph.D., which focuses on journal writing for adults who are themselves experiencing life changes or serious illness or injury, or who are caring for a seriously ill or injured family member. I also plan to study how writing about the stages of one’s life and one’s life experiences can enrich the lives of senior adults. This project will be based on research that supports the positive benefits of journal writing. Please understand that although there are no risks associated with this workshop project, your participation is completely voluntary.

Because I also work in the health care field as a physical therapist assistant, I have come to believe that more non-medical options are needed to support the emotional needs of people experiencing new phases in their lives or the serious illness or injury of a loved one. As a result, I am hoping that this writing workshop will meet a real need in your retirement community and will encourage participants to record and share their valuable life experiences. As a volunteer in this informal workshop, you can expect to benefit from structured workshop environments that encourage self-exploration and self-expression through journal writing; you will also benefit from the companionship of a writing community. However, your participation is completely voluntary, and your relationship to any members of your retirement community who may have recommended you for this program will not be affected in any way by your decision to participate or not participate. Replying to this informed consent either immediately after this presentation, by email, or by U.S. mail will indicate that you are willing to participate. You have the right to withdraw your participation at any time during this research.

The following details will help you decide whether to participate in this journaling workshop. You must be at least 18 years old to participate in this workshop. My research will take place during the fall 2005 semester [specific dates to be entered here when decided upon]. During our workshops, we will use reflective writing techniques to further explore experiences and create a community collection of stories and narratives. However, before we start journaling workshops and online journaling activities, I will be privately interviewing participants about their writing habits, their leisure activities and any stressors in their lives, including personal experience with illness or injury; I will also ask questions about the ways participants cope with their stressors. Once our workshops and online journaling activities are completed, I will re-interview participants about these issues to learn what specific affects (if any) the journaling workshop may have had. These interviews will be conducted under your alias and
audiotaped so that I can refer to them as I write my dissertation; once my project is complete, I will retain the audiotapes, which I may use in future research; however, I will at all times maintain your privacy and anonymity. I would also like to study the specific writing samples that are produced by individual group members. Specifically, I will be asking for participation in:

- a pre-workshop interview
- a post-workshop interview
- a six- to eight-week workshop
- follow-up weekly postings to a private online journal site
- use of journal writing and/or posts within our private online journal site
- use of the collection of stories that may be produced by a group
- a post-program anonymous questionnaire requesting general retrospective feedback about the overall value of the therapeutic writing program, interest in its continuation, and suggestions for improvements.

Although you do not need to participate in the online journal activities of the project, should you decide to use the online journal, you will not need any special software or hardware other than Internet access. If you do not have Internet access, or do not wish to use an online journal site, you are still encouraged to participate in the workshops, follow-up weekly journaling, interviews, and questionnaire. In this case, you can use traditional pen and paper to complete the journaling.

During the fall, I anticipate that each participant will spend approximately:

- 30 minutes in a one-time private pre-interview
- 30 minutes in a one-time private post-interview
- 45 minutes to 1 hour in the 6-8 weekly workshops
- Time spent on follow-up (between-workshop) online journal or pen and paper journaling activities will be at the discretion of each participant, but an ideal weekly writing commitment would be 15-20 minutes 4-5 days per week.

I will request your permission to look at your journal writing, online journal postings and/or group story collections. You will be asked to complete and return, by email or via a postage-paid envelope, an anonymous, post-program questionnaire survey to assist me in overall evaluation of this program. I plan to give each participant in this research study an alias to protect privacy, and any reference to an individual’s writing or interview responses will be cited under the individual’s alias, unless that person notifies me in writing that he or she wishes to be identified by his or her real name.
I will use the information from this research to write my dissertation, which will fulfill my requirements for graduation. I also intend to use this research in future conference proposals and presentations and in possible publications. I will share the results of this research with interested faculty and participants. However, I will at no time divulge the real names of participants and their writing unless they expressly permit me to do so through written consent. If you are interested in this research, you may contact me after my dissertation is completed.

Please place an “X” in the box next to each level of this research in which you are willing to participate:

- **Private, individual pre-interview**
  If you agree to this section of the research study, I will interview you prior to the first workshop during the fall of 2005. I plan to audiotape this interview to assist me in follow-up transcription and accurate representation of your comments. Once my project is complete, I will retain the audiotapes, which I may use in future research; however, I will at all times maintain your privacy and anonymity.

- **Private, individual post-interview**
  If you agree to this section of the research study, I will interview you during the week following our final workshop during the fall of 2005. I plan to audiotape this interview to assist me in follow-up transcription and accurate representation of your comments. Once my project is complete, I will retain the audiotapes, which I may use in future research; however, I will at all times maintain your privacy and anonymity.

- **Participation in six to eight 45 minutes to 1 hour weekly writing workshops.** These workshops will be made up only of residents of Swan Creek Retirement Village.

- **Online journal postings**
  If you agree to this section of the research study, I will create a online journal account specifically for members of our workshop group through “blogger.com” where you can complete your between-workshop journal entries. *Although you are encouraged to use first names or aliases only to protect your anonymity and privacy, because online journals are*
automatically indexed by search engines, they may be accessible to anyone using a search engine.

Please check one:
- Please create an alias when referring to my online journal samples.
- Please use my first name only when referring to my online journal samples.
- You may use my actual first and last name when referring to my online journal samples.

Journal Writing Samples
If you agree to this section of the research study, I will ask to copy (at my expense) your journal writing, stories, and/or your online journal entries at the end of our 6-8 week session.

Please check one:
- Please create an alias when referring to my writing samples.
- Please use my first name only when referring to my writing samples.
- You may use my actual first and last name when referring to my writing samples.

Post-program questionnaire survey (anonymous)
If you agree to this section of the research study, this questionnaire will be handed out to you after our final workshop meeting with a stamped, addressed envelope to return it to me.

If you have any questions or concerns about this research study, you may contact Lucie Shetzer, Researcher, (419) 352-6718 or shetz@bgnet.bgsu.edu, Kristine Blair, Dissertation Director, (419) 372-8033 or kblair@bgnet.bgsu.edu. For questions regarding the conduct of the study or your rights as a research participant, please contact the Chair of Bowling Green State University’s Human Subjects Review Board at (419) 372-7716 or (hsrb@bgnet.bgsu.edu).

I sincerely appreciate your time,

Lucie Shetzer

________________________
Printed Name of Participant

________________________                               ___________________
Signature of Participant                                                                   Date
APPENDIX E: THE VICTORY CENTER AND ST. VINCENT’S INTERVIEW QUESTIONS

Pre-interview Questions

1. When did you or your family member become ill or injured?
2. Was the onset of the illness or injury sudden or gradual?
3. At this time, how would you classify you or your family member’s illness or injury (i.e., stable, critical, in remission, in relapse)?
4. If your family member is ill or injured, does he or she know that you are participating in this writing workshop? If so, how does he or she feel about your participation? If not, is there a reason why you have not communicated about your participation?
5. What are some of the ways in which the illness or injury has affected your life?
6. What are some of the ways in which the illness or injury has affected your relationship(s)?
7. What are some ways you’ve worked to cope with you or your family member’s illness?
8. Do you ever feel isolated and alone in coping with you or family member’s illness? Why or why not?
9. In your experience, are any of these coping methods more effective than others?
10. Before now, how often would you say you write (daily, weekly, etc.)? Describe the types of writing you do most often (i.e., letter writing, e-mailing, shopping lists, to-do lists, etc.).
11. In general, and based upon your past experiences with writing, what are your feelings about writing?
12. Can you describe the type of writing experience you had during your formal education?
13. Have you ever kept a journal?
14. In general, and based upon your past experiences with computers and the Internet, how would you describe your comfort level with the technology?
15. Have you ever participated in a chat room or other online community? If so, how would you describe your experience?
16. What do you hope to gain by participating in this writing workshop?

Post-interview Questions

1. At this time, how would you classify you or your family member’s illness or injury (i.e., stable, critical, in remission, in relapse)?
2. Has this status changed since you began to participate in this writing workshop?
3. If your family member is ill or injured, does he or she know that you have participated in this writing workshop? If so, how does he or she feel about your participation? If not, is there a reason why you have not communicated about your participation?
4. Since beginning this writing workshop, how often have you written about you or your family member’s illness or injury ( ___ minutes per day, weekly, only during the workshop times)?
5. What factor(s) have limited or supported the amount of time you have spent writing about you or your family member’s illness or injury?
6. What writing technologies have you used during this workshop (i.e., paper and pencil journal, online journal)?
7. What type of writing did you prefer (i.e., narrative, poetry, etc.)? Can you offer some reasons for your preference?
8. To what extent have you been able to use writing as a method of coping with you or your family member’s illness or injury?
9. In your experience, has writing been an effective coping mechanism for dealing with the illness or injury? If so, how has it been effective? If not, why was it not effective?
10. Do you think your general comfort level and/or past experiences with writing were factors (positive or negative) in your using it as a successful coping mechanism during this workshop?
11. Do you think your general comfort level and/or past experiences with computer technology were factors (positive or negative) in your using it as a writing tool during this workshop?
12. In your opinion, has regular journaling had any impact at all on the ways in which the illness or injury has affected your life?
13. In your opinion, has regular journaling had any impact at all on the ways in which the illness or injury has impacted your relationship(s)?
14. Since beginning the workshop, how often would you say you write (daily, weekly, etc.)? Has this amount increased from prior to the workshop? Has there been a change in the type of writing you do most often?
15. In general, have your feelings about writing changed either positively or negatively since beginning this workshop?
16. Can you describe the type of writing experience you have had during this journal writing workshop?
17. Do you intend to continue your writing journal beyond the completion of this workshop? Why or why not?
18. As a result of this workshop, has you comfort level with computers and the Internet, changed either positively or negatively?
19. If you participated in the online journal activities, how would you describe your experience?
20. As a result of this workshop, do you feel more comfortable sharing your writing with others? Why or why not?
21. As a result of this workshop, have you formed significantly supportive relationships. More specifically, do you feel that you belong to a community that shares your experiences and concerns?
22. What do you feel you have gained by participating in this writing workshop? Are these gains more or less than you anticipated?
APPENDIX F: SWAN CREEK RETIREMENT VILLAGE INTERVIEW QUESTIONS

Pre-interview Questions

1. How long have you been a resident of Swan Creek Retirement Community?
2. Do you live alone or share an apartment with your spouse?
3. Before moving to Swan Creek, where did you live?
4. Describe your level of education.
5. What was your occupation? For how long were you employed at this occupation?
6. Are you retired? If so, how long have you been retired?
7. Was your retirement voluntary, or the result of an illness or injury of yourself or a loved one?
8. At this time, are you satisfied with your retirement decision?
9. How would you describe your level of independence?
10. At this time, how would you describe your health and/or the health of your spouse or other loved one?
11. Have you ever experienced the loss of a spouse of loved one? Was this loss sudden, or the result of a long illness?
12. How did that loss change your life?
13. Would you say that you have become more or less independent as a result of that loss? In what ways?
14. Have you ever experienced a personal illness or injury or the illness or injury of a family member?
15. Do you currently provide care or support to an ill or injured spouse or loved one?
16. When did you or your family member become ill or injured?
17. Was the onset of the illness or injury sudden or gradual?
18. At this time, how would you classify you or your family member’s illness or injury (i.e., stable, critical, in remission, in relapse)?
19. If your family member is ill or injured, does he or she know that you are participating in this writing workshop? If so, how does he or she feel about your participation? If not, is there a reason why you have not communicated about your participation?
20. What are some of the ways in which the illness or injury has affected your life?
21. What are some ways you’ve worked to cope with you or your family member’s illness?
22. What are some ways you’ve worked to cope with you or your family member’s illness?
23. Do you ever feel isolated and alone in coping with you or family member’s illness? Why or why not?
24. In your experience, are any of these coping methods more effective than others?
25. Before now, how often would you say you write (daily, weekly, etc.)? Describe the types of writing you do most often (i.e., letter writing, e-mailing, shopping lists, to-do lists, etc.).
26. In general, and based upon your past experiences with writing, what are your feelings about writing?
27. Can you describe the type of writing experience you had during your formal education?
28. Have you ever kept a journal?
29. In general, and based upon your past experiences with computers and the Internet, how would you describe your comfort level with the technology?
30. Have you ever participated in a chat room or other online community? If so, how would you describe your experience?
31. What do you hope to gain by participating in this writing workshop?

Post-interview Questions

1. At this time, how would you describe your health and/or the health of your spouse or other loved one?
2. Has this status changed since you began to participate in this writing workshop?
3. If your family member is ill or injured, does he or she know that you have participated in this writing workshop? If so, how does he or she feel about your participation? If not, is there a reason why you have not communicated about your participation?
4. Since beginning this writing workshop, how often have you written ( __ minutes per day, weekly, only during the workshop times)?
5. What factor(s) have limited or supported the amount of time you have spent writing?
6. What writing technologies have you used during this workshop (i.e., paper and pencil journal, online journal)?
7. What type of writing did you prefer (i.e., narrative, poetry, etc.)? Can you offer some reasons for your preference?
8. To what extent have you been able to use writing to record significant experiences (past or present)?
9. In your experience, has writing been an effective coping mechanism for dealing with your daily stressors? If so, how has it been effective? If not, why was it not effective?
10. Do you think your general comfort level and/or past experiences with writing were factors (positive or negative) in your using it as a successful coping mechanism during this workshop?
11. Do you think your general comfort level and/or past experiences with computer technology were factors (positive or negative) in your using it as a writing tool during this workshop?
12. In your opinion, has regular journaling had any impact at all on the ways in which you reflect about your past or present experiences? Please describe.
13. In your opinion, has regular journaling had any impact at all on your relationship(s) within the Swan Creek community?
14. Since beginning the workshop, how often would you say you write (daily, weekly, etc.)? Has this amount increased from prior to the workshop? Has there been a change in the type of writing you do most often?
15. In general, have your feelings about writing changed either positively or negatively since beginning this workshop?
16. Can you describe the type of writing experience you have had during this journal writing workshop?
17. Do you intend to continue your writing journal beyond the completion of this workshop? Why or why not?
18. As a result of this workshop, has your comfort level with computers and the Internet changed either positively or negatively?
19. If you participated in the online journal activities, how would you describe your experience?
20. As a result of this workshop, do you feel more comfortable sharing your writing with others? Why or why not?
21. As a result of this workshop, have you formed significantly supportive relationships? More specifically, do you feel that you belong to a community that shares your experiences and concerns?
22. What do you feel you have gained by participating in this writing workshop? Are these gains more or less than you anticipated?
APPENDIX G: POST-WORKSHOP QUESTIONNAIRE SURVEY

Post-program Questionnaire Survey

Directions: Please respond to the following questionnaire. Be as detailed as possible; doing so will benefit my research process and help me to improve upon future journaling workshops. **Be honest, and feel free to remain anonymous.** You may use extra paper, if necessary. Return the form by U.S. mail in the pre-addressed, stamped envelope.

1. How has this workshop been of benefit to you?

2. How could the workshop have been of greater benefit to you?

3. How could the workshop be improved?

4. Would you like to this workshop to be offered again?

5. Please comment on the effectiveness of the workshop facilitator.

6. Please comment on the effectiveness of the workshop location.

7. Please comment on the effectiveness of the workshop content.
APPENDIX H: PRE- AND POST-INTERVIEWS OF BARB

Victory Center: Pre-Interview of Barb

LUCIE: All right. The first question is, when did you become ill?

BARB: I was diagnosed with cancer two years ago in June – this past June. Well, no I guess it was in April really, that I was diagnosed.

LUCIE: Oh, relatively – oh, so two --

BARB: Two years ago.

LUCIE: Two years ago. Okay. Was the onset sudden or gradual?

BARB: Sudden.

LUCIE: Just went to the doctor and –

BARB: No, I had just – like I said I was – I always go and have a mammogram every year. And I had large fibrocystic breasts, so they always called me back saying, you know, they needed to re-screen because they couldn’t tell, so – but for some reason this year, there were – we had all kinds of stuff going on. My father-in-law who lives in Peoria and we had to put him in a nursing home and then he died right after – yeah, right after they called me to come back. Well, anyhow, I hadn’t gotten my mammogram – they always send you a card, telling you need your mammogram. Well, I hadn’t gotten it or anything, but for some reason, I swear it’s my angel, just told me, “You need to get a mammogram. And you need to do it now.” So, I called the doctor’s office and said, “I want to schedule a mammogram.” I went in and did it and then they called and said, you know, we need to re-check and I had to go down to Toledo, but, you know, that’s like the third or fourth time, so I really wasn’t that concerned. And then my father-in-law died, so we went to – had to go to Peoria and do the funeral and all that and came back and the day after we got back is when I went in for – yeah, it was very overwhelming. Went in
for my mammogram, only this time it was – I could tell something was different because they kept coming back in and saying we need one more picture, we just need one more picture. And then finally, the radiologist came in and I knew something was wrong. And he said, well, whatever this is, it’s not going away. It’s there. We need – you need to have a biopsy.

**LUCIE:** Oh boy.

**BARB:** Yep.

**LUCIE:** Did they do an ultrasound?

**BARB:** Yes, yep, yep. They do an ultrasound.

**LUCIE:** Okay. At this time, how would you classify your illness? In remission, stable, or --

**BARB:** Right now?

**LUCIE:** Uh huh.

**BARB:** The cancer I would say is stable. I don’t know if you would call breast cancer in remission? Not really, because hopefully it doesn’t come back like other cancers. Unless you get a reoccurrence, but I would just call it stable. It’s status quo right now.

**LUCIE:** Good. Okay. Let’s see. The next one, well, I’m not sure really applies because it has to do with if a family member is ill and you are doing this for coping, but --

**BARB:** I told you, I have that too. So, --

**LUCIE:** Oh, yeah, that’s true, you did.

**BARB:** In fact, that’s one reason I was a little late. My husband – whenever he gets a cold or something, it almost always goes into pneumonia. So I had to take him up for a chest x-ray and we’re waiting for the results. So, yeah, for the past thirteen years, he’s had heart problems and he’s had everything under the sun since then.

**LUCIE:** You’re also a care giver?
BARB: Very much so, a care giver.
LUCIE: So, in that --
BARB: Even while I was having cancer, I was a care giver.
LUCIE: Oh my.
BARB: So, yeah, I can answer your questions on that one.
LUCIE: All right. Well, if – if your family member is ill or injured, then does he know that you’re participating in this writing workshop and, if so, how does he feel about your participation?
BARB: Yes he does, but you know, I’m not doing this because of him.
LUCIE: Right. What are the ways in which the illness has affected your life? Your illness or --
BARB: Well, my illness is what I’m here for. So--
LUCIE: Right.
BARB: Many ways. I mean as far as negative ways, well, you know, it slowed me down. I wasn’t able to do a lot of the things that I wanted to do. But, to me, I’ve gotten a lot more positives out of it. I’ve learned how to – you know, I’ve got a whole different outlook on life. I’ve learned to be able to, you know, the things that used to just throw me over the edge, no longer do because I know they’re, you know, they’re minor. After, you know – really it changes your outlook on life. It strengthened – it has strengthened my faith tremendously. That’s what gets me through this – through all of it and – it’s changed my relationship with a lot of people.
LUCIE: Well, I think that’s my next question. What are some of the ways in which the illness has affected your relationships with others?
BARB: Okay. Again, it’s negative and positive. You learn really fast when you have cancer who your true friends are. Very much. Oh yeah. Yeah, you’ll read that in any book because a
lot of people – I mean, not that they don’t want to be your friends, but they don’t know how to deal with it. So, rather than, you know, put themselves in an uncomfortable situation, they’ll just withdraw.

**LUCIE:** Wow.

**BARB:** Yeah.

**LUCIE:** Maybe it’s scary for them, too?

**BARB:** Very much so. Very much so. Or you’ll have the people that – I have my own sister, you know, who just about drove me crazy, you know. I was the one that was consoling her because she was flipping out because, you know, if I have cancer then it’s, you know – yeah, --

**LUCIE:** Oh dear.

**BARB:** And I’m like, okay, you know --

**LUCIE:** So it’s in the family?

**BARB:** Yeah. So, in that way, but as far as my own family, my youngest daughter, like I said before, has been wonderful. She, you know, she was there for me all the way. She was just wonderful. My older daughter, the one that’s married, is a whole different personality. She does not know how to cope with – and that’s what a lot of your friends are too – don’t know how to cope with this – can’t handle any kind of, you know, major problem or she doesn’t like any – so she more or less backed off. Which was not what I needed at the time, but I learned to deal with it. And my husband, like I said, although he was ill, he was very, very supportive and it really was a good wake up call for him, because it had always been me taking care of him, me sitting in the hospital while he was going through the surgery, you know, and he had no concept until he had to sit through a six and a half hour surgery for me. And that’s what he told me, he said, I
never realized what you had gone through and he said I never realized until I was sitting there
how much I loved you. So, in that respect, it did help our relationship.

**LUCIE:** Great. Okay. What are some of the ways that you’ve worked to cope with your
illness?

**BARB:** Let’s see. Well, basically, I simply do not let it get me down. I keep going. Like I
said, I volunteer. I do – I work with other women that have the same thing that I do, you know.
Well, and in a lot of daily life, you have to learn – you have to learn your limitations, which is
very difficult. Because, you know --

**LUCIE:** You have to learn to say no.

**BARB:** Exactly. I had – I had Fibromyalgia before, which wears down your system, but then
after all the surgeries, you know, my surgeon told me, he says, it’s going to be two to three years
before you ever gain back your energy where it’s at. So that’s really been my biggest – you
know, I’m used to going out with – I get my grandkids and we go out and play, you know, and I
run with them and do stuff and now I just get tired so, so fast. But, you know, I just have to learn
to accept and pace myself and go on.

**LUCIE:** I’ve often wondered if it’s like – if there’s like a Fibromyalgia personality?

**BARB:** Yeah, I think so.

**LUCIE:** I think so too. Like people who are likely to get it. All right, let’s see. Do you ever
feel isolated and alone in coping with your illness?

**BARB:** Oh, not so much now, but, yeah, there was a time I think – and I think every cancer
patient goes through that. Really, I do. Because, like I said, you might have your family, your
friends around you, but you still feel alone because they – there’s no way they can comprehend.
When you hear the word cancer, it’s like – it’s a whole new—whole new world. I mean, at first,
the first stage is, you know, non-acceptance. It’s kind of like, okay, I hear you, but, you know, this is not me. Really, it truly is.

**LUCIE:** I know. I know.

**BARB:** Just – it’s just total – and then, I know for me it was when I went – before my surgery, I had to go to MCO for the pre-op stuff that you have to have--x-rays and EKG’s and all that stuff, and it was when I walked in there – my daughter was with me, thank goodness, and they handed me my chart and said, well, sign here and it said, you know, my name. And then it said “Diagnosis: Breast cancer.” And it was just like, that’s my name, that’s me, you know. It just really hit me and then the first time I had to walk into the Cancer Institute, it was like, you know, cancer, this is not for me, but --

**LUCIE:** Is that here in Toledo?

**BARB:** I went to MCO to the Cancer Institute.

**LUCIE:** But you said you didn’t have follow up radiation, right?

**BARB:** No. No.

**LUCIE:** Okay. In your experience, are any of your coping methods more effective than others?

**BARB:** Well, writing is a biggie for me. In fact, that’s what I did all the way through when I was having the roughest time was – was writing. That and my church family, that’s – those were my major coping strategies.

**LUCIE:** Before now, how often would you say – before beginning this workshop, I should say, how often would you say that you wrote or have written?

**BARB:** I’m a big writer, if you count – I don’t know if you count back when I was teaching, I did – I taught third grade and we did the writer’s workshop or whatever. We had half – got down to be a half hour every day and I wrote right with the kids. So, I wrote every single day.
The kids had writer’s notebooks and I kept one too and then I would share my writing with them and they would share. So, I did that all the way through until – until I retired.

LUCIE: And how long have you been retired?

BARB: It will be – this is my third year. Starting my third year.

LUCIE: So this happened almost –

BARB: Right after.

LUCIE: Best laid plans, huh?

BARB: Yeah.

LUCIE: All right. So, now – describe the types of writing that that you have done most often. For example, letter writing, shopping lists, the writing that you were talking about with your students.

BARB: Mine is mostly journal writing, story writing. I do – I write little articles and stuff. In fact, I’ve got one that I’m going to send into a Women’s magazine.

LUCIE: Oh, do you!

BARB: And see if – yep, my angel story and I will have to share that with you before I go.

LUCIE: Yeah, please. That’s really interesting to me. So, you want to tell that now? Go ahead.

BARB: What happened was, like I said, I had just gotten – it must have been two years before I found out I had the cancer, my best friend, my neighbor next door changed churches and she asked me to come with her and I went with her and fell in love with the church and became very active in it. In fact, I was doing a play at church when I found out that I had cancer and I went ahead and did the play anyway. So, but anyhow, I’m a big angel collector. My mother and I both. I have angels everywhere. We got this new – we got this entertainment center, oh probably
about a year before I got the cancer, a brand new one. The kind that has the lights at the top, you know.

LUCIE: Yes.

BARB: On the sides. Well, for some reason, the light on the left hand side would never work -- never ever worked. My husband went and got new bulbs and tried it and nothing. We had the people that sold us the thing come out and said, well, you know, we can give you a whole new entertainment unit. We don’t know why this light won’t work. We said, no, we don’t want to go through all that, you know, just for a light. So, we didn’t do anything about it. Well, that day that I told you about that I went for my pre-op, which was like maybe three days before my surgery, my daughter and I came home, walked in the house, and that light was on. Yeah. And nobody had been there to touch it; so, when my husband came home, he went and turned it off and then tried to see if it would turn back on. No, nothing. And I have angels up there. I have this big blue angel that’s right underneath the light. So, you know, we went ahead. I had my surgery and I was not the least bit afraid. It was amazing. Just totally amazing. And then – and then I couldn’t have my next surgery until six weeks later. So, I went through six weeks of hell.

LUCIE: Wait, the next surgery? Oh, for the --

BARB: My mastectomy. Uh huh. Because they had to schedule, you know, both surgeons --

LUCIE: They made you wait that long?

BARB: Six weeks; it was horrible.

LUCIE: Don’t they usually get that out right away?

BARB: Well, they tried, but see, they were doing a double. It was the – my cancer surgeon and my reconstruction surgeon had to match their schedules. Yeah. Yeah. It was just – it was
horrible. So before that surgery, I was — I was a basket case. So, about three or four days before
that second surgery, we came home and the light was on.

**LUCIE:** That’s really weird. Wow.

**BARB:** Yeah, and so this time, I told my husband, I said, do not touch this light. Just leave it
on. I want to see how long it will stay on because those bulbs, even when they work, they’re
those little bulbs and they usually — they’ll burn out if you leave them on two days, you know.
They just don’t last long. So, that was like three days before I went into the hospital. I went in
and had the surgery. The first thing I asked my husband when I woke up was, “Is the light still
on?” And I was in the hospital for four days and every day he came up, I asked him, and he’d
say, “Yes. It’s still on.” So, I went home and the first couple of weeks were really rough. And
that light stayed on for about a total of three weeks. And after about three weeks, I knew when I
woke up one morning that things were starting to go better and that the light was going to be off.
I knew that I had passed the — and sure enough, I walked out and it was off. Yeah, but that isn’t
even the clincher. But then -- then in November, six months later, cause after I had the
mastectomy and the reconstruction, I had to go in every week to the reconstructions for six
months and get injections.

**LUCIE:** For what?

**BARB:** Because they put an implant in there and they have to go in and they make it — they put
injections of saline in there to pump it up to make it to the size that you want it.

**LUCIE:** Oh, is it like a — it’s like a regular breast implant?

**BARB:** Yeah. They have an implant in there, but then they — they build a breast around it.

**LUCIE:** Oh, I see. And then that allows them to adjust the size?
BARB: Yeah. They have a port inside there on that and then they stick the needle in the port and – it wasn’t painful. Because you’re so – you don’t have any feeling. You have no feeling in there. So, it wasn’t painful, but it was just every week. So, then after they got it to the size that I wanted, they’d go back – then they’d go back in and put the permanent implant in and I was so big before that they had to reduce this breast, so I was going in for that surgery. I wasn’t really concerned about it.

LUCIE: So was this a third surgery?

BARB: That was my third surgery, yeah. So, the day before I was going in, I was home all by myself and we still had our old dog and I went to let her out and walked through the great room – we have a great room and everything’s normal. Let her out. I came back in, walked into the great room, and the light was on.

LUCIE: That would have freaked me out. Oh my God.

BARB: I just froze and I walked over to it and something just told me, look down. And I looked down and – are you ready for this? The light was unplugged.

LUCIE: Too weird.

BARB: Not weird. It was my angel. I believe she was saying, “I’m here.”

LUCIE: That is really neat.

BARB: Yeah. Unbelievable. So, yeah, that’s what I wrote about. Because in the Women’s magazine, they have a section on angels – angel stories, so --

LUCIE: That just gives me goose bumps.

BARB: Oh, it’s what got me through.

LUCIE: Oh my gosh.

BARB: That is what got me through because I knew without a doubt that I was not alone.
LUCIE: Wow. That’s a very neat story. Thank you for sharing that. Okay. Let’s see. In general, based upon your past experiences with writing, what are your feelings about it? What are your feelings about writing?

BARB: I love writing. I’ve always loved to write.

LUCIE: Okay.

BARB: When I taught, with my kids, at home, my daughter is a very good writer, too. That’s – I’ve always loved to write.

LUCIE: Okay. Can you describe the types of writing training or experience you had during your formal education?

BARB: You mean, like in college? I mean, I took the normal --

LUCIE: No, actually even earlier. Like – was there anything that maybe made you love to write? Like when you were growing up, cause a lot of people --

BARB: Don’t like to write.

LUCIE: -- haven’t had experience.

BARB: No, I don’t know. I’ve always loved reading and writing. I knew I wanted to be a teacher from the time I was in the second grade and that’s probably right there where it started. I had a teacher who was just really supportive and really loved the reading and writing aspects and I just took off from there, I guess. I took – I went to several writing workshops and I took classes in writing after I was teaching.

LUCIE: Very interesting. Okay. I think that you may have answered this, but have you ever kept a journal?

BARB: Yeah.

LUCIE: For how long have you kept a journal?
BARB: Oh, I – well, I’ve had journals – I had them when I was younger. When I was a teenager and off and on. I’m kind of a sporadic journaler. Whenever I get into it, I go all out --

LUCIE: Okay.

BARB: -- like if I go through a down period or a need, that’s when I pull out the journal and write. And that’s exactly what I did with the cancer, which is wrong, but, you know --

LUCIE: Why?

BARB: Well I started – I should have kept it going. I started from the beginning, you know, and wrote everything down, you know, and kept up until, you know, then after I started, you know, feeling better and didn’t need the journal as much to get me through, then it kind of got thrown off again. Now, I’ve started in on it again, but –

LUCIE: I’m just curious. What was it about the writing that made – because I’m thinking about some research that I read about when you journal through an illness like that or through your treatments. What was it about that that was so --

BARB: I think – I don’t really know how – I think validation is one of the biggest words. Because, you know, it’s hard to put into feelings to other – that other people can understand what you’re going through, you know. And when you have an illness like this, and especially in my case when you have somebody else that is ill, you don’t want to, you know, put all of this on them exactly. So, I put it – I get it out, you know, I’ve expressed my feelings. It’s down there, you know. I can read it back and know that, you know, yes, this is the way I felt and I expressed it. It’s kind of a closure type of thing.

LUCIE: Did you feel like it gave you an aspect of control of your situation?

BARB: Very definitely, very definitely. Because, like I said, that’s one of the biggest things that cancer does is take away your control of everything. You have no control. So, yeah, you
are in control of expressing your feelings, you know, like you don’t feel like you can express them to this person or that, but you can put them down on paper. You can, you know, actually say what you feel, very definitely.

**LUCIE:** Okay. In general, based upon your past experience with computers and the internet, how would you describe your comfort level with the technology?

**BARB:** Oh, I’m okay with the computer and, of course, I did a lot with it when I taught at school. I did a lot of writing on it. But, I’m more comfortable with my little journal, rather than—

**LUCIE:** Okay. Anything – pen and paper.

**BARB:** Yeah, I don’t know. I mean, supposedly the computers are safe, but then you hear of all these viruses and all this stuff, you know.

**LUCIE:** Right.

**BARB:** And it’s just like I just feel much safer and have more confidence in putting it in my little book where I know nobody else is going to come in and look at my, you know, they’re just for me.

**LUCIE:** Have you ever participated in any of – in any kind of an on-line community – no, okay. The last question is, what do you hope to gain by participating in this writing workshop?

**BARB:** Well, I hope to get back into my journal writing, plus I hope to gain lots of information from other people. It’s another way to share, I mean, among cancer patients. I don’t know, there’s a – I feel like an instant friendship there because you share something so different that other people have no idea there is a connection there. And I just think, you know, a way to share with other people and to write – because writing, I love to do. This is just – this is just a real opportunity for me.
**LUCIE:** Okay. Thank you. Is there anything that maybe I forgot or didn’t quite get at that you wanted to add? I know you told me your story about your angel which was really neat, but anything else like that that --

**BARB:** Oh, I don’t know of – I’ve had so much.

**LUCIE:** Yeah. I’m sure.

**BARB:** I’ve had so much, but I can’t really --

**LUCIE:** Okay. Well, you’ve answered a lot of the things very, well. Very succinctly, I think, and you’ve gotten at the heart of a lot of what the research is showing so --

**BARB:** Yeah, very definitely, I – like I told you before, I think, you know, your journal can be – can be your best friend.

**LUCIE:** Okay. All right.
Victory Center: Post-Interview of Barb

LUCIE: Okay. At this time, some of these questions are repetitive and they’re just supposed to be in retrospect now after the workshop. But at this time, how would you classify your illness?

BARB: How would I classify –

LUCIE: You know, stable, critical, in remission, in relapse?

BARB: I would say, in remission, yeah. Stable.

LUCIE: Since you began the workshop, has this status changed?

BARB: Yeah. I think it’s really – it’s made me much more accepting and calm.

LUCIE: But no, but, the status of your illness hasn’t changed at all?

BARB: Oh, no.

LUCIE: Since you began the workshop. Okay.

BARB: Well, except for the medication.

LUCIE: Well, that’s kind of important, though, because you were sick. You changed your medication, what about a month ago?

BARB: Uh huh.

LUCIE: Now, since beginning this writing workshop, and answer these honestly. You know, it’s not going to make a difference how you answer these. Since beginning this writing workshop, how often have you written about your illness? Several minutes per day, weekly, only during the workshop times?

BARB: About my illness specifically?

LUCIE: Or in general.
BARB: Just writing – I’ve been writing a lot more. I’ve been writing two to three times a week. But I don’t always write about my illness. I write about other things, but I would say at least once a week besides this class, I actually sit down and write.

LUCIE: Yeah, after I started this class, I realized the limitations of that question. Some of these questions I realize now, you know, where I should have written them differently.

BARB: You know, but the thing – I don’t know about the other people, but the thing for me is, you know, once you get – I wrote about my illness a lot, you know, when I was going through it and now that I feel like I’m –

LUCIE: Cured.

BARB: Out of it, you know, it’s like I really don’t want to re-visit that place.

LUCIE: Oh, yeah.

BARB: I like to write about, you know, the positive things that have come out of it or other things in my life.

LUCIE: Wonderful.

BARB: I’ve got --

LUCIE: Oh, you brought me some samples. Oh, thank you very much. And is that other form in there?

BARB: It’s all done.

LUCIE: Oh, thank you. All right. So, what factors would you say have either limited or supported the amount of time you have spent writing either about – so you say you don’t write about your illness, but what –

BARB: I still do sometimes, but not in the same light that I used to write about.

LUCIE: Okay.
**BARB:** What factors? Mostly time. That’s the big factor. It’s just taking – setting aside a time and even now that I’m retired, you know, I should have more time, but it still seems like there’s always something to do. It’s just something you have to set aside a time and say this is when I’m going to write and –

**LUCIE:** Okay. Great. All right. What writing technologies have you used during this workshop and by that I mean have you primarily stuck to pencil and – paper and pen, or have you ever used the computer or the word processor?

**BARB:** Well, yeah, to type those up I used the computer, but basically I, no, I use my journal and my pencil.

**LUCIE:** Okay. Great.

**BARB:** It’s more meaningful. It’s more personal than a computer is to me. Type it up, that’s fine, but –

**LUCIE:** A lot of people feel that way. That’s very interesting – that’s one of the things that I’m finding. That people are saying. Okay. Of the type of writing that we did in here, what type did you prefer and can you offer some of the reasons for your preference?

**BARB:** What do you mean by types of --

**LUCIE:** Well, did you enjoy more of the self-reflective prompts or the types – the times that we wrote narratives or some people I know like Elena wrote a lot of poetry. What did – again, I think this question has some limitations that now that I’ve done the workshop, I’m seeing, but can you just say something about the types of writing?

**BARB:** I think I probably liked the more – I liked, I liked all the prompts that you gave, but I’m the type that likes to do my own thing. My own – I mean, I would take your prompt, but I would maybe go with it a whole different way than what –
LUCIE: Oh. Outside of the workshop or during the workshop?

BARB: Both.

LUCIE: Okay. Great.

BARB: That’s just the way I see things. To me, more, I guess you would say type of writing would be more creative, introspective kind of writing. Being able to take a given prompt and go with it the way I want to go with it.

LUCIE: Okay.

BARB: That’s just the way I am in everything.

LUCIE: No, that’s great.

BARB: That’s the way I teach. That’s the way I – you know, you give me what you want me to do and I’ll do it, but I’ll do it in my own way.

LUCIE: That’s great. You prompted me to think of something else with that. Maybe it will come back to me. Okay. No, that’s – oh, I know what I wanted to ask you. Did you ever go back to the prompts, like I know that we had time constraints when we were working in here. Did you ever go back to those prompts during the week and flush them out a little bit or –

BARB: Oh yeah.

LUCIE: Did you? Okay.

BARB: Yeah.

LUCIE: Just was curious about that. All right. I’m not sure if this is – if this isn’t pertinent to you, then just say pass and I’ll just go on. To what extent have you been able to use writing as a method of coping with your illness? Or maybe with some of the things that have been going on with your family members or – ‘cause I know your husband is ill too?
BARB: Right. To me and I think it’s in one of those things that I copied off, it’s a great stress reliever. It’s a way to get all those feelings out on paper without hurting anybody else’s feelings. And still have yourself feel validated. Like, okay, at least I’ve got it down. You feel –

LUCIE: Like you’ve said it?

BARB: Exactly.

LUCIE: Okay. In your experience, has writing been an effective coping mechanism for dealing with your illness, your husband’s illness? If so, how has it been effective? If not, why has it not been effective?

BARB: Well, it’s been really effective for me. It’s like I said, I started writing, I got – as soon as I was diagnosed with cancer shortly after I was given a Reach to Recovery Buddy from, which I am myself now, but – and they bring you, you have a big -- they bring you a big bag full of stuff and in there is a journal. And as soon as I got that, that became my lifeline. I was telling Carol out there that I took that journal with me everywhere. I wrote -- before I went to the doctors, I wrote down all the questions I had. When I came home from the doctors, I sat down and I wrote down everything that I could remember that he said and my feelings about, you know, what he said and what my options were and so forth. And I used it daily. I mean, it was like –

LUCIE: So, you didn’t just use it to record –

BARB: Feelings – I used it for all aspects of my cancer.

LUCIE: Okay.

BARB: And it’s in there and I’ve got from day one, you know, my – how I felt when I first went in for the – I’ve got it all in there.
**LUCIE:** Okay. Great. In your experience, has writing been an effective coping mechanism for dealing with your illness or injury, your husband’s? If so, how has it been effective? If not, why was it not effective?

**BARB:** Like I just said, it’s been a big coping mechanism for me because it helped me deal with all aspects. For me, it was like an in your face thing. Once you’ve written it down, then you can go back and say, okay, this is where I was at two months ago. Now look where I’m at now. Because you don’t – a lot of times with like cancer, you don’t – you don’t realize how far you’ve come. I mean you – you know, you see --

**LUCIE:** You feel so crappy all the time.

**BARB:** Exactly. You’re so used to the – you know, the pain and all the fear and all that stuff, that you don’t really realize that, hey, a month ago, you know, I was way down, look how much farther I’ve come. You don’t sit and think about that, but if you – if it’s written down and you have it to open up and read and say, okay, you know, I am making progress. That’s –

**LUCIE:** Do you think that -- this is just sort of a question that’s come up since I talked to Elena. Do you think that journaling – journal workshop is a good name for this? Or do you see this as maybe – Kelly and I were talking about what to call it the next time around. And originally what I was interested in calling it was Therapeutic Writing or Writing as Therapy. Do you see it more as journaling, writing therapy or does it matter, or –

**BARB:** I don’t know that it really matters, but I would probably go with more of the writing therapy, because journaling, like when we first started, I expected it to be more of a just –

**LUCIE:** And that’s what everyone is saying.
BARB: Yeah, right. Just writing in your journal. But to me, this was been more of a support
group than it has been an actual journaling group. I mean, it has been, you know, I don’t know --
therapeutic writing, I don’t know what you would call it.

LUCIE: Writing is Therapy. Writing for Therapy. Dale says he refers to it as writing for
therapy. It’s just interesting, sort of semantics there. Okay. Do you think your general comfort
level and/or past experiences with writing were factors, either positive or negative, in your using
it as a successful coping method during this writing workshop?

BARB: Very definitely.

LUCIE: Okay.

BARB: I’ve been a writer all my life, so writing has been -- not only a tool, but it’s been a
pleasure to me. Even when I taught, I wrote on my own.

LUCIE: Okay. In your opinion, has regular journaling had any impact at all on the ways in
which illness has affected you? Illness has affected your life? Even thinking back maybe to
when you were more acutely ill?

BARB: Right. Like, I said, it helped my emotional state, I mean it’s not going to cure cancer.

LUCIE: Sure.

BARB: But it definitely had a – played a part in keeping me emotionally stable and I still say
that cancer is more than 50% emotional. It’s – I mean, you can treat the physical and whatever,
but the emotional part stays there forever.

LUCIE: Okay. Great. In your opinion, has regular journaling had any impact at all on the ways
in which your illness has impacted your relationships?

BARB: Has journaling helped?

LUCIE: Uh huh.
BARB: Yeah, I would say that it has again because like I mentioned before, I have the son-in-law from –

LUCIE: Yes. Yes.

BARB: Yeah, cause that’s been a – that was a real, a real traumatic experience for me, during my cancer time not to have my own daughter and son-in-law supporting me whatsoever. I mean, that was – that was very hurtful and I had a really hard time dealing with it, so yeah, it’s all written down. I mean, I would just sit and, you know, get it all out, because I couldn’t understand.

LUCIE: Wow.

BARB: That was the biggest thing. I told my husband, I can’t understand, you know. ‘Cause it’s not in my make-up, you know. I just can’t understand how – you know, you have to learn to accept, but there again, I think writing has helped me to do that. Because, I write down all of the things and then I go back and read over it, you know, and it helped me understand it, ‘cause I’m the type of person that, you know, always blames myself. It had to be me, you know.

LUCIE: Yeah, yeah.

BARB: He was saying that it was my fault, although I don’t know what I’ve ever done except help them, but then when I actually wrote it down and saw it there on paper, it was like, okay, it’s not my fault.

LUCIE: Yeah.

BARB: What could I, you know – so, it helped a lot.

LUCIE: Okay. All right. Since beginning – actually, I think you – I think you answered the first part of this question. How often would you say you write? The next part of that question
was: Has the amount – this amount of writing increased from prior to the workshop? Or/and has there been a change in the type of writing you do most often?

BARB: Yeah, very definitely, there’s been a change in how much I write. Like I said, I was writing a lot, you know, during my cancer, but then once I got back on my feet and got back into the rat race, you know, it tapered off. But this class brought me right back to it again and it’s –

LUCIE: Right.

BARB: I really appreciate that.

LUCIE: Oh good.

BARB: It’s been – and what do I write?

LUCIE: Has there been a change in the type of writing that you do?

BARB: Yeah, I do more focused, structured writing. Before it was – it was always just, you know, feeling types or whatever. Whatever I was thinking at the moment. It was more that kind of writing. Now, you know, through your prompts and stuff, I’ve learned to, you know, focus on – and now I might – I have devotionals and these neat books of sayings and, you know, I’ll pull one out and then I’ll write about it.

LUCIE: That’s so neat. Okay. Great.

BARB: Yeah, it has changed.

LUCIE: Great. In general, have your feelings about writing changed, either positively or negatively since beginning the workshop?

BARB: Well, I’ve always loved to write, but it’s made me see a different aspect of writing. What writing could actually do for me, rather than just writing for a purpose.

LUCIE: Great. Okay. Can you describe your experience during the workshop, in any way?
BARB: I would have to say it was like a revelation. Each session that we had or group, you know, I got a new insight from somebody or, you know, listening to other people share what they wrote was just as meaningful as writing itself, you know. It was an extension of writing. I can’t explain it. It was like a validation, you know, a validation of who you are and what you’re going through and other people are going through the same thing, you know, and hearing them say these things was a real, real booster.

LUCIE: Okay. Do you intend to continue your writing journal beyond the completion of this workshop? Why or why not?

BARB: Very definitely. Because I – I’ve found a new friend.

LUCIE: Oh, okay. All right. As a result of this workshop, has your comfort level – oh, actually, this doesn’t really apply. It has to do with computers and you didn’t really go there. As a result of this workshop, do you feel more comfortable sharing your writing with others? Why or why not?

BARB: Very definitely.

LUCIE: Okay.

BARB: Very definitely. People may not realize -- I used to be very – I don’t want to call it shy, not like what Carol is, but –

LUCIE: Reserved?

BARB: Reserved, yeah. Yeah. I’ve come out of it, but the cancer really helped me a lot to come out of it.

LUCIE: Oh, good. Good.

BARB: Really did. But being in this group helped a lot because it – you made it or whoever – you made it a very safe environment. I think everybody felt the freedom. You know, you didn’t
have to feel embarrassed or afraid to read what you wrote because everybody else was in the same boat and they understood where you were coming from.

**LUCIE:** A lot of empathy. I agree with you.

**BARB:** Exactly.

**LUCIE:** Okay. A couple more questions here. As a result of this workshop, do you feel like you’ve formed significantly supportive relationships and the other part of that question, more specifically, do you feel like you belong to a community that shares your experiences and concerns?

**BARB:** Very definitely.

**LUCIE:** Okay.

**BARB:** I say prayers for all of them every night, especially Elena. There’s just something about her that I just –

**LUCIE:** Yeah. Really touched by, yeah, I agree. What do you feel you have gained by participating in this writing workshop? And then the second part of that question is, are these gains more or less than you anticipated?

**BARB:** I’ll answer the second part first. They are much more than I anticipated.

**LUCIE:** Okay.

**BARB:** Much more. I anticipated, like I said, a journaling class where everybody came and wrote in their journals and maybe we would discuss, you know, this was so much more than what I anticipated, because this was a – it was a sharing group. It was – I gained, I think new friends, you know. New relationships with people that are in the same situation I am, you know. I’ve gained the knowledge that I can write meaningful things, you know. Cause sometimes like when we listen to Elena with her marvelous poetry and it’s beautiful. It’s absolutely beautiful
and you think, uh – cause that’s what Carol said, she said, well, you know, I’m not a writer and after hearing everybody else. I said, but you know, to me that was really freeing because everybody –

LUCIE: Yeah.

BARB: -- everybody accepts you where you are. You know. You may not be a poet, you may not even be a writer, but putting down your feelings and sharing those feelings is a gift.

LUCIE: Yeah. It is. Okay. Anything that you – as an afterthought that you wanted to add.

Those are all the final questions that I have. If you had another –

BARB: I just wanted to add that I am so grateful –

LUCIE: Thank you.

BARB: Sincerely, you have done a marvelous job.

LUCIE: Thank you.

BARB: I know you are one busy lady.

LUCIE: Thank you.

BARB: But you put your whole heart and soul into this and everybody in here could feel it and that’s another – probably the main reason why everybody felt safe.

LUCIE: Oh, that’s really wonderful. Thank you. That’s very meaningful to me.

BARB: You are very welcome ‘cause it’s very true.

LUCIE: Thank you.

BARB: And I want you to have this book.
APPENDIX I: POST-INTERVIEW OF CAROL

Victory Center: Post-Interview of Carol

LUCIE: Some of these questions are repetitive and they’re just supposed to be more retrospective.

CAROL: Well, and I didn’t do the first interview because I wasn’t going to – Remember? I don’t even know if you want to talk to me now.

LUCIE: Oh, well, that’s great. No, actually, I’ll just sort of make a note of that. I do remember that now that you said that. Okay. The first – and then since I didn’t do this with you the first time, what I told people when I did the pre interviews was that if there is any question you don’t want to answer, just say pass and I’ll go on to the next.

CAROL: Okay.

LUCIE: Okay. At this time, how would you classify your family member’s illness, in terms of is it stable, or critical, or in remission, or --

CAROL: I think – we think that it’s fairly stable because he’s getting an artificial hormone, Aricept, and it’s making his hemoglobin raise, and it makes his anemia less of a problem. But we really wouldn’t know if it’s stable unless we would do another bone marrow test and we may do that at some point to see if there are more of the leukemia cells that are --

LUCIE: Forming?

CAROL: -- forming.

LUCIE: Okay. Okay. Has Dale’s status changed since you began to participate in the writing workshop?

CAROL: As far as his physical health, you mean?

LUCIE: Or his illness, or --
CAROL: Not really. I think he’s been taking the Aricept, and like I said, it’s raised his hemoglobin and he feels physically fairly well.

LUCIE: Good. Okay.

CAROL: So, I think it’s mostly the depression of thinking about that he has the disease that gets him down sometimes and when he’s down, then I’m really down too and I have a hard time with that, so –

LUCIE: Okay. Since beginning this writing workshop, how often have you written about your family member’s illness in terms of several minutes per day, weekly, only during the workshop times?

CAROL: I think for the most part, it’s just been during the workshop times.

LUCIE: Okay.

CAROL: I – I do not enjoy writing and it’s not a release for me. I really don’t know that it does anything for me. I’m a thinker. I can think through things, but to write it – it’s more a chore for me and I –

LUCIE: Okay. Well, good. Okay.

CAROL: -- just haven’t done a whole lot, to tell the truth.

LUCIE: Okay. And that sort of leads into the next question. And feel free to elaborate. What factors have limited or supported the amount of time you’ve spent writing about Dale’s illness or about things in general?

CAROL: Well, I think what has supported it, is during the class time, I think your prompts are interesting and while I’m here and I’m focused on doing that, you know, I think it’s been a help to me. Also to hear other people’s writings and their problems and it just – I think it’s one of the
many things that have helped support me. But other than that, like I say, writing is not something that’s easy for me. It’s not something I enjoy, so –

LUCIE: So that sort of limits your –

CAROL: Yeah.

LUCIE: Okay. Great. What writing technologies have you used during this workshop? For example, strictly paper and pencil or paper and pen? Have you done anything on-line? Have you used the word processor?

CAROL: I have – I mean, not for this writing, I haven’t used the word processor. Most of the – like I said, has just been –

LUCIE: Here?

CAROL: -- with him here in class.

LUCIE: Okay. All right. Of the types of writings that we did, what type did you prefer? Can you offer some reasons or some examples?

CAROL: I think that the two that were – I supposed because they were short. The one that we did soon after the class got started about magic moments and that was something that I can really relate to and it was easy for me. It wasn’t something that was long and involved like writing is. And then the other day – last week, I think it was, we did the one where we had different categories and we had to write what things you think you really need and --

LUCIE: Oh, okay.

CAROL: -- so forth.

LUCIE: Okay. Good. Okay, you may have already answered this, but again, feel free to elaborate if you would like. To what extent have you been able to use writing as a method of coping with Dale’s illness?
CAROL: I don’t – I don’t know that – other than hearing other people’s writings and experiences – that, I think has been one of the things that’s helped me cope. My writing – I don’t really think has helped a whole lot. It has meant a lot to my husband to be here and to – I think just to have me be here. You know, he’s the one that’s dealing with the physical illness and he – he just has really been motivated by it. And there aren’t a whole lot of things since he’s been diagnosed that he’s been motivated to do. Whereas before he was interested in knowing many, many things. But, so I think, you know, like I said, seeing him really enjoy the writing has helped me.

LUCIE: Good. Okay. I’m going to skip over the next one because you’ve more or less answered it. Do you – and this is something you might want to elaborate on. Do you think your general comfort level and/or your past experiences with writing were factors, either positive or negative, in your being able to use it as a successful coping mechanism during this workshop?

CAROL: Okay, what was the first part of the question again?

LUCIE: ‘Cause I know that’s long. Do you think that your past experiences or your general comfort level with writing, which you already sort of said that you were not a – you don’t consider yourself to be a writer. Do you think that those factors have influenced, either positively or negatively, your using it as a successful coping mechanism in this workshop?

CAROL: I would say that’s probably something that, you know, has been difficult for me because I don’t enjoy it and I – I have never been a writer and when I’ve had to write things, as I would sometimes, as a teacher, as a student, I think it would take me three times as long to sit and think it through and I think it has been something that probably has really limited my – the experience of going through writing class.
LUCIE: Okay. Good. Fair enough. In your opinion, has regular journaling had any impact at all in the ways in which Dale’s illness has affected your life?

CAROL: I – I really don’t – I don’t see it as a – you have had wonderful prompts and they’re real thought provoking, but I just – I don’t know that I’ve been that --

LUCIE: That’s fine. That’s fine.

CAROL: -- helpful – helped.

LUCIE: Okay. In your opinion, has regular journaling had any impact at all on the ways in which Dale’s illness has impacted your relationships? Or even your personal relationship with Dale? I know you sort of addressed that a little bit.

CAROL: Like I said, he has always enjoyed writing. He’s been really motivated by this class and has looked forward to coming each week and like I said, just to see that he is looking forward to it is something that it makes me feel good, because I – you know, I want to see him be as happy as he possibly can through this. And –

LUCIE: Okay.

CAROL: So hopefully the enjoyment that he’s gotten out of this will be something that maybe will be an advantage to him physically too. Maybe limiting the progress of the disease. I’m not sure.

LUCIE: Okay. Would you say that in general – I’m not sure this next question. I think you may have already answered it – that has your amount of writing that you do, has not increased since beginning the workshop? Okay. The next question is, have your feelings about writing changed, either positively or negatively, since beginning the workshop?

CAROL: I really don’t think that they have changed, Lucie.

LUCIE: Okay, that’s fine. I want you to be honest.
CAROL: No, I – I guess I just feel – I think I’m quite a private person and to write down something is to take the chance that someone’s going to read that and think whatever of me. I don’t know what. So, I just –

LUCIE: All right.

CAROL: And I’m sure that’s not the normal person’s thinking, but it is mine.

LUCIE: No, that’s good to know. Okay. This might be an interesting question for you to respond to. Do you intend to continue your writing journal beyond the completion of this workshop? Why or why not?

CAROL: Probably not on my own I won’t continue writing. I feel real sure that we will continue with your extension of the class, you know, whether it’s a once a week or once a month or whatever, but I don’t think on my own that I probably do –

LUCIE: Okay.

CAROL: -- get a lot more pleasure out of reading than writing, so that’s probably what I would do – will do more is reading.

LUCIE: And you were saying earlier in the workshop that you have been reading a lot of self-help types of interesting books.

CAROL: Yeah.

LUCIE: Can you – and this is an open ended question and meant to be, so – can you describe the type of writing experience you have had during this journal writing workshop?

CAROL: Oh, boy – writing experience – I don’t know how to answer that.

LUCIE: As a result of this workshop, do you feel more comfortable sharing your writing with others? Why or why not?
CAROL: I suppose I feel a wee bit more comfortable because I’ve done it, but I still don’t feel real comfortable doing it.

LUCIE: Okay.

CAROL: Because, I – like I said, I think, you know, they’re my emotions that are in the writing and that I just have a difficult time -- helping -- writing about that and so –

LUCIE: Okay. That’s fine. As a result of this workshop, do you feel like you have formed significantly supportive relationships?

CAROL: I don’t think so.

LUCIE: Okay. So with the other people in the class, you don’t feel –

CAROL: When you say relationship, I guess I think of, you know, a good friend. I have enjoyed, you know, talking with Elena and listening to her, with Barb, with you and I guess there – you know, you are all people who are to me, you are good people. You have good ideas and, you know, all have had experiences that haven’t been so pleasant and so I guess, you know, I’m glad to have known you and – but, as far as getting to be a real good friend – relationship type, there really hasn’t been that – that much time, I guess to spend with each other.

LUCIE: Okay. Okay. Fair enough. You don’t actually – and the other part of that question and maybe this would have influenced your answer in some way or not. More specifically, do you feel that you belong to a community that shares your experiences and concerns?

CAROL: Yeah, I think, you know, like I said we don’t know each other real well.

LUCIE: Right.

CAROL: But we know some of the problems, physical – health and so forth that we’ve had so, yeah, I think it does.
LUCIE: The last question is, what do you feel you have gained by participating in the writing workshop? And then, the second part of that question, are these gains more or less than you anticipated?

CAROL: I think that I have gained – and it’s probably more than I anticipated. I’ve gained – I just think that this has been such a terrible experience, this illness, that I think that any tiny little comment that someone makes is of value to me and help to me and there again, I said that – what I said before, I think it’s helped my husband and that makes me happy too. So, I think, you know, I’ve gained for myself and for my husband.

LUCIE: Good. Okay. Okay. Is there anything that maybe I haven’t touched on that – or something that’s come into your mind that you wanted to add?

CAROL: I can’t think of anything Lucie.

LUCIE: Okay. Okay. Thank you.
APPENDIX J: PRE- AND POST-INTERVIEWS OF DALE

Victory Center: Pre-Interview of Dale

LUCIE: Okay, the first question, Dale, is when did you become ill?

DALE: I believe that was in June. I know it was in June.

LUCIE: And can you describe your illness?

DALE: I have a very rare blood disorder, the disease is called MDS and there is not a cure for it. Well, there is, there’s a bone marrow transplant. But that don’t work for people my age --

LUCIE: Really.

DALE: And, so, anyhow, most everything is clinical trials.

LUCIE: All your treatments?

DALE: Yeah, and we -- when I say we, that’s my wife and I. It was just discovered through a routine blood test. No problems, nothing like that. And the doctor saw the number and said you’re anemic. Called me in and usually that’s Vitamin 12 or iron and my iron is real high, and he said there’s something wrong with that. He sent me to an oncologist who did a bone marrow and came back and said you have MDS and it’s so rare, that I know very little about it. And sent me to Cleveland Clinic, where a doctor – through a clinical trial, we thought it was way too aggressive. So, we went to MD Anderson in Houston, Texas and then we went and visited with a doctor at Stanford University who’s very involved with MDS and bottom line, I take a shot each week. Just had one this morning. And it’s trying to increase the hemoglobin count.

Everything with this disease is very, very temporary. I mean, remission can be months, it can be years, it can be days. So, bottom line, I’m just a guy that looks at my hands and says how in the hell can I feel and look so good and have something so terrible going on underneath that skin.

But, that’s just the way it is, so --
LUCIE: Wow. So, this isn’t leukemia?

DALE: MDS is called pre-leukemia. It often develops into acute leukemia and as I understand it, the one word you don’t want in front of the word leukemia is that word acute. And, in fact, the – one of the doctors says, you know, for technical purposes, you have MDS. You don’t really have cancer. I don’t know what the difference is, technically, but anyhow, he says it is – the nickname is pre-leukemia. So, a lot of people just die from complications from MDS. Cause it affects your red blood cells, your platelets, your white blood cells and all that stuff.

LUCIE: Your immunity?

DALE: Yeah, that --

LUCIE: Do you get sick easily?

DALE: No, that’s the one count that’s really good for me right now. So, I’m not having – I’m not having any health problems.

LUCIE: Oh, you look tremendously healthy.

DALE: Yeah, I’m not having any of that. I’ve been here and with some support groups and listen to some of the stories and watch the people and I can, you know, they look in the mirror, they can see why they’re having problems, so --

LUCIE: Yeah.

DALE: One of the doctors had indicated first that it could be fatal within a matter of a few months. Another doctor has said no, no, no, he said, that’s a long – that’s a ways down the road. You don’t have to worry about that right now. So, we don’t know where we’re at with that. It’s just something you deal with and we have strong faith and a wonderful relationship and a wonderful marriage, so we just do everything one day at a time.
LUCIE: Okay. The next question, you have answered it. Was the onset sudden or gradual?

And it doesn’t sound like you ever had any inkling that you were sick at all?

DALE: Oh my God, no. I had walked in the house from a 3 ½ mile walk and the message from the doctor’s office to call and the doctor said you have MDS and there’s no cure for it. And I’m thinking, Jesus.

LUCIE: And that was how you found out?

DALE: Yeah.

LUCIE: Wow. I think maybe this next question, at this time, how would you classify your illness? I don’t know how they classify – is it stable, in remission or --

DALE: It’s – those are very interesting questions about this disease because I would describe it more as early stages. But I don’t know how you really do describe that.

LUCIE: Okay. Fair enough. And this next question, I am going to put to you and I think I kind of understand the answer, but it – does your family member know that you’re participating in the workshop? And if so, how does she feel about your participation and – well, the next part of the question is, if she doesn’t know, but obviously your wife –

DALE: Oh, no, she’s the one that brought it to my attention somehow. ‘Cause she had come here with me on a couple of those support group meetings. And maybe she had read it in some of the literature they sent us. She’s a retired school teacher and she’s very much a perfectionist when it comes to writing literature and all that and I’m a retired railroader and everything opposite of that.

LUCIE: My goodness.

DALE: I don’t care why there’s a semicolon.

LUCIE: Well, this isn’t even about that.
DALE: So, I mean, I do enjoy sitting down at the computer and putting my thoughts on a word document and I’ve done that for – off and on for years and --

LUCIE: And that’s basically what this is going to be about, so – all right. What are some of the ways in which the illness has affected your life? And that can be positive, negative?

DALE: I’m not sure of very many positives. The negatives are the unknowns, very much so. I mean, that phone call turned our whole life upside down because we’re both retired. And all of a sudden, the majority of my wife’s time is spent on the computer studying MDS and that’s what they encourage you to do. And when first indications are that you might have months – just months to live, it’s – it’s – I don’t want to say difficult, just kind of slows you down. Gives you some different priorities.

LUCIE: Yeah. Do you have children or --

DALE: Uh huh, sure do. We have two children. Each of them is married and each one has two little girls, so we have four granddaughters that range in age from 8 to 4. And they live – one of them lives in Pittsburgh and one is a professor at the University of Arkansas at Little Rock.

LUCIE: What are some of the ways in which the illness has affected your relationships? And again, either positively or negatively?

DALE: I think it’s put a lot of emotional stress of – I don’t know if that’s a good word. I don’t know. You just kind of deal with the time limit and all of a sudden, time means more, to spend more time together, although we spend time together. It’s an interesting relationship that we’ve had. We’ve been married 43 years and what I tell people is, and I’m a person that wears all my emotions on my sleeve. My wife will – keeps them all buried in her heart, but it doesn’t take an illness like this for us to know how blessed we are. I mean, we’ve expressed that throughout our
43 years. So, there’s – there is no anger at God. There’s none of that kind of stuff going on. So, I don’t know of anything good that’s come out of it.

**LUCIE:** Okay. Fair enough. Do – let’s see. What are some of the ways that you’ve worked or are working to cope with your illness?

**DALE:** I try to be a realist. How do I cope with it? We made the decision, one day at a time. That’s definitely a horrible decision to have to make, but when you go from depression to doing a high five and saying the hell with it, we’re going to do one day at a time and hopefully have lots and lots of one of those – of those one days. And when we get down a little bit, we remind ourselves how fortunate we were to have that particular day again and looking forward to tomorrow. So, we’re not on a miracle cure chase. We deal with it as if what’s going to ever happen is going to happen. And the further away it is, the finer it is, but whenever it happens, however it happens, it just simply happens.

**LUCIE:** All right. Do you ever feel isolated and alone in coping with your illness?

**DALE:** Not – not really. I come from a family of six. Our family is very, very diverse and we’re very separated in distances. But we’re really, really a super close family. So, there’s a tremendous support system within our family and that – I not only have that with my wife. I have that with my brothers and my sisters and so, no, it’s not a lonely journey at all.

**LUCIE:** Wonderful. Okay. In your experience, are any of these coping methods more effective than others? Some people have described that they’ve tried yoga or massage therapy or different types of treatments. And I’m just wondering, have you found anything to be more effective than anything else?

**DALE:** We’ve come up here a few times to – I think three different support group meetings. Definitely, I recognized – I recognize, first of all, support groups are good. Just from the theory
of that, but from the reality and the participation, it adds strength to my thoughts about that. One 
of the support groups we attended here was for newly diagnosed people. And you get a sense 
pretty quick that you’re not in a boat by yourself on how you feel because these people have 
been through it and I think it’s been since June and I’m probably still somewhat in denial 
because I don’t see all the adverse affects that people see when they look in the mirror like when 
I look in the mirror, but I also know the results of my tests. So, I’m not really in denial, but I’m 
somewhat in denial. But that newly diagnosed syndrome, I’ll call it, was helpful. And I’m kind 
of – I’m very glad that we attended some of that because that is a tough period to go through, 
that newly diagnosed period. So, just having conversation with people that have actually been 
through it, is supportive.

**LUCIE:** Is that how the support group is, that it’s people who are further along or in remission?

**DALE:** Well, I don’t really know who picks and chooses to go to those and I don’t know what 
they reasons they go them because the majority of the people that I sit in the room with up here 
appear to be well along – well into their diagnosis and treatments and how they happened to sit 
into the newly diagnosed group, I don’t care why they did, but – but they weren’t going through 
newly diagnosed like I was. But they certainly recall their early diagnose and the feelings they 
had and I could feel very quickly how similar mine were to what theirs were. So, I don’t – I 
really don’t know how that group gets together.

**LUCIE:** I was just curious as to whether it was people who were offering support for those who 
have been newly diagnosed, from the standpoint that they were in a different phase now. Maybe 
remission or something?

**DALE:** I have no idea how that’s put together. I mean, it was just called newly diagnosed and -
LUCIE: It’s interesting. Okay. Before now, how often would you say that you write? Daily or weekly, etc. Sort of tied in with that is, describe the types of writing that you would do most often, if you do. For instance, letter writing, e-mailing, shopping lists, things like that -- to-do lists.

DALE: No, I don’t bother with to do lists and I don’t do shopping lists and – writing to me, there is not any system, there is not any schedule. There is nothing like that. I just kind of experience an experience, whether it’s humorous or whatever it is and I’ll say, damn, that would be cute to sit down and write my thoughts on that. And my wife and my family – I mean, these are usually pretty short little stories and that’s what they are. They’re just very reality stories.

LUCIE: Sort of like little anecdotes – personal?

DALE: Yes. And I enjoy that and it was interesting. This friend of mine the other day, we was talking about this – this teacher, and I had told him I just wrote one and so he wanted to read it, and I gave it to him to read, and he calls it “really raw emotion writing.” And it was fun to talk to him because he said, “There’re so many styles of writing,” and he said “they’re based upon your audience, you know. Do you change your writing for your audience?” And he says, “Who’s your audience?” And I said, “I am.” I mean, I’m really my own audience, and so most of them are really – what I write is strictly like you say, antidotes [sic] – and I don’t even know if – I don’t consider myself a writer at all. I’m a person that enjoys, on occasion, having something impact me and sit down and just use my thought process to put that on a piece of paper.

LUCIE: In general, and based upon your past experiences – well, you’ve sort of answered this, Dale. What are your feelings about writing? So, I’ll go on to the next. Can you describe the type of writing experience you had during your formal education?
DALE: I have very little formal education. I’m a person that’s – I’ve been very successful in my working years. I graduated from high school and I went to Heidelberg for one year, down in Tiffin. Raised on a farm. Very small community. I did not like school. I didn’t dislike school, I didn’t like school. I went to college to be a minister. Took the aptitude test and they told me I ought to be an undertaker.

LUCIE: Oh my goodness.

DALE: So, I went to school – keeping all that in mind, and I’ve often related to folks that that probably was the worst year of my life, just going to school because I did not – I just am not interested in formal education. My wife is a person today that still continues to want to learn, learn, learn. And me, I’m a life experience guy. And I want to learn from that and I went to work for the railroad. Hired out as a fire man on the railroad. A few years later, I was very active in the union and a short while after that, I went into the management side of the railroad. And spent the next 25 years in the management side and did pretty well -- for a farm boy, did pretty damn good.

LUCIE: How many years were you with the railroad, Dale?

DALE: 35 years.

LUCIE: My goodness.

DALE: About 30 of it, I guess, was in the management side. So --

LUCIE: And what prompted you to go into the railroad?

DALE: In the railroad, in those days, the fireman – you had a engineer and a fireman. The fireman would put the coal in the – made the locomotive and when I hired out, they didn’t even have coal, but they still had fireman and fireman became an engineer and I became an engineer and then I went into the management side. So, my wife comes from a very large family also,
farm family. She is the first one that ever got a formal education and when we raised our children, we had a pact that it was never going to be, “If you want to go to college, mom and dad will be here.” It was always, “Whatever college you select, mom and dad will be here.” And our boys both did very well in formal education. One’s got a master and one’s got a doctorate. And so, we feel very, very good about that. But as far as my professional experience, many and many and many a meeting I went to with our company, we would sit around these big tables and basically everybody starts every meeting by who is everybody that’s there and what is your background. And somehow that always leads to college. So, you know, I graduated from Harvard. And I graduated from Michigan State and my comment always simply was, I’ve simply never graduated and I’m continuing going to the school of hard knocks. So, I always put that very much into perspective. College educations are very important and they’re almost a necessity, but a college education doesn’t make anybody any smarter than me.

**LUCIE:** That’s true. Okay, thank you for that. Let’s see. I have a couple more questions here. Have you ever kept a journal?

**DALE:** No. I mean, on the railroad, yes. But not life experience type journals. I mean, they were reflective notes.

**LUCIE:** Okay. Great. In general, based on your past experience with computers and the internet, how would you describe your comfort level with the technology?

**DALE:** Compared to some people, I’m an absolute genius and compared to the geniuses, I am absolutely inept. So, I can stumble through and, you know, I really love the computer because it has spell check. The grammar part, they can take that out of there, because I don’t pay any attention to that – fragmented sentences and all that kind of stuff. But, I’ve worked with
computers enough that I can stumble through most stuff and it does not intimidate me. In fact, it’s sometimes a challenge to figure out what keys can do what.

**LUCIE:** And have you ever tried to participate in an on-line support group of any sort or --

**DALE:** We’re into one right now and it’s a very, very interesting one. And I’ve had very minimal input, but it deals with – it’s an MDS support group. The minister where we go to church lives somewhat close here. In fact, he’s the one that got Carol and I to come to Victory Center. And he found this site for me and showed us how to get signed up to it. And it’s an MDS support group. It’s a tremendous group. In fact, getting back from – we took last week and went to Maine to look at the leaves and stuff like that. Getting back from that, I got on the computer and there must have been 60 or 70 entries from this group. Now, they’re not addressed to me.

**LUCIE:** Right.

**DALE:** You can ask questions of the group or you can communicate with any one individual. And so, I’m – although I did say to Carol last night, that the trip – we need to get out of the house more. We live on a farm.

**LUCIE:** Oh, you still do?

**DALE:** We live on a farm. Live in a woods. All of that good stuff. And you can spend too darn much time in front of that damn computer. That computer can be very, very depressing. And going through a lot of these messages last night, reading exchanges between people, with MDS there is not a lot of good news. I mean, if somebody celebrates a seven-year anniversary, everybody writes and says great. I guess if I thought I was going to live for seven more years, I would really be excited. But that’s a pretty damn depressing note to be involved in and congratulate somebody that’s in their 40’s that they’re going to make it seven more years or
something. I mean, that’s – bottom line, I think there’s good information ‘cause well, say I went to this doctor. I got this treatment. This friend did this in New York. This friend went to Texas or whatever it is. Just -- so there is some good information and there’s only a few – there are only maybe two or three what they called standard treatments for MDS. None of them are cures. But one’s Vidaza, which is a cancer type drug.

LUCIE: Like chemotherapy?

DALE: Chemo, yeah, chemo type drug. And there’s one that’s on the market that’s just being proved right now called Revelet or something like that, for blood transfusion dependent people, which a lot of folks become, which I’m not at that stage. So, there are very, very few. In fact, I mentioned two – there’s another one out there. This one that I’m on now, Procrit.

LUCIE: I’ve heard of that.

DALE: Yeah, this – the one I’m taking is relative to Procrit. So there’s – I don’t think there’s five or six standard treatments. So different people will talk about their reaction, how it affected them, you know, so it’s enlightening, but it can be depressing as hell. When I got off that computer last night, I actually was depressed because it just brings back to home each time that there’s nothing really good out there.

LUCIE: So, it’s almost like it just encourages you to just – like brood on it or --

DALE: Well, I really like this site. And I like all the exchanges that’s going on between people because you really understand, there’s a lot of people involved in this, even thought it’s very, very rare. There’s a lot of people involved with it. And it’s good to hear little success stories, you know, I took it and I didn’t have any side effects. I took it and I had side effects. But the bottom – but the whole picture in perspective, there’s nobody saying, damn, I whipped this. You know prostrate cancer – no matter what the cancers are, there’s some success stories, real success
stories. MDS – haven’t found, other than blood transfusion – or bone marrow transfusions, there’s no cure for it. And the mortality rate for some – I’m 63, the mortality rate for somebody at my age to go through that, you’ve got less than 50% survival rate. So, if you’re real young, if you’re in your 30’s, 40’s, which this disease doesn’t hit very often, bone marrow transplant is something that can really be considered. When you get into your late 50’s and 60’s, you got to be pretty desperate to take that step. And there’s a lot of horrible side effects if it doesn’t work. So, it’s just a disease out there and it’s – I’ve got it and I’ve got it and that’s all there is to it.

**LUCIE:** Okay. The last question, Dale, is what do you hope to gain by participating in this writing workshop?

**DALE:** I try to consider myself an optimistic person and the word that was related to me is that this is a type of therapy.

**LUCIE:** Yes.

**DALE:** And so if there is a – if there is something that a person can do to make themselves feel a little bit better over and above something else they’re doing or something else they’re doing, then, you know, that makes some sense to me. And, so it isn’t nothing about making the disease go away, it’s just making yourself feel just a little bit better.

**LUCIE:** A coping mechanism?

**DALE:** Uh huh.

**LUCIE:** Okay. Is there anything that I didn’t touch on that you feel like you’d like to add?

**DALE:** I have absolutely no idea what the therapy is.

**LUCIE:** Okay.

**DALE:** I mean, if I sit down with one of my little stories and write one of my little stories, it always makes – I always enjoy that. When I get done, it’s a page or page and a half of
something. I always just feel good to have put my thoughts on paper. And I thought well, you know, I’m not interested in writing a novel, none of that kind of stuff. Nothing at all. And this friend of mine, Jim, he’s real excited about it and I’m saying, Jim, I don’t know what in the hell you’re so excited about. Well, he said, I just think it’s a really super interesting concept. He says if you have people write for therapy.

LUCIE: This is your friend at the University – at Firelands?

DALE: Yeah.

LUCIE: Okay.

DALE: He worked for me on the railroad for a number of years and then he took a separation from the railroad and he already had his – I think his masters in teaching English and he really didn’t want to go to high school teaching, so he’s at Firelands. So, he’s just getting that career started and he’s in his late 50’s and just a guy I love. And so, he’s just really excited. He just thinks that whatever you’re doing, he said would just be a great idea. He said it’s just something he had not ever heard of, so he’s really supportive of whatever you’re trying to do. So, I don’t know what my concepts are. If I feel that what we’re doing isn’t doing much for me or not worth the drive to come up here, it won’t be – you know, I just won’t do it. That’s all there is to it. I’m really super independent.

LUCIE: You’re coming from far, aren’t you?

DALE: Well, not far. We’re --

LUCIE: Port Clinton?

DALE: No, we’re further than that. We’re down around Norwalk. Do you know where Norwalk’s at?

LUCIE: I do know where Norwalk is. I used to work at Fisher-Titus Medical Center.
DALE: Well, that’s where I was this morning to get my shots.

LUCIE: Oh, really.

DALE: So, you worked at Fisher-Titus?

LUCIE: That was the first place I worked when I graduated and worked as a PT assistant and I drove – at that time, I was living in Woodville and I was driving from Woodville to Fisher-Titus every day. And my children were really little.

DALE: Going right down Route 20?

LUCIE: No, actually that was when they first opened up the turnpike exchange in Elmore.

DALE: Oh, so you would take the turnpike to Avery?

LUCIE: To 4, Route 4. And then I would – the route that’s right past 250, I believe.

DALE: Well, if you got off at Route 4, that’s were we got on -- today.

LUCIE: Okay.

DALE: I mean --

LUCIE: Then I used to go through this little town and then I used to make the “L” and go into Norwalk, I think it was on 250.

DALE: Well, you probably went into Milan.

LUCIE: Oh, that sounds familiar, yeah.

DALE: Yeah, Milan on 113 and then goes into Norwalk. But anyhow, we’re just seven, eight miles away from Fisher-Titus.

LUCIE: So, that’s where you are. Norwalk is a nice place.

DALE: Well, we live, like I say, we live on a farm out in the country.
Victory Center: Post-Interview of Dale

LUCIE: These questions are similar to the original questions, but they just have more of a retrospective flavor to them, so, I’ll just sort of – and the same applies as before, if there’s something you don’t care to answer or can’t answer, just say pass. Okay. At this time, how would you classify your illness? The same question as before, you know, stable, in remission, critical?

DALE: I really don’t know – the disease has not changed.

LUCIE: Okay

DALE: The disease in my condition is simply fatal. There’s only one thing you can do and that’s have a bone marrow transplant and the survival rate for that is around 40% for somebody like me, if you get a perfect match. And the 60% isn’t – you just don’t make it off the table. It’s a long drawn-out horrible outcome. So, that’s really not being anticipated or even being considered, so the disease is there and how fast it’s going to progress is just something we really don’t know.

LUCIE: And has this status changed since you began to participate in this writing workshop?

DALE: It’s only changed in that it’s part of time – and time is not on your side in this. I mean, time is on your side whenever you talk to people and they’ll say every day is important because they might come up with a cure. So, on that side, every day is important, but on the other side of the coin, every day that goes by is just a day that’s closer to the – to the fatal part of the disease.

LUCIE: All right. Since beginning this writing workshop, how often have you written about your illness and in terms of that, I mean, you know, have you written several minutes per day, weekly, only during the workshop times?
DALE: The questions that deal with the workshop, in fact that’s one of the things that I answered here, is how you could better improve it or something like that.

LUCIE: Uh huh, uh huh.

DALE: And my response was to that, is that’s a – to me it’s an individual thing that if you would take it out of the workshop and take it home and concentrate on it, that would be an improvement because that’s something I haven’t done a lot. I really concentrated or had lots of good in-workshop experience and I would say the prompts from the workshop caused conversation between Carol and I outside of the workshop. So, it’s not a totally within-workshop thing.

LUCIE: Oh, that’s good.

DALE: But to go home and sit down and journal, no, I haven’t done – I haven’t done that. As far as writing about my illness, you know, I might share thoughts with friends and family over the internet or the e-mail system, but not really in the sense of writing – just journal writing, I would say.

LUCIE: What factors have limited or supported the amount of time you have spent writing about your illness outside the workshop?

DALE: Well, like I say, I’ve done a lot of writing outside of the class, but it’s not really been in the format of a journal.

LUCIE: Okay.

DALE: The class certainly prompts you to think in a positive manner about good things in your life. That’s the best thing about the whole class. Through sharing with other participants the prompts in your preparation papers, all to me are aimed at the recall of good parts of your life. And not just simply even recall, but to focus ahead on good things in your life, instead of just
emphasizing or being hung up on the darkness of the disease you’re faced with. So I think the class has prompted me to be able to communicate better with friends and family, with Carol certainly. So the only – the only thing that’s inhibited me is just my lack of sitting down and saying, I’m going to do journal writing.

LUCIE: Right.

DALE: I mean in the class I’ve enjoyed that. The right atmosphere for – to go home and just do all that homework – never was good at home anyhow.

LUCIE: What -- you know, that just sort of – this is just a question that Elena and I were discussing and I’m wondering if you have any feedback on this. What do you think about the term journaling or journal writing? Do you think it’s appropriate for this class or do you think that the term Therapeutic Writing or – is more appropriate or –

DALE: I just think terms mean different things to different people. I mean, when I – when I tell people about coming up here to Toledo, I never use the word journaling. It just doesn’t fit with me. I always use Writing for Therapy. But I mean that just fits for me. That doesn’t mean there’s anything wrong with the name of the class, but Writing for Therapy hits right at home with me.

LUCIE: Right. And I think that’s what I sort of heard you saying in your response, that, you know, to go home and journal is not necessarily the same thing as it is for you to come here and write.

DALE: Yeah, I have this vision of journaling, like keeping a diary.

LUCIE: Yes.

DALE: And I’ve never been a diary person.

LUCIE: Uh huh.
DALE: I don’t – I don’t write for therapy as a diary at all.

LUCIE: Okay.

DALE: I mean, each individual exchange, like I say, be it on the internet or whatever, is – meets the need for whatever that topic happens to be at the moment.

LUCIE: Okay.

DALE: But it’s not a daily journaling or diary for me at all.

LUCIE: Fair enough. What writing technologies have you used during this workshop and by that I mean, have you stuck primarily to paper and pen? Have you used the computer at all?

DALE: Totally paper and pen. As far as the classroom goes – as far as the session goes, it’s really been – Carol – she’ll sit down at home and write and I just haven’t. So, mine’s been right here in the class.

LUCIE: Okay. Of the type of writing that we did, what type of writing did you prefer and can you offer some reasons for your preferences?

DALE: It’s very interesting to me how far off my thought process got from the general outline that I first read when you would hand them out. And I don’t think anything jumped out off of that paper at me as I would be able to answer it. Or respond to it. But then after sitting and thinking a little bit, and putting some life happenings together, they ended up falling into place with basically the very thing that you were asking. But I had to go a different route to get there. Like, I was just rewriting this one on pivotal moments. Much of the prompts really deal with – a number of them, seem to deal with kind of instantaneous things that happen to people and I turned a pivotal moment, which I couldn’t come up with a pivotal moment. But, boy, a pivotal period of time really fits me. I can really, really put my heart into that. So, when I – once I got away from the word moment -- or coincidence, I’m not a big believer in coincidence, but there
was a session on that. When I put together things that happened over a long period of time in our life and then you look back and say gosh, was that a coincidence, maybe it was a coincidence. But it wasn’t anything that would have jumped off of a page of here’s a coincidence that changed my life or that stood out.

**LUCIE:** To what extent have you been able to use writing as a method of coping with your illness?

**DALE:** I’ve always been good at that. Although when I say always, it sounds like I’ve had this disease forever. But to be able to experience something and sit down and put my thoughts on a piece of paper, I’ve always felt very, very blessed that I’ve been able to do that. And now it’s worked over into my illness situation to where I feel fortunate that I can express, sometimes to others, but really to myself, my thoughts. And I feel very, very fortunate about that. I like to write. I have no desire to write a book to anybody. Nothing like that. But to sit down and put my thoughts on a piece of paper and really paint a picture with my thought process and my writing abilities, very simplistic, nothing technical about anything I write as far as words or anything else, little short words and a lot of color. I just feel that I’ve been fortunate to be able to do that. And it helps me. It helps me an awful lot.

**LUCIE:** Do you think that your general comfort level and/or past experiences with writing were factors, either positive or negative factors in your being able to use it as a successful coping mechanism during this workshop?

**DALE:** I definitely feel that’s true on a plus side. My limitation on it was by not doing it at home, not being motivated to keep a diary as such at home, limited me because I pretty much did what I did during the couple of hours that we would be sitting here. So I didn’t take an idea and go home and run with it. I pretty much got those thoughts down on a piece of paper and we were
under time restraints and that’s okay. I mean, I understand that. The session can’t go on for hours. But I think I accomplished a lot for myself even with the time restraints and even without following up on it at home.

LUCIE: Okay. Let me just follow up on that a little bit more. The idea that I had originally had was that the time restraint idea would get you started on a thought pattern and then perhaps it could be continued. Is there anything -- on your own time, is there anything that I could do differently to make that more of an appealing option for people to continue something that they’ve started in class?

DALE: I don’t really know the answer to that. I think somebody like my wife – I don’t know how she would answer that question, but I would say – you ask her to go home and do something, she’s going to do that. I mean, that’s her life. You know, we’re here. We get some instructions. It’s a classroom. You’ve got homework to do. She’s going to do it. I don’t fault you in any manner, in any manner, because I’m saying when you’re dealing with me, I just – classroom’s over, classroom’s over for me. I’m saying – you’re not going to really give me a lot of incentive to do that, and you’ve got to have that incentive to want to do that.

LUCIE: Okay.

DALE: No, I’m telling you that the couple hours that we’re here each week, that’s a hell of a lot of time to be concentrating on a subject that we’re concentrating on it. And the value that couple hours to me was very, very – the value was exceptionally good and I don’t think I missed out on a lot of not going home and doing it.

LUCIE: Okay

DALE: And I don’t know how to really express that, or I wouldn’t have been coming to the class.
**LUCIE:** Yeah, that’s –

**DALE:** So that’s a couple of hours out of my life every week basically, so how do you – how do you give me incentive to spend another two hours during the week. I already spent two hours.

**LUCIE:** Right.

**DALE:** And that two hours is really, really beneficial.

**LUCIE:** Okay.

**DALE:** I mean to sit here and share with people that are in a lot worse shape than I am. Hear their emotions and hear their optimism. Hear the problems they’ve gone through. But how they face it, with a – somewhat with a smile. It’s not just a support group. I guess maybe it is. I don’t know. But, it’s different. When you write this stuff and share your personal thoughts – that couple of hours a week and that’s basically what it was, a couple of hours. Boy, that’s a lot of good constructive time for people like myself, anyhow, to donate out of that week to myself.

**LUCIE:** That’s actually very valuable information for me, because most people have not – because of either time constraints or other responsibilities have not been able to write outside the class. And it’s – yet it’s very valuable information for me to know that this time was meaningful. You know, sort of had a carry over.

**DALE:** Well, also, like I say, it gave Carol and I things to talk about and that wasn’t writing, but that was certainly a carry over from the – from the class and from the prompts.

**LUCIE:** So the idea of communication comes into play there. That’s really good. Thank you for that. All right, let’s see. In your – well, you sort of answered this and if you just want to pass on this, that’s fine, but maybe you’ll – maybe this will spark some additional thoughts. In your opinion, has the regular writing had any impact at all on the ways in which the illness has affected your life?
DALE: I’m saying the class has. The session time, because, again, I go back to saying that it gives you an opportunity to dwell on the sunshine instead of just seeing all the clouds. And there’s not a lot of time in the class in those number of weeks that were spent on the cloudy days. The different participants each threw in some sunshine into the conversation. These are – these aren’t people with colds This is serious damn stuff.

LUCIE: Yeah.

DALE: And to find a – some sunshine in it, damn right it’s good. Absolutely, it’s good.

LUCIE: Okay. And again this one – you have sort of touched on this, but I’ll see if this prompts anything else. In your opinion, has regular writing had any impact at all on the ways in which your illness has impacted your relationships?

DALE: Yeah, that kind of falls back into two or three of the previous questions because, like I say, Carol and I leave here. We’re different than the rest of them. I mean, we’ve got an hour drive ahead of us when we leave here and a good share of that hour is often rehashing the thoughts that went on with the different people or with our own thoughts or what we meant to say and didn’t get said or what we wanted to write and didn’t write. So, I don’t know if those doors are just automatically opened all the time or if it’s because – I’m saying it’s because of a class or session like this that those prompts enable you to better discuss things that sometimes you just don’t want to discuss.

LUCIE: Yeah.

DALE: You can’t just block it out. It don’t go away. So, it does open some doors to make it, for me, easier, but, of course, I had my wife here. So, she was seeing what was going on and I can see what was going on with her. I don’t know about the other participants, but I think having your spouse here was a huge, huge benefit for me.
LUCIE: Okay. That’s very interesting. In general, have your feelings about writing changed, either positively or negatively since beginning the workshop?

DALE: I guess that’s another one of those that -- instant moment decision. And I, like I say, I’ve always enjoyed putting my thoughts on the piece of paper. What this has done, is it’s built prompts that’s allowed me to put things on a piece of paper that I hadn’t thought about putting on a piece of paper. So, it’s been beneficial. Does it make me maybe want to write more?

LUCIE: Uh huh.

DALE: I don’t think of it as more or less. I’m just saying it’s an opportunity and there’s a prompt and it’s like many things that will set me off to see if something in the pretty flower that set you off, this class set you off. It gives you opportunity to think of things and if that results in you sitting down and writing something nice, not necessary even just writing. I mean, I found it enjoyable with some of our friends and family that have been interested in this class also that they want to know what goes on, so there’s an exchange there that’s happening. It’s not writing, but it’s an exchange, and that’s beneficial. Here’s what we’ve talked about. Here’s what we did. God, I hadn’t even thought about that and I wrote that down. Jesus, I’m kind of glad I remembered that. You know. So, those end up being conversations, but beneficial. .

LUCIE: Great. Okay. And again, feel free to pass if you’ve already said what you need to say on this. Can you describe the type of writing experience you have had during this writing – I’m sorry, during this writing workshop.

DALE: Very reflective. And very positive reflections. I’m a person that often has said, I don’t know why God’s blessed me with all that he’s blessed me with and the reflections that have been prompted have been not hidden medically, not suppressed thoughts, and anything like that, but it’s – but because of the prompts and asking yourself questions, all of a sudden, you start
bringing some additional things out that give additional meaning to your life. It’s not brand new revelations, but it’s reflections. And it’s – somehow your class, you put it together, so that the reflections come out – it might be prompted through a negative reflection, but then the positive reflection is always as forceful. You think of this little negative and how did that turn into a positive and I think everybody that was in the class responded on the positive side.

**LUCIE:** Your comments are so interesting. Thank you. Okay. Do you intend to continue your writing journal beyond the completion of this workshop? Why or why not?

**DALE:** Well, again, we’re going back to whether it’s journal or diary or whether it’s reflective thoughts. And I will say that I won’t journal – what I think journal really means or diary – what I think diary means. I think it will reinforce – well, I don’t even know about reinforce, cause I enjoy it to start with. Yeah, let’s say reinforce. That it’s fun – not just fun, that’s interesting, isn’t it? It’s not just fun, but that it’s kind of necessary. The things that I’ve considered as fun, a lot of deep stuff that I’ve written, even though there’s some funny stories, they have some deep reflections in them. The class says it’s really important to do that. Not just because, like I have thought of it as fun, or sharing a thought, but, by God, it really does make me feel good to put that stuff on a piece of paper. So, yeah, reinforce and encourage you and not for just the fun thing, but as a – almost a necessity.

**LUCIE:** Okay.

**DALE:** I don’t know if any of that makes any sense.

**LUCIE:** Yeah, that’s a very interesting comment. Thank you. As a result of this workshop, do you feel more comfortable sharing your writing with others? Why or why not?

**DALE:** No, I’m just not inhibited at all.

**LUCIE:** Yeah.
DALE: It would be interesting to hear what Carol would say about that, but I’m not inhibited whatsoever.

LUCIE: Okay.

DALE: I wear all my feelings right out on my sleeve.

LUCIE: Okay. And I think you were like that from day one. As a result of this workshop, do you feel like you’ve formed significantly supportive relationships and, more specifically, do you feel that you belong to a community that shares your experiences and concerns?

DALE: Oh, I don’t think there’s any doubt about that. I mean, we haven’t gone out to dinner with anybody in class.

LUCIE: Right, right.

DALE: But, I think when you’re going through the kind of things folks are going through, you develop an openness to be able to share really – and again, I’m not an inhibited person. I can share with a hitchhiker. But I think I’ve probably seen in the class maybe some other folks that maybe aren’t quite as open that have become more open. Specifically – oh, not specifically, that includes Carol. I mean, Carol keeps a lot of her thoughts to herself and I’ve seen even her as the class went on, open up a little bit more to people that, my God, she never knew them at all, much less family or close friends. So, yes.

LUCIE: Okay.

DALE: Did you want any of these things answered with just a yes or a no?

LUCIE: Oh no. They’re supposed – they’re open ended.

DALE: I’m supposed to be rambling, huh?
LUCIE: There’s only one more question. What do you feel you have gained by participating in this writing workshop? And the second part of that question is, are these gains more or less than you anticipated?

DALE: I would say I had probably little or no expectation. Had absolutely no idea what it was even going to be about. So, knowing that I enjoy putting my thoughts on a piece of paper, I thought well, maybe that’s what this will kind of end up being and it really was. So, I guess I did have some expectations.

LUCIE: What do you feel that you have gained? Are these gains more or less?

DALE: Well, I, you know, even like I say, without even doing the work at home, just a couple hours a week prompted recall of good things in my life. And I just think it’s really fun to – and beneficial to think about good things in your life.

LUCIE: Okay.

DALE: I mean, it’s – you know, the class, Lucie, I’m not sure is going to turn anybody life’s upside down one way or the other. I don’t think anybody that would come to the class would have that idea. But when you’re dealing with illnesses that are this serious, little things mean a hell of a lot. So, I hope as an instructor or a prompter or a coordinator or whatever you consider yourself.

LUCIE: Facilitator.

DALE: Facilitator.

LUCIE: Yeah.

DALE: Whatever that role is, you have to be very, very satisfied with little tiny moments of gratification. Cause, it’s not like painting a black room white. It’s making little, tiny in roads in people’s lives and those are significant.
LUCIE: Okay. Is there anything that you want to add that maybe I haven’t addressed here or that popped into your mind after we had moved on to another question?

DALE: Things that I would want to add is that we all deal with doctors – really sophisticated, bright, intelligent doctors -- people you really, really like. In some cases, I know people aren’t that fortunate, but I am. But they still have a professional life that they’re dealing with you on. And in the situation that you’re dealing with, it’s just as critical as that doctor’s profession. I mean, he’s prescribing this medication and various operations, or something, but, Lucie, there’s a whole lot more than just the physical well being of the body. There’s also the really, really huge need to work the mind and, you know, when the doctor’s got 20 patients out in the waiting room, you’re not – you’re going to have a little bit of time and I’m lucky with my doctors that they take that kind of time, but it’s a wholly different scenario. And it would be really good that if classes like this, somehow were introduced to these doctors where they would encourage patients to come to things like this to meet needs that the doctor don’t really and can’t really meet.

LUCIE: Right.

DALE: It’s not his ball game.

LUCIE: Yeah.

DALE: And it’s not necessarily like going to a psychologist or a psychiatrist. It’s something different than that that the class meets with people like that, that are in pretty touch shape. So, I needed to add that.

LUCIE: No, thank you. That’s very helpful.
Victory Center: Pre-Interview of Elena

**Lucie:** I’m going to start asking these questions. If there are any questions you don’t want to answer, then just, you know, we’ll just pass on them.

**Elena:** Okay.

**Lucie:** The first one was, when did you become ill?

**Elena:** According to the oncologist, I was in an advanced state of multiple myeloma when he finally diagnosed it, so he thought I had been ill probably three years prior to my diagnosis. And I did feel things, you know, more pain, more body – more difficulty in terms of bending and competing in the sports I was in. It was harder to run, you know, for training and it was much harder to go to a curling, say a curling tournament where you were – they’re called bonspiels or the nationals where you had to play multiple games, because it’s a hyper-extension of your body when you’re rolling out of the hack on the ice to deliver your -- and I’d get more and more – just stiff and it would get harder and harder to stand back up and I could feel it in my body, I just thought I wasn’t in condition because I was putting in lots of hours at Adopt America and that was not only a full time job, I did a lot of fund raising and speaking and traveling for the organization, so some weeks I could log in like 65 hours or I wouldn’t get home until 10:00 or if I was speaking, maybe midnight and driving long distances back and forth and things and I just thought – I’m just over working and I’m not doing any yoga or flexibility or the kinds of things that sort of make me feel nice and tranquil and my body nice and flexible. I didn’t realize, though, that I was really sick. I was still traveling back and forth to other countries and doing things and I – and it just didn’t occur to me that – I knew I needed to do something, there was something bothering my system and I needed some kind of maybe vitamins or maybe something
more than that, but – on one trip to Scotland I got quite ill and when I came back, I had a severe
gallbladder attack and I was, I was in a state where, you know, you are – what is the state where
you, where you’re liver bile backs up and you have yellowing of the skin?

LUCIE: Oh, jaundice?

ELENA: Yeah, I was jaundiced. My eyes – the whites of my eyes were rather yellow and so
when – after they took out the gallbladder and said, well my gallbladder needed to come out right
away, and I thought well that would solve it. That must have been what was bothering me. But,
I never – the basic problems never seemed to be solved. So, the question that you asked was
when I was diagnosed. A year ago in February, but the doctor had said I had probably been sick
for maybe three years or so before that.

LUCIE: Wow.

ELENA: So probably multiple myeloma has affected me, which is the blood plasma cancer. It’s
probably affected me about, about five years.

LUCIE: Wow.

ELENA: The last fifteen months that I’ve know about.

LUCIE: So, is it – is it a relatively slow moving --

ELENA: Yeah, it begins slowly apparently and it spreads throughout your bone marrow so that
you begin feeling the stiffness and the pain in your bones. The bones start to weaken a bit. After
I was diagnosed, they do a bone scan and I had said I had never had any broken bones, but when
they did the bone scan, they found that I had probably several fractures, mild fractures and ribs
on both sides that had healed and a fracture in my lower spine. I had a lot of back pain. Oh, and
I’d had problems with vertebrae in my life, with one that had ruptured completely. And so I just
assumed as I got older, you know, the pain would continue, the back pain and things. And I
guess little by little, as the pain got more intense and it got harder to walk up multiple flights of stairs and things, I just thought it was old age and arthritis starting to come in to play.

**LUCIE:** Did they check you for arthritis or for rheumatoid or anything like that?

**ELENA:** When they had started – I had complained to my – my doctor, my primary care doctor that I really wanted a good physical -- about the time I’d been at Adopt America a few months. And then after that, every time I would go in for my annual, I’d say, you know, I think there’s – I really want you to check, because I have more and more body pain. I have – I had a number of symptoms that certainly said something wasn’t right. I started having cramps, a lot of cramps in my legs at night, just over and over again. So, it was hard to sleep. And they were severe enough they were breaking veins up and down my legs and my feet. And there were other things. I started breaking out in rashes, like hives, several times during the day. They’d just come and they’d go away. And there were – I could name five or six symptoms that were indicative that something was wrong. But everything appeared to be okay. And my conditioning – if I took a stress test and things, I would always come out really in good shape. And I had good muscle tone still, so it was hard to say – every time I would go in, they said, well, you look good. You know, --

**LUCIE:** You do now, I mean, yeah.

**ELENA:** And well – this aged me a lot and there are a awful lot of things that – I mean, I can see the pain etched in my face, you know, in terms of all the lines from after I was diagnosed and they started the treatment. But, overall, even the oncologist said, you know, we’ll do this test just to rule this out, he said, but I – you just can’t – you’re not going to be one of my patients, you can’t be. But a bone marrow – a bone marrow test confirmed that I had the disease and that I was quite advanced. When the doctor told me, it didn’t seem so strange. Because as I thought
back about all the things that I had experienced, I thought, oh, that is why. You know, that’s what I was experiencing. It got harder on trips, you know, to walk multiple miles and that’s why I would feel so exhausted all the time, you know. I’d go to bed -- I’m just as tired as when I went to bed. My husband was incredibly shocked, though. It was the last thing in the word he would have expected. And so it’s been – I guess I’ve been living with the disease quite a bit longer than I was since I’ve been diagnosed.

**LUCIE:** Was it just a blood test?

**ELENA:** No, a blood test showed that I had a protein spike that was abnormal, but that had been showing up for some time. And my primary doctor did not think it was indicative of anything too serious. I did get tested for other things, you know, that were ruled out, ovarian cancer, pancreatic cancer. A few things, you know, in the months preceding, but she really didn’t think it was anything and every time we get a test, you know, there’s nothing really – you know, really wrong with you, kind of thing.

**LUCIE:** Wow. Okay. So, I think that kind of answered the second question. Was the onset of the illness sudden or gradual?

**ELENA:** Uh huh.

**LUCIE:** Okay. And so at this time, how would you classify your illness? Is it stable, in remission?

**ELENA:** Well, this is one of the cancers that unfortunately is terminal. There’s no cure for it.

**LUCIE:** Oh.

**ELENA:** When I was diagnosed, I was told – because basically I seemed so strong, that I probably have – it’s hard to tell how fast it will progress, but that I’d probably be able to hang around for some time. And reading the materials, the average multiple myeloma patient lives for
two years. And I was pretty sure that I would live quite a lot longer and I’ve met a number of people at a conference then after I was diagnosed who have lived three years, four years, even a few five years. So, I figured, with luck, you know, I would probably be in that kind of a situation. But right after I was diagnosed and we started the treatment, we started something called salvage – salvage chemo treatment, which knocked out my immune system and I hadn’t been diagnosed a month when I ended up in the hospital in very critical condition. I was brought in by a rescue squad and I had totally dehydrated because I had – it took about 72 hours to diagnose it, but I had salmonella poisoning. Which just absolutely was toxic and I had non-stop, very verilant diarrhea for over – probably it was a good two weeks, with that. And I had pneumonia in both of my lungs, too, at the time. I apparently had had pneumonia several times without knowing it. But it was probably all after the multiple myeloma had struck. Because when they started looking at my lungs, I had a lot of scarring. So, I spent, I was diagnosed mid-February, late-February and I spent into the first week of March I entered the hospital and I was in ICU in isolation for, oh goodness, about three weeks. And I was in the hospital until the first of April. I got out on the 1st of April. I spent almost a month in the hospital. Much of it in ICU and it was pretty critical. But the nice thing that happened there, I mean, it wasn’t nice, but my body went through such extreme stress with what was happening that it lowered my cancer rate. They check it by something called – there’s blood counts, IGG counts and things.

LUCIE: I’ve heard that, yeah.

ELENA: My IGG count put me in rather a dangerous situation and it got lowered enormously. So, as a count, one count, of how much the cancer had advanced, it dropped down. So that then my body started really responding to the treatment after – after, but it took quite a while to come through what had been really a severe devastating kind of problem in terms of what had
happened to my body. So, it took me quite a while to build my strength back up and to be able to start taking cancer medicine again.

**LUCIE:** Is that like a chemo?

**ELENA:** Yes.

**LUCIE:** Yeah. So, they don’t do like bone marrow transplants for this or anything?

**ELENA:** They can. But I was too far advanced. They felt at the time that I would not have lived through a bone marrow transplant. Now, I would probably be eligible. But since I – my immune system, even though it’s much, much stronger, I would be the one that would go to the hospital to be treated for a bone marrow transplant and the bone marrow transplant would be successful, but I’d die from a cold. I really -- the doctor has said – my oncologist has said, let’s not put you in situations if we don’t have to that are really invasive on your system. And we’re saving it. It will be kind of our ace in the hole. I’ll do the bone marrow transplant after the various medical treatments are no longer effective. And they keep coming out with new drugs. They don’t have a cure, but – and maybe they will. You know, maybe I’ll live long enough to see something that will turn this into – which is the expectation, that at some point in time, this will be a drug like diabetes, where very few people die of diabetes. They have it all their live, but, you know, you can live for a long time by having various medications. And hopefully that will happen someday with multiple myeloma.

**LUCIE:** Yeah, I never heard of it until you mentioned it. I’ve heard of lymphoma, but not --

**ELENA:** Yes. Lymphoma is much wider spread in the population. Multiple myeloma is – was called an orphan disease for a long time. But about 15,000 Americans are diagnosed every year. So, there’s more people with multiple myeloma and at one time when you got it, it was a very ugly disease so that it was a death sentence immediately, you know, within a very short period of
time and it was a fairly agonizing death. Now, they have made progress with the medications that are available. And people do live a little bit longer to, you know, I mean, there’s a difference between a few months and a few years.

**LUCIE:** Sure. Okay. Let’s see. This next question asks if your family member is aware that you’re participating in this workshop? But I imagine that --

**ELENA:** Sure. The answer is yes.

**LUCIE:** Okay. What are some of the ways and I know you’ve touched on some of this. But, what are some of the ways in which the illness has affected your life?

**ELENA:** Well, most profoundly, the work that I truly loved, that I thought I’d think of as really my life, work – why I was here, I’m unable to fulfill that role. I’m still able to be a part of the organization and I’m involved in activities of the organization and ultimately and trying to make it successful as an organization. But I can’t be there every day and doing what I was doing before.

**LUCIE:** Okay.

**ELENA:** It’s also, of course, affected relationships with my friends and my family, but probably for the better. Because we won’t – you know, we’ve had a chance to interact in very meaningful ways and you take the time to say the things you want to so and to spend precious hours with people.

**LUCIE:** Yep. Okay. What are some of the ways you’ve worked to cope with your illness?

**ELENA:** Well, I did – I read as many things as I could – did as much research as I could. Talked to both people who I respected that have the disease and have gone through treatments. Doctors that I believed had a good understanding. I tried to do everything that seemed logical to me that was offered by western medicine. And then I’ve explored a lot of other realms that I
thought would help me, both dealing with a terminal illness, looking at my life and feeling that it was a worthwhile kind of thing. I’ve done some things that I considered following spiritual paths. I’ve spent more time learning meditation, reiki, various massage and human touch sorts of things. I’ve had sessions with shamanic healers. I’ve done journeying myself – spiritual journeying where you work with a shaman and you go into a different type of state and you journey into a different type of realm and you find your power animal and you find out about your soul – soul retrieval type of journeying where the shaman goes and looks at different parts of your life and then finds parts of what he believes are your missing energy or your missing soul parts and brings them back to you. I would never have done that. I would have thought that was sort of a non-scientific or something that made no – it was certainly not something I wanted to be involved in while I was living my life the way I used to view my life. It’s made me very open to feeling that there are many people in the world that you can share bonds with and I also explored a lot of things. I’ve had a little more time now that I’m feeling okay and can usually manage my physical body. I went to an Irish Music Institute, which I never would have done before, too, because I really wouldn’t have had the time and I took – I took lessons playing the bodhran, which is an Irish drum that my son plays, has played in a band. And I’ve done storytelling with that band, but I never played an instrument. So, I was able to do that. And met people there, I met my – in fact, my teacher had been on a pilgrimage and brought me back then when he met me, had brought back a medal that had been blessed by the current Pope and had been pressed to the tomb of John Paul and it has the Madonna of Czestochowa on the back, the lady who – the Madonna that’s called the Black Madonna and she has a lot of healing power and that was given to me as a present. Well, in the past, having been raised a Protestant in a rather conventional mingling Church, I don’t know if I would have even appreciated that. But it seems to have had a
great deal of healing energy for me. And I’ve met people who feel a great need to give me something that will help me in terms of healing, that never would have – would have been probably afraid to approach me before. So, I think I must have in part of this coping, I must be far more open to all kinds of interventions and maybe you’d say certainly non-traditional, non-Western ways of approaching illness, whether it’s an herbalist and healing teas or meditation and freeing yourself of stresses and being able to focus on something else. The lady here at the Victory Center that does the healing touch kind of thing. Or the shaman, the medical shaman that I have seen a couple of times in Indiana. It just seems like everything is working toward helping me have the energy to fight this illness.

**LUCIE:** Wow. Okay. Thank you. That’s really interesting. Do you ever feel isolated and alone in coping with this illness?

**ELENA:** No. I feel – I feel held up by all kinds of people and spirits and – I don’t at all.

**LUCIE:** And you seem like you are open to different support, so I’m sure that that helps. Okay. In your experience, are any of these coping methods more effective than others?

**ELENA:** At certain times, I may find one or more of them helpful and I’m more drawn to them than others. But consistently, I don’t think – I don’t think I would say one is – somehow I gain – I gain strength or comfort from many different things.

**LUCIE:** Okay. And just before, you indicated that you thought that it was the combination of all of the approaches that are helping?

**ELENA:** Uh huh.

**LUCIE:** Okay. Before now, before beginning this writing workshop, how often would you say that you write?

**ELENA:** Daily.
LUCIE: Daily.

ELENA: But not this kind of writing. Writing’s always been a part of my adult life. I’ve always been a communicator in writing from – well, lots of different things. Letter writing, report writing, articles for magazines, whether it be in scientific journals at one point, all kinds of things. I’ve written – I’ve written travel articles for different groups that I’ve been involved with. I’ve written – I was a national officer for a Greek organization, not Greek -- fraternity and sorority and I did a lot of their communications as the director of their member education program. And my work at Adopt America, or my work at the University, every single day, I directed publications and promotion for all the special programs of the University, so I was always involved with creating things for the writers and artists and at Adopt America, I did much of the communicating in writing, whether it was the electronic newsletters to the volunteers, the publications that we did for the public, reports to foundations. I did stories a lot about the children and the families. I’ve always written a little bit for myself. There were times in my life where I wrote a lot of more introspective free verse kinds of things or poetry. When I’m really busy, I do nothing in that realm. Sharing experiences through letters with my friends. E-mail became very, very important in my life as a way to communicate and we used to have two or three little women’s groups things that – just friends that got together and we would share things back and forth, through e-mail primarily. And it became almost an informal kind of newsletter, but very story oriented. So, yeah, probably very few days in my life have gone by where I haven’t been using some form of writing and I would say while some of it was extremely directed to a particular thing, that – and you would have called it in more of a technical or report writing, that there was always a great deal of personal woven into the majority of my communications.
**LUCIE:** And did that go back to when you were growing up? Were you very --

**ELENA:** We were encouraged to write a great deal, even when we were quite small. We used to, in our family, we were encouraged – when the family was together, we had guests, to – everyone offered things, whether it was songs, or poems and we were encouraged to memorize poems and some of them were quite long and do various sorts of narratives and I had always organized the group – a group in our neighborhood when I was young into doing plays and we – we had all kinds of things, we were involved in. And as soon as I realized what diaries were, I had a diary with a lock and key and I kept diaries, wrote letters, and one of my – probably the most significant gift I ever got, my grandparents knew I wanted to write or be a writer and my grandfather gave me a typewriter. But he didn’t tell me how much it cost. In fact, he even told me it cost half as much and he made this deed up for me. I think I was in 5th grade or going into 5th grade, maybe, and he had me write him a letter with the typewriter every week and then I sent him money to pay for it. And at that time, you were lucky to make $.50 when you babysat or $.75 and I tried to send him a dollar every other week. So, I did a lot of dog walking and berry picking and weeding of people’s gardens and babysitting and things to do that and when I finally reached about $40.00, he sent me the entire deed to it. And it probably had cost, I think, when I saw the bill of sale, it actually had been about $112.00. It was an Underwood typewriter with a case and I just thought that was so – that was incredible. I kept it up until I was in college and then we had access to other typewriters and I sold it to my sister who was in high school for $20.00. My grandmother was incensed at the time that I did that, but – and it was – it was , I suppose because my grandfather had given it to me in the way that he had, that maybe I should have kept it forever and forever, but I was ready for another typewriter actually and it was prior
to, you know, computers, and I needed one before graduate school anyway and Jeannie needed
one to do her high school papers on, so --

LUCIE: So, it worked out.

ELENA: Yeah. Well, I thought it was working out very nicely.

LUCIE: Okay. In general, ‘cause you’ve answered 10 about the types of writing that you do
most often. The next question: In general, based on your past experiences with writing, what are
you feelings about writing?

ELENA: Well, for me, it was – it’s always been crucial. It’s been a way of communicating. I –
as a college professor, of course, I did a lot of lecturing and then I’m a storyteller, I joined this
traditional Irish band mainly because they wanted to have a storyteller who would do legends
and folk stories of the Celtic culture, so during their breaks because they all had an instrument,
but they also liked myth and legend and they didn’t have someone in the group. So that was
good for me because I got to come and be part of their group and listen to their music and then it
gave me a chance to be part of the group. So, myth, legend, storytelling, poetry, I like creative
forms of writing a great deal.

LUCIE: Okay.

ELENA: As a teacher, I did a lot of that with children, high school students, but I loved
working with the young children that were beginning to discover, you know, the power of words
and --

LUCIE: They’re so open to it. Yeah. Okay. Can you describe the type of writing experience
you had during your formal education?

ELENA: Well, in formal education, from being a freshman in college through graduate school,
you were writing generally as an assignment and whether it was English essays early on or later
– good lord, I can remember in graduate school, both in the masters and doctorate program, there were times when you wrote in some English classes where you had to write – I can remember one, you know, doing five papers at least. Another one, you had to read books by ten different people and write papers on them. So, you were writing a paper virtually every other week, or even more than that. A lot of long exams where you had to bring together many different concepts and then – and good old blue books, you know, you’d have a stack at the end – if you were an English graduate school student that you’d have a huge amount at the end of the year that you had put together. So, yes, at that time, my writing and it was pre-computers. You did a great deal of writing. Filled a great many notebooks over a period of time and most of it required you to synthesize ideas, to have a concept, to tie things together. Probably all good training.

LUCIE: Okay. Have you ever kept a journal?

ELENA: No. Probably a few times, something like a journal when I was traveling or involved in a seminar workshop, but it would be pointed – not so much, this is my life, I feel this way today. It was usually about what was happening or I was experiencing in the travels. A lot of personal reflection, though, tied in. I think I did that – I know I did that in China, but then I always – and Turkey to some extent, but I was always going to be writing something afterwards. Like in China when I had been asked to come in this group to China, I was supposed to be writing up things about the food for their travel publications that would make it more appealing to people from the west who were afraid that the food was going to be just ghastly and they couldn’t eat these terrible things to show them how rich and varied it was and how delightful it was going to be. So, it wasn’t – I would say, yes, it was a lot of myself in those things, but it wasn’t exactly like probably – maybe perhaps I have a wrong – a misconception of what we
actually are doing with this kind of journaling, but I would guess this is a great deal more on the feelings and emotions of yourself and there won’t be something else that we’re talking about.

**LUCIE:** In general, based upon your past experiences with computers and the internet, how would you describe your comfort level with the technology?

**ELENA:** Well, it’s fairly good. In terms of accepting it as a tool, I can remember thinking, oh, God, it’ll probably kill me. As far as creativity, ‘cause I did a lot of writing and I thought, you know, computers, you know, I write on yellow tablets and it probably when I am actually using a tool like that, it will probably absolutely stifle me. And, of course, as soon as I started, I fell in love with it because it just – it made it so fantastic, plus it’s a research tool, but it’s just – to be able to type, cut and copy, and move them around and put them in different clipboards and files, that was so fantastic compared to how many times I had rewritten something and ripped off pages and taken one notebook and taken – had to recopy something to something else. I was amazed at how liberating it was to have, to have a computer.

**LUCIE:** I had the same experience. Have you ever participated in a chat room or other online community?

**ELENA:** Usually not chat rooms. I have very limited experience with chat rooms or even when you’re – what is it called when you’re all writing at one time, back and forth, and you get instant messaging. I like e-mail. I like to read something and then respond to it. And I even like knowing somebody’s there and we e-mail back and forth two or three times a day. I’m not – for a couple of reasons. One, I just didn’t have time for chat rooms. And it didn’t really facilitate getting the task at hand done. Now, I haven’t tried it since I’ve been away from Adopt America and not working full time. Maybe I would. Particularly around particular topics -- there were a number of opportunities to do that with cancer groups and I just didn’t – I listened to a couple of
the phone conferences and things, you know, where you were able to ask questions if you had
gotten a cue and you could ask questions and they would answer them, but, no, I haven’t done
chat rooms. And I don’t have a real strong desire to either.

LUCIE: Well, I think that I should probably modify that, just say, you know, not necessarily a
synchronistic type of communication, but an asynchronistic one where you could access it at
your convenience and respond to something that’s been posted by somebody else.

ELENA: Interestingly enough, I’ve gone through– there are several geneology ones and ones
for Scottish history kind of thing where I had some interest and I’ve actually looked at where
they had a thread, you know, with messages posted and things and I actually used some of that
material, but I haven’t generally – oh, maybe I’ve responded once or twice when I had something
that was useful to other people. But I haven’t really gotten deeply involved in that at all.

LUCIE: And the last question, what do you hope to gain by participating in this writing
workshop?

ELENA: I see it as again being very open to exploring and finding out more things about
myself. About what is happening to me at this. Making me more ready for what’s coming next.
I don’t have a specific expectation – it just feels like the right thing to be doing right now.

LUCIE: Okay. Thank you. Very good.
Victory Center: Post-Interview of Elena

ELENA: Do you want to – after you’ve asked a couple of questions, test to see if the sound level is going to be okay, or if I need to talk louder?

LUCIE: Actually, this thing is so --

ELENA: Works, good.

LUCIE: It’s wonderful. All right. At this time, Elena, how would you classify your illness or injury in terms of, you know, stable, remission?

ELENA: Well, multiple myeloma is a terminal disease, so I’m still considered and always will be a terminal – terminally ill patient. But, I think I’m doing very, very well. And doctor says I’m kind of his model patient. I’ll have ups and downs, cause I’m real susceptible to infections, being immuno-suppressed, and there will be some – there are bad times and good times. I just got over that systemic infection, but I also went to Scotland and hiked and – so, I’m really enjoying, I think, a pretty good quality of life.

LUCIE: Great.

ELENA: And there’s no reason to think that that won’t continue now for maybe a good long while, if I’m very fortunate.

LUCIE: Has this status changed in any way since you began to participate in the writing workshop?

ELENA: My health has remained about the same. The writing workshop has added to my enjoyment of life and just has enriched me a great deal.

LUCIE: Okay. Since beginning this writing workshop, how often have you written about your illness? In terms of say, minutes per day, or week, or only during workshop times?
**ELENA:** Well, apart from the workshop time, I probably have written a total of maybe two hours a week.

**LUCIE:** Okay.

**ELENA:** Not every day. There were a few assignments where you asked us to try to jot things down every day and so maybe I would hit four out of six days. But, I really find, if I can find a block of time, an hour, an hour and a half, that if there was a particular assignment we had in class that I wanted to continue or it stimulated an idea for a poem or something else that I usually worked on it in a block of time.

**LUCIE:** Okay.

**ELENA:** And then I would say, maybe I picked up my journal two times a week.

**LUCIE:** Okay.

**ELENA:** But I’m also working on other journals as well. I did a journal while I was in Scotland about what was happening. My impressions of just Scotland – separate, and then I started three other journals, one for each of my children. And, so, all together, in class, I’ve worked – since class started, I have four different journals going.

**LUCIE:** Wow.

**ELENA:** Plus a few poems and other things that are separate files on my computer.

**LUCIE:** Okay.

**ELENA:** You stimulated a lot of writing. You got me writing a lot.

**LUCIE:** What factors would you say have limited or supported the amount of time you’ve been able to spend writing, about your illness or --

**ELENA:** I’ve had a few periods of real sickness. An example would be the systemic infection, where I was just too sick to even think about writing. But as soon as the antibiotics started and
we were on the plane to Scotland, I started a new journal. I have had so many activities, other activities. My family has had two or three special events. We’ve gone away for weekends. We have had things happening in the evening. In the morning, I tend to do my exercising, ‘cause that’s when I’m strongest. So, if I can do yoga or I can work out on the elliptical walker or lift weights, that’s when I do it. So, I think writing gets squeezed by time and then if somebody’s around or my husband wants to do something, I tend to get involved with other people, rather than spending the time by myself, sitting down and writing.

LUCIE: What writing technologies have you used during this workshop? I know we talked about this before informally and I’m thinking paper and pencil versus computer, on-line, any types of activities?

ELENA: Well, you know that I really like to see the handwriting forming, as an ideas is forming. So, a lot of pen to pencil and pen and a formal journal. Sometimes, I’m just scribbling on yellow sheets from tablets or the back of envelopes and then, you know, moving that idea into a journal. I’ve set up several files with different themes on the computer and I’ve cut and pasted and moved things around in using the more electronic technology. And as usual, I’ve done a lot of electronic communication and in a few places, I’ve forwarded something from writing class to someone else. The poem about, “Will You Remember Me When I’m Gone From Here”, I shared with a lot of friends by attaching that file to my e-mail. And then I had written a piece after the class started because someone had asked me – I did a trip to China, a long trip to China and part of it, we climbed a mountain called Tai Shan, which is – Tai Shan is a sacred mountain that the emperors used to climb to convene with the Sun God, because they were considered the Sun God on earth and there are still monasteries on the mountain and a lot of interesting things. And someone who was very interested in the Buddhist tradition asked me, did I know about the
mountain and when I did, they asked me if I could tell them more about it. So, I went back to a notebook where I had kept a journal when I was in China. I didn’t even remember that when this class started. Pulled out that old notebook, took the notes from Tai Shan, looked it up on the internet and saw that there were actually all kinds of pictures that another person who has like a site where you can go in and look at different parts of China and see what it looks like through pictures. And I took some of those pictures and that stimulated then writing about my experience on Tai Shan and when I sent it to the first friend, she told several people who then e-mailed me and asked, would I share that with them. So, I have done some sharing electronically.

My friend who gave me the medal that I wrote about, about the John Paul medal that has the Madonna of Czestochowa on the back. I don’t think I gave you that whole piece, but I’m not positive. If you look and you don’t have it, that was very long.

LUCIE: That was beautiful.

ELENA: I’d be very glad to give you a copy of that.

LUCIE: Thank you.

ELENA: But, that friend, had e-mailed me back and forth about – after he had given me the medal and had also copied a poem for me. It’s really a prayer from the internet. And had given me a little tiny journal that he wrote some ideas and thoughts for me about the medal. And then I told another friend about that and she did some internet research and then e-mailed me all of that material about Madonna of Czestochowa and sites. So I downloaded some of those and then after I’d shared the one thing in class, I brought in that material. You know, with the Madonna and things. I guess, I have used the internet in ways that supported what I was writing.

LUCIE: Wow.

ELENA: During this class. More than I realized until I’m just talking about it now.
**LUCIE:** Great. Oh, that’s very interesting to me. Okay. What type of writing did you prefer? That you did for the course? For the class – the workshop? I know that you were one of the people who often chose poetry versus narrative and can you offer some reasons for your preference?

**ELENA:** Well, I have always responded to metaphor and allegory and poetic images describing life and emotions, landscapes, from very descriptive kinds of experiences to emotional and behavioral kinds of experiences. So, poetry’s always been a good outlet. I like descriptive writing, though. I like narrative. I’m not as fond of straight exposition and I found – I often was writing descriptively, even if it was – you asked us to do something that became a list and I would – if I wasn’t writing poetry, I would write descriptive phrases about something as I saw it. But narrative, I used an awful lot, too. Where I was describing an experience, even bringing in some dialog, with individuals. But metaphors worked very well for me, which work in poetry and then the piece I wrote about pain, I personified and created out of the different kinds of pain that I feel, a whole list of characters. And then I gave – I gave them life-like qualities and make them actual living entities. So, all of those kind of things probably enter into my writing.

**LUCIE:** Great.

**ELENA:** It would have been harder for me, though, to do a documentary or do exposition writing about my pain, my experience. Although I wrote about my experience, it was more of a narrative and then I think in a very disguised way, that I’m not really talking about facing death. And that somebody would pick this out. I am really talking about it -- the poem “Tranquility” is really about my experience and where I am now emotionally. And yet a person reading that would not know that underneath all of that is my experience with multiple myeloma. And the fact that I know that I’m terminally ill.
LUCIE: Maybe you touched on this. Can you offer some reasons for your different preferences or choices of writing?

ELENA: I think it’s just that writing is so incredibly personal that my personality – my background leads me to see the world in ways that are metaphorical or descriptive in a poetic kind of way. More than necessarily wanting to express myself and the cold objective facts. Even though part of my academic training would lead me to see the world that way and to deal very objectively with death – to come up with a hypothesis and then support it through a collection of data and analysis. It seems to be sort of a cold, dull way of looking at life. When I’m trying to write, I want it to be warm and vivid and personal and the mechanisms that work best for me are the ones I’m describing to you.

LUCIE: Wonderful. Thank you. To what extent have you been able to use writing as a method of coping with your illness?

ELENA: It has been – it has been a way of processing both thoughts and emotion and it has been incredibly valuable in reflecting upon and dealing with both the reality of the disease and what I’ve been giving up. Because this was another example of receiving so much and being able to do something that I love doing, but never had the time to. And not really thinking about it in terms of it being a great gift until I actually started doing it and realized how much fun it was. And how satisfying. So, it’s been – it’s been great at the level of just adding an activity that was always very enriching for me. Like reading was very enriching for me.

LUCIE: Right. Right.

ELENA: And I used to always gripe about – I don’t have time to read enough. I don’t have time to read. Well, I do have time now. I’m doing so many things, maybe I don’t do as much reading as I’d like to, but I’m doing many times more reading than I’ve ever done before. Well,
since I’ve been an adult and working and raising a family and doing all the other things. So, reading and writing have been two extremely rewarding activities at that level and then beyond that, the writing, the writing in your class has given me a wonderful channel for working through thoughts, reflections, of what’s happened to my body. What’s happening in my life. What will happen to my family. And letting me wrap things up and pass things on to others that give me a great deal of satisfaction in doing.

**LUCIE:** Great.

**ELENA:** And it’s been very comforting. It’s helped me a great deal. I keep waiting to have to cope with extreme depression and it really hasn’t happened. It will be almost two years since I’ve known I was dying and except for a couple of very brief periods, you know, like maybe a week of feeling extremely anxious and stressed, I don’t think I’ve actually even really scratched the surface of depression. And I’m beginning to wonder now if that really will be – ever be a real major factor in my life. When you read about people who are terminally ill, that’s one of the very, very difficult things that they deal with. And being able to process the kind of emotions and look at them and know that I can move above that and beyond that. It has been one of the things that, of course, thinking, but writing has helped with so much. If I go back and read something I wrote, it ties things together for me and helps me process at a fairly deep level.

**LUCIE:** You are the second person who has said that.

**ELENA:** Well, that’s good then.

**LUCIE:** Yes. You are the second person --

**ELENA:** Because I don’t know how many people would know that that could be a real outgrowth of something like your class.
LUCIE: But, the ability to go back and re-read something helps you to relive the experience. That’s been said before.

ELENA: Good.

LUCIE: Interesting. All right. The next question you more or less answered, so I’m not going to go through that. Do you think that your general comfort level and/or past experiences with writing were factors, either positive or negative, in your using it as a successful coping method during this workshop?

ELENA: Oh yes, yes. I think I’ve alluded to that or said it or practically shouted it. Yes. It’s been extremely valuable. I would call it, you know, therapy. A very therapeutic method. I find meditation helpful. I find yoga helpful. I find certain physical therapies, like swimming very freeing, but this is a form of therapy that both frees me and allows me to process and grow in the experience, so that I arrive at a much more mellow, comfortable place both physically and mentally.

LUCIE: Let me repeat a part of that question, ‘cause I want to make sure that I relate this to you properly. Your general comfort level with writing and your past experiences. How do you think that they factored into the way you were able to use writing during this workshop?

ELENA: Well, I probably had more experience with writing, both doing it and teaching it, maybe than the average person coming in. So, I felt in some ways I was sort of jump started and then you stimulated us in ways that were so successful that maybe I had the tools and the past experience that – and then what you did. I wondered, you know, would I – how I would respond to writing in a group, cause it’s always been a very private experience for me. But I found I was incredibly comfortable from the very beginning. Both with the workshop atmosphere and with had the process of getting thoughts down on paper.
**LUCIE:** Do you think that your general comfort level with computer technology were factors in your using it as a writing tool during the workshop? And I know we kind of talked a little bit about it, but --

**ELENA:** Yes, but I could have gotten along without the computer. I could not have gotten along without a pen and a journal. So, the pen and the journal were far more important. I would never have been comfortable with bringing my laptop, for example, into the workshop. And I know a lot of people would. That would be my son, a number of my other friends. That would have been what they would have wanted to do. You know, come in and share and then share what’s on the screen or attach it to a printer and print it out for the class. That would have been an obstacle for me. I could have done it, but I felt so much more comfortable with my journal and my pen. I did – I think I told you how I used – it was very helpful in getting research material and some things I found I could do much faster if I was working on the concept to do it on the computer and cut and paste.

**LUCIE:** Right.

**ELENA:** But, for the most part, I could have lived without that computer and had a really successful experience in your writing workshop.

**LUCIE:** In your opinion, has regular journaling had any impact at all on the ways in which your illness has affected your life?

**ELENA:** I think – I think it’s allowed me to be even more reflective and to move beyond the terrible days, when I wake up and everything hurts so bad. I know it’s going to be hard to get out of bed and get my clothes on and get my shoes on and I don’t really feel like going down and taking my protein and my meds and looking at what I need to do on the calendar. I can think the
thoughts that I have written about or I can go back and read something and – or I can sit down and write how I feel and, yes, it makes it – it makes it more possible for me to keep going.

**LUCIE:** Okay.

**ELENA:** It’s giving me a more long range view. It’s also helped me – move me by the – through the moments that are not very good. I think you’ll see that in that piece about pain.

**LUCIE:** Okay.

**ELENA:** I mean, if you can do a stand up comedy routine, essentially, or use black humor in relationship to what’s happening, that sometimes it’s just excruciating and absolutely debilitating – that you can – you know I’m not stuck in that spot. That I’m already thinking about the next good day.

**LUCIE:** Okay. In your opinion, has regular journaling had any impact at all on the ways in which your illness has impacted your relationships?

**ELENA:** I would say yes, profoundly. The journaling will help me leave a lasting legacy for each of my children, where they will understand the bonds of love we share and just for me doing it, it is a gift from journaling. It will be a gift for them for a long, long time. I know it will be very, very meaningful. So, yes, I think it’s going to be a very beautiful part of our relationships and strengthening them. A couple of times when I’ve been very irritated with my husband because I think, for the most part, overall he’s been highly supportive and sensitive, but when those times when he hasn’t been, whether I write it down or I think it – through it, in a way that I would write it down, it’s been very freeing and very forgiving and allows me not to get stuck in that moment of being upset or provoked. So, yeah, I guess I think it’s helped my day to day relationships to a degree. And I think it’s going to be profoundly important in both my long term relationships with the people I love and the legacy I leave behind to them.
LUCIE: Since beginning the workshop, would you say that the amount of writing that you’ve done prior to the workshop has increased? And sort of a second part to that question, has there been a change in the type of writing you do most often?

ELENA: Yes. I had apparently written more journal type things than I realized. You know, like going back and finding the journal from China. I imagine there have been other points in my life – ‘cause I think I told you, I never had done much journaling or I had done diaries when I was a young girl and high school girl, maybe. But, and I have always been writing. I did a lot of writing – Adopt America, all of the newsletters and stories about families and a number of other kinds of communication, but I’m really doing a lot of private, personal writing now. I had written poetry before and a few short stories, but I’m – I’m finding this to be a part of my life that will probably keep continuing because I’m finding it so satisfying. I want to start working – pulling out after Christmas the pieces I started on the life of my grandfather. Which really will become a historical fiction because I don’t – there’s not enough total, total facts there that it would make – even to do a short story on one section of it. I would have to round it out with fictional kinds of material, but there’s that. There’s a lot more poetry that I want to – I want to deal with and I have the journals to finish with each of the children and then maybe I’ll do them for some of my really close friends and my husband and I see myself doing a lot of journaling from here on to the end.

LUCIE: Okay. In general, have your feelings about writing changed, either positively or negatively, since beginning this workshop?

ELENA: I’ve always loved writing. I’ve loved other people’s writing and reading different styles and different forms of writing. And I’ve loved writing myself. It just – it got crowded out with all the other kinds of things. I’ve thought several times about joining writing projects,
writing groups, but since my doctorate days when I actually was an intensive part of the research and working with little children, I’ve been so busy with other kinds of things that it just didn’t seem like I could take time to do it. And, if anything, I fell in love with it again. Now that you brought that back into my life in a way that is – I don’t think – I don’t think that I’ll ever lose that affection for writing and desire to be involved in it.

**LUCIE:** Okay. The next question, you’ve – if you think that you’ve commented on this, then we can move on. I’ll just say it in case it triggers anything new. Can you describe the type of writing experience you have had during this journal writing workshop?

**ELENA:** Well, I mentioned some of the types of things I’ve had and I guess, you know, if I wanted to, you know, grade the overall experience, you know, it was an A+ experience being in your – the way that you had structured the group and brought us through the different writing experiences. It was incredibly productive, I thought. I’m surprised, you know, looking back at – my journal is pretty full. And then if you look at the other journals I’ve started and other pieces on the computer, this is a very, very productive time as far as – I don’t know about quality, but quantity – I produced a lot.

**LUCIE:** Sure, sure. Okay. As a result of this workshop, I think that you commented on this earlier. I’m not sure if was when we were interviewing or not. But maybe you could elaborate. As a result of this workshop, do you feel more comfortable sharing your writing with others? Why or why not?

**ELENA:** I think the answer is, again, yes. I don’t know if I’d stand up in the middle of a crowded auditorium and read something, but I feel really comfortable with the kind of positive responses in our little group and how warmly I feel toward everybody in that group. And that was not the case before I walked into the room the first day. I would have hesitated to read
anything out loud. I don’t think I would have been volunteering to bring in poems. I don’t think I’ve ever – well, when I was a professor, the students pushed me to publish a couple of poems in an anthology they were doing. And I was hesitant about that. But I did it. But other than that, I’ve never shared most of that kind of writing with anybody.

LUCIE: Okay.

ELENA: I’ve showed a couple of things to my husband and I may have just done that since we’ve been in the class. I don’t know – I guess I’ve – maybe over the years, I wrote him a couple of little things, but I notice I’m less reluctant to send things – put things in front my husband and children and then I have been e-mailing things to people and maybe in response to their requests. Like, did I know anything or had I been to Tai Shan and what was my feeling about that. And I – I had, although you didn’t get it, e-mailed you a couple of things which now you have. And I’ll probably, now that I’m comfortable with that, I’ll probably be sending things back and forth to people more often.

LUCIE: This next question may be particularly relevant. As a result of this workshop, have you formed significantly supportive relationships? More specifically, do you feel that you belong to a community that shares your experiences and concerns?

ELENA: Oh, yes. And I think that’s why everybody in our little group doesn’t want that to disappear. They don’t want to lose those links.

LUCIE: Right.

ELENA: I think we all know that meeting on a weekly basis would be impossible, but that to really keep those ties where we have a forum for sharing our experiences as well as our writing, that we’d like to continue in some manner to be brought together and I think everyone sees that if you’re involved, it’s much more likely to remain a cohesive body where we do that.
LUCIE: And the last question is, and this is very open ended. What do you feel you have gained by participating in this writing workshop? And are these gains more or less than you anticipated?

ELENA: Well, I’ve gained a great deal more, because I really wasn’t even sure that the workshop was the right thing for me. I thought it had a high probability of being a positive experience. I didn’t realize how positive or just how wonderful the experience would be. Both in stimulating my writing and also as a factor in letting me look at and reflect upon and get some closure and move on or grow in relationship to my illness.

LUCIE: One of the things that I – that’s the last official question I have. But I was wondering about your response to this. One of the things that I was thinking about earlier when you were talking about – I hope I don’t lose this thought. Kelly and I had talked about if we thought that maybe the term journaling was a turn off to people and I noticed that you said in one of your comments just before that – it was the question that I asked about the type of writing did you prefer? And you had mentioned that if it was more of a chronological type of writing, it would not have been as meaningful to you. And I’m wondering if that term journaling is something that people are associating with just that? And, I don’t know --

ELENA: That’s a really good point because all the way along since I’ve been diagnosed, I’ve received material that says, how to cope with your illness. And, invariably, there’s something about a journal. Journal. Keep a journal. Have a list of things to tell your doctor about your symptoms. Because they won’t all come to you when you go to the office, so be sure you keep a diary of what’s happening every day, you know, when you feel nauseated, how the meds are working, and that sounded so – I thought I should probably do that, but that did sound as exciting as filling out more insurance forms. And I’ve never done it. Every time I get one of those, I
think, well I should do this. But it sounds like scrubbing the kitchen floor and waxing it. It’s not something I want to spend my time doing. And yet, what we did, was so incredibly different and creative and liberating and growing, it was not at all like what I perceived they were suggesting you do. And they did use the term, journaling, sometimes. And I guess when they talked about it, they talked about journaling and some – Kelly in a couple of the fliers or of the writing thing --

LUCIE: Right.

ELENA: I really – I think that – I really wasn’t sure that this would be an incredibly useful experience, but I thought it had the potential and then when we got in the class and the writing was so much broader and so much more open ended, that I had perhaps thought in the beginning, that I was – it was so much more than I expected. So, maybe – maybe the term journaling does create a sense that it’s going to be a much more focused task on describing your experiences with your illness.

LUCIE: Yeah. Because I notice, then the other thing that sort of – somewhere here in our interview in the last few minutes, you’ve talked about – you said something about it really being therapeutic, so maybe that is a better emphasis and actually that is – the way my dissertation is being titled, so maybe that should be the emphasis on therapeutic writing, rather than journaling.

ELENA: I don’t know how other people would respond – I – I think some people are totally frightened by the concept that they’re going to be sharing something intimate and other people are frightened by the fact that they weren’t good writers or they flunked Freshmen English and they’re scared that they’re exhibiting how poor their skills are in front of other people. So, I’m not sure what would attract the most people, but if I thought we were going to be – doing a daily diary, diary in a journal about our medical symptoms, and what our experiences with nausea were on that particular day, I probably would not have wanted to be part of it.
LUCIE: Do you intend to continue your writing journal beyond the completion of this workshop? Why or why not?

ELENA: I’ll continue this journal and other writing projects. I have, as I said, journals started for each of my three children and if I live long enough, I’ll do them for maybe other friends and my husband and I also want to work on writing from my grandfather’s journal and turning that into something that can be passed on in the family. And hopefully, will have our group continuing in some manner and I’m going to join this rather loosely constructed group of – of creative women who are involved in different things from other forms of arts as well as writing. And they have a Friday salon that meets at least once a month. I think generally twice a month where they spend the afternoon, about three hours, doing what they want to do and then there’s a area for meditation and just relaxing and people stop and have tea and they do other things and chat, during that time.

LUCIE: Very neat. Okay. Thank you. Anything else that you want to add, Elena? I want to make sure I didn’t interrupt you in any way or --

ELENA: I think your questions are so open ended that they triggered maybe even more than you wanted from me, but –

LUCIE: No.

ELENA: And I’ve said this over and over, but I thank you so much, Lucie. It was – you gave me a great gift with this and I think other people would say the same thing. Maybe in a different way, but this was a wonderful, wonderful experience.

LUCIE: Well, it was for me, too. And I certainly hope that we can --
St. Vincent’s: Pre-Interview of Duane

LUCIE: Okay. Duane, when did Karen become ill?

DUANE: Well she had her mamm done in January of 2003 and then in March is when she had her surgery.

LUCIE: Okay. So, would you say that the onset of her illness was sudden or gradual?

DUANE: That portion was sudden. We weren’t expecting what they gave us – that was.

LUCIE: Okay. Okay. At this time, how would you classify her illness, stable, critical, non-existent or --

DUANE: Non-existent. She’s – the cancer’s all gone.

LUCIE: Okay. Okay. The fourth question, I don’t think really applies because obviously you guys are both here, so you know that you’re doing this.

DUANE: Right.

LUCIE: Okay. What are some of the ways in which the illness affected your life?

DUANE: Well, I’ve always – you always worry about your spouse, but you worry more once you find out that there’s something that serious wrong. ‘Cause you really don’t know what the outcome was going to be at the time.

LUCIE: Okay. And what are some of the ways in which you would say that the illness affected your relationship?

DUANE: I don’t think it affected us anything – any way. She said closer.

LUCIE: You get to say that.

DUANE: No, ‘cause I feel that when you’re married, you know, everything is connected. So what she’s feeling, I’m feeling. So, to me, I didn’t feel that there was any difference at all.
There was more concern on my part, you know, for what was going on, but I mean, as far as any extra love or anything, it couldn’t be more, ‘cause it’s all there anyhow. So, I would say that’s what it is.

**LUCIE:** That’s very sweet. Okay. What are some of the ways that you worked to cope with Karen’s illness?

**DUANE:** By going with her to her meetings with her doctors, go to the radiation, this type of thing. It kept us both in connection with what was going on. She wasn’t going to have to worry about telling me what was going on, I was right there. What I would miss, she would collect. What she missed, I collected. So, we just worked real well together, I believe.

**LUCIE:** Okay. Great. Did you ever feel isolated and alone in coping with Karen’s illness? Why or why not?

**DUANE:** No. No, cause we were together all the time. So, I knew exactly what was going on all the time with her. I knew if she was – she didn’t ever have a bad day. That was one thing. She had an uplifted spirit through the whole thing. She was never down. So, I think if she had been down, the situation would be a lot different and I would have different things to tell you other than what I’m telling you. Because, with her being up all the time, it was just like it was our normal life.

**LUCIE:** Wow. Okay. In your experience, were any of the coping methods you tried more or less effective than others?

**DUANE:** I don’t think so. I think it was just a balance all the way through.

**LUCIE:** Okay. Before starting this journaling workshop, how often would you say that you write? And the options are daily, weekly, etc. But sort of in combination with that question, is
to describe the types of writing that you do most often. For instance, it can include things like letter writing, e-mailing, shopping lists, to-do lists.

**DUANE:** Okay. I’ve written a lot. I do journaling as far as when we go on vacation or any type of trip, I journalize that. Because I like to be able to know what we did per day. And then it’s easier for anybody that wants to read it that they can just go ahead and see just what we did. And if I’ve got pictures, it’s something I can collate with it. And then as far as what have I done in types of writing, that type is the journaling for going out on our trips. I have done letter writing. I’ve done e-mails to companies that I’ve had problems with or something like that. If you got an e-mail, I send that out to them. That’s about basics.

**LUCIE:** Okay. Good. In general, and based upon your past writing experiences, what are your feelings about writing?

**DUANE:** I like it because you can express yourself.

**LUCIE:** Okay.

**DUANE:** You can, you know, things that you might not be able to say, you can put it in writing and to me, in writing, it gives a person a longer time to acknowledge what you said. You know, over the years, you know, if you went back over and looked at stuff later on, you can still see it.

**LUCIE:** Great. Okay. Can you describe the type of writing experience you had during your formal education?

**DUANE:** All ages, in basic school, you had your types of reports that you had to do, but then when I worked at the bank, you had to do reports and I did a lot of report writing then because I was an auditor. So when you went in and audited the departments, you had to then give a report on what you found in that department and then we also did flow charting which then you’re
doing interviews with people and you’re getting all this information as well. So, I’ve done all that.

**LUCIE:** Okay. So it’s been mostly in a business – business type --

**DUANE:** Business. Yeah, and now with me working in the schools, I do referrals on kids and then you get to do much more experienced writing. It’s much more elaborate. I love that, because you can add a few touches that you couldn’t use otherwise.

**LUCIE:** So it sounds like you do enjoy writing?

**DUANE:** Oh, I love it.

**LUCIE:** You answered the next question about keeping a journal.

**DUANE:** Yep, I do.

**LUCIE:** That’s fine, you already answered that. In general, and based upon your past experiences with computers and the internet, how would you describe your comfort level with the technology?

**DUANE:** Mild.

**LUCIE:** Okay.

**DUANE:** That’s something that changes all the time and if you’re not connected with it on a daily basis to be using it like in a business, that’s a little difficult. When I was working at the schools, I was on the computer more. So, that was – that kept me more up with what was going on. And I was also able to find out what the school was doing with the computers. Well, now I’m not in that capacity, so now I’m back to my wild state again.

**LUCIE:** Have you ever participated in a chat room or other on-line support kind of community?

**DUANE:** No.

**LUCIE:** Okay.
DUANE: No, I’ve always kind of stayed clear of that because you never know what’s out there. If you can’t see their face, forget about it. Just like, I don’t go to an ATM. I never use an ATM because I said if I can’t see the person taking care of my money, they don’t get my money.

LUCIE: Oh, wow. Okay.

DUANE: I don’t – I strictly deal with the banks -- I gave the card back to them and I says, keep it. I don’t want it. They were charging me $1.00 for the fee for it and I said, credit my account, ‘cause I said, I’m not using the card. I said I worked in a bank for too many years. I know what can be done inside the bank illegally. So, I said, there’s no way I want my stuff played with through a computer. So, I said, I will do it myself.

LUCIE: Wow. That’s pretty neat, though that you – you know, I think it’s true. Once you work in a system, you are much more suspicious or critical.

DUANE: You’re more alert to what’s going on and now it’s more sophisticated than it was when I worked at a bank ‘cause that was in ’81 when I left. And things have really exploded since then as far as technology goes. So, I said, there’s no way I want one.

LUCIE: And then the last question is what do you hope to gain by participating in this writing workshop?

DUANE: See my wife learn how to do it.

LUCIE: You’re too funny.

DUANE: She’s is one that does not like to write. She doesn’t like to do that kind of stuff. I do it and I think – I have a lot of fun with it. I want to see her do the same thing.

LUCIE: Great. That’s great. Oh boy. Now the pressure’s on you.
St. Vincent’s Post-Interview of Duane

LUCIE: All right. At this time, how would you classify Karen’s illness or injury actually, her illness, essentially the same question as the last time.

DUANE: She’s doing fine.

LUCIE: Okay. And has this status changed since you began to participate in the writing workshop?

DUANE: No, no, she still hasn’t been sick.

LUCIE: Since beginning this writing workshop, how often would you say that you have written about Karen’s illness. If you want to talk about it in terms of minutes per day or weekly or only during our workshop times?

DUANE: Needless to say, I haven’t done much.

LUCIE: Okay.

DUANE: It’s just that I have not had time to do it.

LUCIE: That’s the next question.

DUANE: You know I don’t have the time to do it. I think that after the holidays, I think is when I’m going to be able to actually – that we can actually sit down and I can start doing more of what I want to do. I’ve done some of the journaling, but, you know, cause I did some in class, but then I want to be able to do more. But I need to have her input on some of this stuff because I want to make sure that all of it --

LUCIE: Dates are right.

DUANE: -- jives correctly.

LUCIE: Yes, I can imagine.

DUANE: And she has all that information and she would know.
LUCIE: The next question has to do with what factor or factors have limited or supported the amount of time that you’ve been able to spend writing about Karen’s illness.

DUANE: Too many things going on. Just have not had the time. Eventually, that’s going to change, hopefully.

LUCIE: I know. I hear you. Okay. What writing technologies have you used during this workshop. By that I mean, pencil and paper, did you do anything on the computer?

DUANE: I haven’t done anything on the computer, other than if I’m writing a letter to a business or something, I’ve done that. But as far as otherwise, it’s all been paper and pen. I’m not a pencil writer. I cannot stand writing with a pencil. To me, it doesn’t look as neat.

LUCIE: Uh huh. It smears.

DUANE: It smears, right, right. ‘Cause you’ve got to be very, very cautious on how you handle that paper afterwards. And I just prefer the ink and I always use black ink, I never use blue. I’m strictly a black ink person. But, I journaled while I was in Florida.

LUCIE: Did you?

DUANE: I journaled while I was down there. I got my Mom journaled and she also helped me with journaling my Dad.

LUCIE: You interviewed them?

DUANE: Uh huh. Well, my Dad’s gone. So, she said I’ll give you as much information as I possibly can about your Dad. And I said that would be fine.

LUCIE: So you just sat down with her?

DUANE: And we sat down for a day and it was just the two of us and we talked.

LUCIE: That is incredible.

DUANE: And we had a great time, great time.
LUCIE: And you wrote it all down?

DUANE: I wrote it all down.

LUCIE: Oh, my goodness. Did you use a tape recorder at all or just wrote it?

DUANE: Nope, nope, just wrote it. I would just tell her to slow down ‘til I made sure I got everything on it that had to be put in. And then she said, she said now there’s certain things like with my Dad that I can go ahead from then in one spot and do because I was around and old enough to know what was going on. And especially for like his ministry and this kind of stuff and how that started. I can do that part. But as far as my Mom working, I never knew that she worked so many different jobs, you know, before she got married. And then after that, then when she got married, then she didn’t work anymore, ‘cause it was strictly raising the family. But I – they got pregnant for me out in Cape Maine in New Jersey when my Dad was on his Navy tour here and so once she got far enough along, he told her, you come on back home and that’s where I was born then. So, yeah, there -- all this steps up to this -- a lot of it I didn’t know before.

LUCIE: Oh, that’s wonderful.

DUANE: And so it was interesting to hear a lot of it. It was neat.

LUCIE: That’s great. Now, what about the scrap booking? While you’ve been in the process of doing this journaling workshop, have you done any scrap booking?

DUANE: I’m doing scrap booking right now for Christmas gifts for my son and daughter-in-law. And I’m doing some journaling in it, but not a lot because I told them, I says you know, it’s not fair for me to go ahead and write down things about these pictures because you might have a different memory than what I do.

LUCIE: Different perspective, yes.
DUANE: And I says, I would prefer to leave that there for you and she goes, that’s fine, she says I’ll probably bring it back to you and you will write it.

LUCIE: Who’s that, your mother?

DUANE: No, my daughter-in-law.

LUCIE: Oh, your daughter-in-law.

DUANE: She says, because she says your handwriting is better than mine. And so she said that she was going to go ahead and have me journal then what she wants done as it shows – she’ll describe it to me

LUCIE: She’ll describe and --

DUANE: Right. So, I’m in the process of doing that service, so.

LUCIE: And I think that’s just so cool. That’s wonderful. Let’s see. What type of writing that we’ve done since -- in the workshop did you prefer? Can you offer some examples or some reasons for your preference?

DUANE: The reflection, I think, was more -- because you can reflect back onto different times and different events. And then by writing it, it bought it back to life.

LUCIE: Oh, neat. Okay.

DUANE: Where, you know, you can remember things in your mind and that, but if it’s never brought out anyplace – then it’s just still here, in your head; that’s it. Where by writing it down, then, it just kind of brings it more like it’s happened yesterday or today.

LUCIE: Right.

DUANE: And that’s just one thing I like about it.

LUCIE: Wonderful. Okay. So, it’s kind of like re-living the moment?

DUANE: Yes.
LUCIE: All right. I’m not sure that this is terribly applicable, but it probably isn’t. Just tell me if you don’t have anything to say about this. To what extent have you been able to use writing as a method of coping with Karen’s illness?

DUANE: I really don’t think that really – is part of it, because she is doing so well and we coped with it in the first place, where we had no problem with it. We dealt with it in a light-hearted manner and jolly way, instead of making it a depressing type of a disease. Because we both learned so much about it. I think that was one of the things, it was a learning tool for us as well.

LUCIE: That’s very interesting.

DUANE: ‘Cause otherwise, we – you know, we’ve never had anything to do with cancer. And then to go into all these doctors and hear everything that they were saying, we were like a sponge, absorbing everything that we possibly could. And that’s – I think that would be about the way I’d look at that.

LUCIE: Do you think that your general comfort level and/or past experiences with writing were factors, either positive or negative, in your using it as a successful coping method in this workshop or using it successfully in this workshop?

DUANE: Yeah, I would say that my previous experiences would be – because –

LUCIE: Positive?

DUANE: It worked -- very positive one -- because I worked in the bank before and we did writing of reports all the time. So, I was constantly writing there. You were always having to come up with everything and put it onto a sheet of paper and tell this boss what was going on down in that department. So, you had to be able to communicate well on that piece of paper.

LUCIE: Wow.
DUANE: So, I did it there. Then, when I worked at – as a credit manager at Warren Radio, you had reports there, so there’s more report writing again and now with the school system, we’re writing referrals and this kind of stuff on what’s going on with a child, so you’re constantly writing in these areas as well.

LUCIE: So, you’re very used to putting thoughts into written format?

DUANE: Yeah. Yeah.

LUCIE: Okay. I’m not sure, again, that this question is relevant, but just let me know. Do you think that your general comfort level and/or past experience with computer technology were either positive or negative factors in your choosing to use it or not use it as a writing tool during this workshop?

DUANE: It’s still -- I think it’s still positive, because I’m not really – not that I won’t do it.

LUCIE: Okay. You just prefer --

DUANE: I prefer the writing because I think I can think better when I’m writing versus typing at the same time. I’m not sure that – ‘cause I’ve never had to do it a whole lot, other than to write to a business or something like that on the computer. You usually – at that time that I would be writing on the computer, then I was usually pretty upset and that’s why I was writing and boy those words can fly then. And you can really do it. But, if you’re constantly thinking of how you’re going to write something otherwise on an event or something, then I think that I might have a little bit more of a hesitation.

LUCIE: So you would rather compose on --

DUANE: I would rather compose on here [paper] and then take this and go onto the computer.

LUCIE: That was what I was going to ask you. Do you think you’d ever get to point where you--
DUANE: I think I could go ahead and take my journal and put it on after I wrote it.

LUCIE: Okay.

DUANE: I think I can do that. But it’s just that I would prefer to have it down to where I could actually see it first. And make sure that everything is the way I wanted it and then I don’t have to re-edit it off of a computer.

LUCIE: That’s what I was going to ask. You do think that you would simply type from there to the computer or do you think --

DUANE: I would read my stuff first and edit it then – ‘cause, I’ve already re-edited some of the stuff I’ve written now. And like put little arrows and stuff like I wanted a word inserted here, this kind of stuff. So, I prefer to edit my stuff there and then put it on and then I know when I put it on my computer it’s going to be just the way I want it. That will speed up the process, really.

LUCIE: So you’d use it as like a typewriter?

DUANE: Right.

LUCIE: Okay. Let’s see. In your opinion, has regular journaling had any impact at all on the ways in which – well, I don’t believe that this is going to be relevant, but, in the ways in which Karen’s illness has affected your life?

DUANE: I don’t think it has any --

LUCIE: Did you journal while she was ill?

DUANE: No, ‘cause I was – that was something I did afterwards. I started journaling afterwards. I didn’t journal at the time, because I think the – we were so involved with what was going on, that we were there for each other, that I think journaling was one of the things that wasn’t even on my mind.
LUCIE: Now she did, right? She kept --

DUANE: She kept her notes – she kept notes. Well, she kept logs, because she had her calendar and this kind of stuff on what was going on and where she was going to have to be and blah, blah, blah, all the time. So, she has kind of a running map of what was going on that way. And this stuff can then bring it back to memory real quick.

LUCIE: Okay. Since beginning this workshop, how often would you say you write? Daily, weekly, just in this workshop? There are a couple parts to this question, but go ahead.

DUANE: Okay, probably about – I would say more like weekly.

LUCIE: Apart from this workshop, in preparation for this workshop?

DUANE: No, apart from it.

LUCIE: Okay.

DUANE: ‘Cause, like when I was down in Florida, I journaled my Mom and that and then I also started – I didn’t finish the journaling, but I started my journaling of my daily stuff while I was down there. What we did, events, ‘cause we went and saw the Festival of Trees, which was very, very nice. It was a place where they have every tree decorated in a different theme. And it’s a humungous big building that’s got this. And they auction these trees off then for charities. Which is really a nice deal, you know, for them down there. But being down in Florida and seeing these Christmas trees all done up, was just beautiful, you know. Then I called Karen on Thanksgiving and wished her a happy Thanksgiving, and she goes, we got white snow up here. And I said I got white sand, so we’re all set.

LUCIE: Just to rub it in, right?

DUANE: No, no, no. I just wanted her – I wanted to paint the picture for her.
LUCIE: That’s cute. All right. Now, would you say that the amount that you have journaled since being in this workshop has increased or decreased from prior to doing the workshop?

DUANE: Seems probably about the same. Same as what I was doing before.

LUCIE: Has there been a change in the type of writing you’ve done?

DUANE: Maybe as I give a little more thought to what I’m doing now than what I did before. You know, because my basics were there before, from what I was doing. It’s just that some things were just fine tuned a little bit for me.

LUCIE: In general, have your feelings about writing changed, either positively or negatively, since beginning this workshop?

DUANE: It’s all positive.

LUCIE: Right. Or has it – I mean, has it remained the same?

DUANE: It’s the same, and it’s still a positive – it’s still a positive mode.

LUCIE: Can you describe the type of writing experience you have had during this journaling workshop?

DUANE: I don’t know what you mean by that.

LUCIE: I know it’s open ended; it’s meant to be. Just – can you describe your experience? Can you describe the type of experience that you’ve had?

DUANE: Well, it’s brought more things to memory, some of the things I’ve written. That you kind of didn’t go into before and now when we were starting to do some of the journaling that we did, it brought some of that stuff out.

LUCIE: Great. Okay. Do you intend to continue your writing journal beyond the completion of this workshop?

DUANE: Oh yeah.
LUCIE: Okay. Why?

DUANE: That’s an ongoing thing for me. It’s just – that’s just me. You know, some people can do stuff like that and some people can’t. So, and I – I like doing it, so --

LUCIE: Why do you think that? That some people can do it and some people can’t or some people choose to? Why do you think --

DUANE: I think it has a lot to do with the fact that some people just don’t feel that they’re – they’re talented enough for it, maybe, or they don’t feel good about themselves to do it, but they can do it. You know. This whole thing was – the reason I came to this was to get Karen to go because I know that Karen can do it, but she’s just never done it. And this was my stepping stone for her. ‘Cause to me, I really didn’t need it as much as what she did. You know, I was doing it for her so that she could get some of her feelings and stuff onto paper. Which --

LUCIE: What’s so interesting about that is that this other couple I was telling you about that comes to the Victory Center, it’s exactly the same.

DUANE: Oh really.

LUCIE: Yes. The gentleman came and wanted his wife to do it because he felt she needed it. That is just so neat to me.

DUANE: Karen – it’s not so much that Karen needs it; it’s that I think that she needs to be able to write down events and this type of thing that she would want to keep for herself. Like she said that she likes reading my journals, because it brings everything back to her. Well, if she can write some of her stuff down that she has gone through or thought of or whatever, any of her experiences, it will be something that she can go back to and read later and enjoy again. So this is my main reason for, I think doing this.
LUCIE: And I think it would be really neat too, if you both did it for a while and then compared your different perspectives to see if they were different even, or maybe the same.

DUANE: Right, right.

LUCIE: That would be really neat. Yeah. Okay. As a result of this workshop, do you feel more comfortable or the same about sharing your writing with others? Why or why not?

DUANE: I can’t remember what I said the first time. And I would imagine it would be the same as what I said before. It’s the fact where if it was something I’d feel like sharing, I’ll share it. If I don’t, I won’t.

LUCIE: Okay. And that’s what it’s meant to be, so that’s wonderful.

DUANE: Right, right.

LUCIE: And then the last question is what – this is a two part question. What do you feel you have gained by participating in this writing workshop?

DUANE: Seeing Karen do the writing.

LUCIE: Really.

DUANE: Yep. ‘Cause that was my main goal. To see her get involved. And she did.

LUCIE: Okay. Are these gains more or less than you anticipated?

DUANE: More than I thought. Yeah. We’re both kind of alike in some things. If it’s something that we’re not really enthused about, we don’t do a whole lot with it. And I don’t know if it’s – maybe it’s the combination of me being in it with her and seeing me doing my writing – because she sees how fast I can write my stuff down and it takes her more time. But I said that has nothing to do with it, because I says, my thought base is maybe faster than what yours is. And I says, and you got more going through your mind as to what you’re trying to think and want to get down and what do I want to actually put down on paper and what don’t I.
Where you’re doing it all in your head where I said I just keep writing. And then once I get done, I re-read it and if there’s something I don’t want, I can put a line through it. And if there’s something I want to add, I’ll just add to it. So, I says it’s kind of a two-fold thing on that.

**LUCIE:** It sounds a lot – it sounds to me, though, that you’re just generally – you’ve just generally used writing more?

**DUANE:** Mine is because of what I experienced in my working life. When you’re constantly doing that, this writing here is just nothing then. You know, you just do it.

**LUCIE:** Right. Yeah.

**DUANE:** You know it’s just like you get up in the morning and go to work. Basically about the same way, the way I look at it, anyhow. Other people may not do the same, but I do.

**LUCIE:** Wonderful. All right. Now, that’s all I have formally. Is there anything you’d like to add that you had wanted to say and maybe I interrupted you or had forgotten?

**DUANE:** No, I just thought it was, you know, interesting.

**LUCIE:** Great.

**DUANE:** It was interesting to do. So I have enjoyed it.

**LUCIE:** Good!
LUCIE: All right. Karen. When did you – now, this is from your perspective. When did you become ill?

KAREN: I had my mamm in January – the first of January and a week later I had --

LUCIE: Of 2005?

KAREN: Oh, 2003, three.

LUCIE: Okay. That’s okay.

KAREN: And then I had to come back for a spot compression and then I didn’t have the biopsy until March. And the doctors tell you 80/20% it’s nothing and the tech told you 80/20% it’s nothing. Then a week later, she called the house and told me I had cancer. And I asked her, I said what happened to that 80/20 and then I said, I’m only joking. And March 31st, I had my surgery.

LUCIE: That just gives me chills – it’s terrifying.

KAREN: Nobody could feel anything. It was only through the mamm and I had them done yearly. And they did see something before, but it had not changed until this time, you know.

LUCIE: So, I’m not sure how you’ll respond to this question, but was the onset of your illness sudden or gradual?

KAREN: I would say sudden because I didn’t expect it. Even though they saw something, you know, they were watching – I didn’t expect it.

LUCIE: Did you know that they were watching something?

KAREN: Yes. ‘Cause I can get my own reports and look at them.
LUCIE: Oh, okay. But they didn’t tell you they were watching something? Your doctor didn’t say --

KAREN: Really, they were watching something in the other breast.

LUCIE: Oh, my goodness.

KAREN: Yeah, ‘cause I thought they told me the wrong one. ‘Cause, I said, you mean the left one? And they said, no, the right one. I said, no, you’ve been watching something in the left one and but then when I went back and read the report, they did see something before in the right one. But we were more concerned with the left one, ‘cause one time the GYN doctor called me at work and wanted me – scared everybody but me, ‘cause I was at lunch and I had to call him back and then they were gone from the office. It was a Friday. They said tell Karen to call me immediately and this one girl that took the call, just went through it – a biopsy. And she said you call him at home. I said, what I don’t know won’t hurt me. I’ll call him on Monday. So I called back Monday and they just wanted me to go back for a repeat. But they said – that was years ago.

LUCIE: How scary.

KAREN: But they said that at that time that one was nothing, but it’s still there, on the left one.

LUCIE: So, did you end up having a mastectomy?

KAREN: No, a lumpectomy.

LUCIE: a lumpectomy, and only on the one --

KAREN: In the right one. And then they took out 13 lymph nodes. And that affects you more than anything, because of your arm.

LUCIE: I’ve heard that.
KAREN: Yep, uh huh. And I was never told to exercise my arm immediately and so the damage was already done, you know.

LUCIE: It got all swollen?

KAREN: No, just a little bit, to where I do have garments to wear, but it didn’t get out of hand. But, it bothered me a lot, ’cause I lost some use of my arm and I had to go through --

LUCIE: Physical therapy?

KAREN: Well, I had trouble with my shoulder, too, so I had to go through physical therapy and then she helped with the lymph edema. She was great.

LUCIE: Okay. Okay. At this time, how would you classify your illness?

KAREN: The cancer’s gone, but I’m still -- working with the arm.

LUCIE: Oh, okay. So you’re still going for therapy?

KAREN: No, you just have to do stuff at home and watch it. And, you know, you’re supposed to protect your hands so you don’t get any cuts or – ’cause you start the lymph edema up for cuts or --

LUCIE: Again, the fourth question I’m going to skip with you because it doesn’t really apply since Duane is here. The fifth question, what are some of the ways in which the illness affected your life?

KAREN: The one thing, when I first had my surgery, I missed – we had a little grandson and I couldn’t pick him up anymore. You know. And I missed out on that. But – affected our life? You have to just be more cautious of things.

LUCIE: Okay. Okay. What are some of the ways in which the illness affected your relationships? Not just with Duane, but with others.
KAREN: Nothing really. Duane and I are closer because I got such loving, tender care and don’t do this and don’t do that. I mean, he was really great.

LUCIE: Okay. Okay. And as far as your children – no one treated you any differently or --

KAREN: No, not at all.

LUCIE: Okay. What are some of the ways in which you have worked to cope with your illness?

KAREN: Just take better care of myself and --

LUCIE: In what way?

KAREN: What way? Well, I have to be very careful in my job, with my arm.

LUCIE: Oh, what do you do?

KAREN: I lift x-rays all day long. So, while I was going through my treatments, I wasn’t allowed to work, because of the arm.

LUCIE: Oh, wow.

KAREN: So, I was off for six weeks and at work, I have to still be very careful. ‘Cause, I’m more using my left side now. And even sweeping hurts. Pushing a sweeper. But you never forget, ‘cause you always feel something.

LUCIE: But in terms of exercising or eating differently or trying any types of massage or anything like that, did you try any of that stuff?

KAREN: When I was going through radiation, we got a massage every Thursday. And then I went to the Victory Center and got a couple. And then whenever we’re out – I have to – I can’t just go to a regular massage. They said you have to be – go to somebody that knows lymph edema. So, they said, don’t let anybody touch you otherwise. But, we’ve been out – where they were giving free massages. We went to a scrap booking thing and a woman was there giving massage – and I just wouldn’t let her touch the right side. And she did everything --
LUCIE: Okay.

KAREN: Yes, love the massages.

LUCIE: All right.

KAREN: And Duane was taught how to do massages.

LUCIE: For the lymph edema?

KAREN: Yeah.

LUCIE: Okay. You gotta do that first.

KAREN: Yeah, he doesn’t do that anymore.

LUCIE: I see. Oh, they really get in there and --

KAREN: Oh, yeah. You know, ‘cause your chest starts hurting, you know, and I’ll say, oh – my chest really hurts and he has to do – and I mean, he actually sees the fluid then. ‘Cause you massage and you have to roll over and he – the fluid – you take the fluid to the back. Yeah, and then you’ve got to open the lymph nodes down your spine for the fluid to drain. So, he sees it as its – he’s massaging.

LUCIE: As it’s draining?

KAREN: Yeah. And it makes a difference.

LUCIE: Do you actually get swollen up in here?

KAREN: I don’t --

LUCIE: You don’t see it?

KAREN: I feel swollen, yeah, under the arm and on the side over here. That’s when I say I really need something, you know.

LUCIE: Still even now?

KAREN: Oh yeah. And we’re going to go on our first airplane ride in December.
LUCIE: You were telling me that. So, he’ll have to get his massage hands ready. Okay. Let’s see, where are we here. Did you ever feel isolated and alone in coping with your illness? Why or why not?

KAREN: No.

LUCIE: No.

KAREN: No, cause Duane was always there for me.

LUCIE: Okay.

KAREN: When we went to classes, I mean, cope classes and when I went to the exercise classes that St. V’s offered and then we’re in the support groups now. There’s always somebody there.

LUCIE: Before now, how often would you say that you wrote? And then the other part of that question is to describe the types of writing that you do most often, letter writing, e-mailing, shopping lists, to-do lists.

KAREN: Nothing. No writing.

LUCIE: No writing. So, this is really something new for you?

KAREN: Right. Well, I do a grocery list.

LUCIE: Fair enough. In general, and based upon your past experiences with writing, what are your feelings about it?

KAREN: Well, I want to learn how to, you know, do the writing and I just love to read his [Duane’s] journals.

LUCIE: Oh, okay.

KAREN: It brings back a lot of memories when you read the journals like he’s done for our vacations.
LUCIE: That’s very interesting. So, can you describe the type of writing experience you had during your formal education?

KAREN: Only book reports that we had to do.

LUCIE: Book reports. And I think I know the answer to this question. Have you ever kept a journal?

KAREN: No.

LUCIE: Okay. In general, and based upon your past experiences with computers and the internet, how would you describe your comfort level with the technology?

KAREN: I don’t.

LUCIE: Okay.

KAREN: I use a computer for work, but you’re doing the same thing continuous [sic], you know.

LUCIE: Just like data entry type things?

KAREN: Looking up people’s results and stuff.

LUCIE: Have you ever participated in a chat room or other on-line support group?

KAREN: No.

LUCIE: And the last question is what do you hope to gain by participating in this writing workshop?

KAREN: To write down memories. That maybe we’ll pass on to the kids. ‘Cause my mother’s gone and you can’t ask any questions any more. You really miss out on a lot. So, with Duane now writing, I’ve got to start.

LUCIE: Well, it doesn’t sound like he’s about to stop!

KAREN: No, right.
St. Vincent’s: Post-Interview of Karen

LUCIE: Okay, Karen, at this time, how would you classify your illness? Stable, critical, in remission?

KAREN: In remission. Yep, I’m doing fine. It’s just the after affects.

LUCIE: Yes, you’ve been talking about that. Which are with your --

KAREN: With my sternum hurting so bad. Yeah.

LUCIE: Did you say you have the acid reflux from it?

KAREN: No, it – she called it inflammation of the sternum. Which when I get that, to where there’s something up here, you know, she thinks it’s damaged so I go on Nexium for that.

LUCIE: Has this status changed since you began to participate in the writing workshop?

KAREN: No.

LUCIE: No. All right. Since beginning this writing workshop, how often would you say that you’ve written about your illness and I’m talking either minutes per day, weekly or only during the workshop?

KAREN: Our lessons we had to do for the workshop.

LUCIE: Okay, is what you focused on?

KAREN: Uh huh.

LUCIE: All right.

KAREN: Or while we’re here.

LUCIE: What factors limited or supported the amount of time you’ve been able to spend writing about your illness or been able to spend writing?

KAREN: Limited it?

LUCIE: Yeah, what limited your being able to write, say every day?
KAREN: ‘Cause I’m not that good at it.

LUCIE: Oh, Karen.

KAREN: I have to think and think and think what I’m going to write.

LUCIE: Okay. But that’s an interesting perspective. Most people say that it’s time. That they don’t have the time; so yours is an interesting perspective. What writing technologies would you say that you’ve used during this workshop? Just basically pencil and paper? Have you done anything on the computer?

KAREN: Just pencil and paper.

LUCIE: And of the type of writing of the things that we did in here, what type of writing did you prefer most?

KAREN: Writing about the family; remembering the good times.

LUCIE: Can you give any reasons for that?

KAREN: ‘Cause I think you forget about a lot of things. And this has made me remember a lot.

LUCIE: That’s great!

KAREN: I even talked to my sister and I said I had to have something to write about and she said, oh, she gave me ideas. But then last time, ‘cause she said, any memories, she said write about how you used to buy us Christmas presents and we found them and opened them up.

LUCIE: Your sister?

KAREN: My sister.

LUCIE: Is she a lot younger than you?

KAREN: Seven years. Seven, eight years. Yeah. And then they used to wrap them back up and I finally found out they did that and I had to keep them at somebody else’s house. ‘Cause I always bought them --
LUCIE: How old were you when this happened?

KAREN: Probably about – let’s see, if there’s eight years, so probably about 15 or – no, has to be 16 or something like that.

LUCIE: Oh, that’s so cute. And they would wrap them back up.

KAREN: Yeah, they would wrap them back up. Uh huh.

LUCIE: That is really cute.

KAREN: ‘Cause I took all the money I earned and spent it on the two young ones. Gifts – every week I got paid for ironing and cleaning houses by – the people I did it for went to Fostoria on Fridays to shop and I went with them and spent all my money on the two young kids. ‘Cause we didn’t have much money, you know.

LUCIE: And the one was seven years younger and how much younger was the other one?

KAREN: Fourteen months younger than her.

LUCIE: Oh, how sweet. Do you think that your general comfort level and/or past experiences with writing affected, either positively or negatively, your using it in this workshop? If you need me to re-state that, I’ll try. I know it’s a long question.

KAREN: Yeah.

LUCIE: Okay. So, when you came to this workshop, you had certain feelings about writing, okay?

KAREN: Right.

LUCIE: Based on your past experiences or your attitudes toward it, based on those past experiences or attitudes, do you think that they affected in any way your – the way you participated in this workshop?
KAREN: Well, when I came here, I only came because Duane signed up. I would never have come by myself. Yeah. And then, no, I really enjoyed it. Otherwise I – I never wrote. Yeah, never wrote. And he always kept a journal. Which I love to read his journals and it makes me remember what we did.

LUCIE: That’s so cute. Let’s see. Since beginning this workshop, how often would you say you write?

KAREN: Right now, just when – for class.

LUCIE: And has this amount increased or decreased from prior to the workshop?

KAREN: Oh, increased, ‘cause there was none before.

LUCIE: Has there been a change in the type of writing that you’ve done?

KAREN: Well, I never did any, so --

LUCIE: In general, have your feelings about writing changed, either positively or negatively, since beginning the workshop?

KAREN: Oh, positive, because of all the memories – yeah, I’d really remember stuff and start writing.

LUCIE: Can – and this is open ended and it’s meant to be. Can you describe the type of writing experience you have had during this journal writing workshop? The type of experience?

KAREN: Well, I have brought out thoughts that I even surprised myself on. One day I made a comment in class, and I thought, “Did I really say that?”

LUCIE: Just because of the way you are or just because you didn’t remember that?

KAREN: I don’t know. It was when we were talking about my family, about being from a big family and how people look down on you for that, and I thought, “I said that?” And that week, I thought about that all the time and I thought, “Why did I say that?” Which, you know --
LUCIE: No, it’s like feelings that you just have --

KAREN: Yeah, uh huh, cause I had never said that before.

LUCIE: I felt that way when I was raising my children, when they were little and I had all these little stair steps. People – I’d take them to the grocery story and people would look at me, as if to say, “Haven’t you ever heard of birth control?”

KAREN: Yeah.

LUCIE: And I have felt that way many times.

KAREN: Have you?

LUCIE: I don’t know that I ever vocalized that to anybody. Maybe just my family, but – it’s really true in this society. I think that that’s really – we really do tend to look down on, you know – people usually have one or two kids at the most, if any.

KAREN: Right, right.

LUCIE: Okay. So, let’s see. Do you intend to continue your writing journal beyond the completion of this workshop? Why or why not?

KAREN: Yeah, I think I’d like to. Sure, with memories, yeah, like with sisters and that.

LUCIE: Okay. This is a two part question, the last question. What do you feel you have gained by participating in this writing workshop?

KAREN: Knowledge in writing.

LUCIE: Really?

KAREN: Yes.

LUCIE: Good.

KAREN: And being forced to do it.

LUCIE: Which wasn’t so terrible.
KAREN: No, it wasn’t.

LUCIE: And are these gains more or less than you anticipated?

KAREN: More. I didn’t know I would enjoy it.

LUCIE: Did you?

KAREN: Yeah, uh huh.

LUCIE: Were you surprised?

KAREN: Yes.

LUCIE: Great.

KAREN: But like I said, though, it just helps with Duane being here too and participating in it. Doing it together and discussing.

LUCIE: It’s like when I’m walking with my husband, you know, I could make a million excuses for not doing it, but if he’s ready to go, I guess, okay, I’ll get my coat on. Especially now that the weather is cold, I hate it. And sometimes I am genuinely busy, but, you know, it makes it so much easier when he goes walking with me, because it’s just having the support, you know.

KAREN: Uh huh.

LUCIE: Is there anything that you wanted to add that maybe I haven’t touched upon or I interrupted you, maybe a thought that you had or --

KAREN: No, I don’t think so.

LUCIE: Okay. Great.