

ABSTRACT

MORTON, JANET LEE. Giving Light to Voice: Individual Stories of Photovoice Research Participation. (Under the direction of Dr. Brad Mehlenbacher and Dr. Diane Chapman).

The purpose of this research was to describe the individual experiences of support group members from a vulnerable population who had participated in Photovoice, a participatory action research strategy aimed at social change. The two research questions that guided this research were: 1. What are the experiences of individuals participating in a Photovoice research project aimed at social change? 2. How do members of a support group make meaning of their participation in a Photovoice project? Foundational areas of literature were (a) the social perspective – participatory action research and Photovoice; (b) the individual perspective – Orem's self-care deficit theory, self-efficacy, and a variety of individual change models; and (c) the perspective of photography as art, not merely a documentary technique, but a potential means of transformation and healing which, along with storytelling, leads to presentational knowing. Visual narrative inquiry was the methodology used to explore the individual experiences of support group members who had participated in Photovoice research. The four major findings were (a) choices and challenges about entering into and persisting in the research process, (b) personal and interpersonal growth and learning in a variety of areas and dimensions, (c) influence and change in the very areas of life that were challenging them, and (d) finding meaning and purpose in the Photovoice experience through restorying, reflection, and retelling their stories. This research highlighted both the positive and cautionary aspects of involving members of a vulnerable population in research aimed at social change, while also revealing the life-changing individual experiences the participants had as a result of being part of a Photovoice project. This study demonstrated the potential of presentational knowing through photography and storytelling to add rich dimensions of

personal growth, learning, transformation, and meaning making to the Photovoice experience, while also enhancing relationships within the context of the support group. Implications for practice, research, and theory are provided for persons using the Photovoice research methodology, persons with disabilities, health care professionals, educators and administrators designing learning experiences, and persons working with special populations. Recommendations for further research include studying the individual experiences of other support group members with a disability or chronic condition who have participated in Photovoice research. A concurrent method of documenting individual experiences during the course of future Photovoice studies would be especially beneficial for continuing to explore the individual effects of participation in such research aimed at social change.

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Giving Light to Voice: Individual Stories of Photovoice Research Participation

by
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DEDICATION

This dissertation is dedicated to all the late bloomers in my life: to Marilee, sculptor, artist, and long time family friend, who at 99 is writing her first book, to my grandfather Jack who at 90 restarted his architectural business solo, to my grandmother Raleigh, who had her first art show in her 80's, to my father Herbert who wrote a widely acclaimed lexicography book in his 70's, to my uncle Lawrence who started an evening concert series while in his 50's, and to my first dissertation chair, the late Dr. Colleen Aalsburg Wiessner, who started a promising academic career in mid-life after many fulfilling years as a religious educator.

BIOGRAPHY

Janet Morton came from a family with artists on one side and musicians on the other. Although her parents were very literary and appreciated both art and music, she gravitated to the sciences, obtaining first a baccalaureate degree in conservation, followed by a second baccalaureate degree in nursing. She subsequently obtained a master's degree in nursing and joined the world of academia, teaching RN to BSN students, traditional and accelerated baccalaureate students, and master's degree students. She also worked in asthma rehabilitation, community health, home health, and occupational health. In more recent years, she completed a parish nurse preparation program and serves as the parish nurse for a large congregation, providing education, counseling, and spiritual care. By teaching and precepting community health students in the congregational setting, she has been able to introduce students to community health concepts within the faith context while maintaining her academic connections. Her foray into Photovoice as a dissertation topic and the creativity it engendered not only in her participants, but in herself, seems to be bringing her back to the artistic and literary origins of her family.

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CHAPTER ONE: INTRODUCTION

*In the middle of one night
Miss Clavel turned on her light
and said, "Something is not right!"*

(From *Madeline*, Bemelmans, 1963, p. 17)

Whether change is individual, group or societal, its origins are often rooted in the feeling that "something is not right." Our world today is fraught with many problems from natural disasters, wars, and political unrest to poverty, homelessness, and health disparities.

A problem area that is dear to my heart as a health professional and educator of adults in an inner city congregation is marginalization. When people are set off on the periphery of mainstream society for whatever reason, a whole host of other problems ensue such as social isolation, loss of voice, decreased access to care, and increased health disparities. Discussion of marginalization is a common thread within and across a variety of disciplines from adult education to health to sociology because it is an issue warranting action for social change. Writing in 1937, Eduard Lindeman said "adult education is not merely education of adults; adult education is learning associated with social purposes" (Brookfield, 1987, p. 76). While the terminology may have changed over the years with new voices added, the basic tenet remains that much of adult education is about social change.

The Problem of Marginalization

This section focuses on the overarching problem of marginalization that calls for compassion and action to help those whose position in society puts them at risk and in danger from numerous threats to body and soul. One of the origins of marginalization is in the ways some people are categorized, pigeonholed, stereotyped, and often set aside by others (Crisp,

2007). Crisp said that categorical thinking is useful for defining ourselves and giving us a sense of who we are. The same thinking also defines our relationships with others, but taken to extremes, can lead to prejudice. Lynam and Cowley (2007) also discussed the problem of marginalization in terms of categorization, noting that marginalization and social exclusion lead to health risks due to a variety of factors such as discrimination, environmental hazards, and limitations on access to care. Their focus of study was first generation migrant teenage girls and their mothers in Britain and Canada. Lynam and Cowly placed particular emphasis on the presence of markers that others use to justify exclusion. These markers can be almost anything from race, class, and gender to speaking limited English or having an accent, all of which can lead to social exclusion. In explaining the process of stigmatization, Jones et al. (1984) discussed the problem of markers, being marked, and the lengths to which some people go to conceal a markable condition that is stigmatizing. President Franklin Delano Roosevelt's concealment of his paralyzed legs by only being seen or photographed standing up, unless he was at a desk, is a prime historical example of trying to hide a stigmatizing mark. When his Memorial in Washington, D.C. was being planned as an accessible site, there was much controversy over whether he should be shown in a wheelchair or not. The eventual decision was to show him sitting in a chair that had casters on the back. Many disability rights activists wanted him in a wheelchair, while others still wanted to avoid the stigma of weakness implied by his disability ("Franklin Delano Roosevelt Memorial," n.d.).

In the process of human development, there is an early need for babies to begin to learn that they are separate individuals from those around them, so the child eventually develops the understanding, whether it can be verbalized or not, that they are a separate being

from other beings. This is a necessary step of development, but also one that eventually leads to the question of who is the Other and how can we come to understand him or her? (Kemmis, 2008). Whether the Other is a person or an object, we know they or it are something different. Some people may respond to the Other with interest and warmth while others may react with fear. If the reaction is fear that fear can lead to a cascade of prejudice, avoidance, oppression, and violence.

When enough people are Othering on an individual level, it can become a societal force that leads to marginalization of entire groups of people. An extreme example of Othering may be seen in the case of refugees and immigrants who are fleeing adversities such as war, natural disasters, and disease and seeking asylum in other countries (Grove & Zwi, 2006). Grove and Zwi saw this as a tremendous public health issue because when people “are outside of their ‘proper’ place of belonging and within our boundaries they are increasingly represented as a threat to the notions of community and sovereignty, forcing questions of ‘who is in’ and ‘who is out’” (Grove & Zwi, 2006, p. 1934). When society in general perceives refugees and immigrants as a threat to the health care system by producing an overload, additional barriers such as detention or other means of social isolation may be created that keep the new arrivals from being integrated into the culture. These barriers in turn keep them from being able to tell their stories and gain necessary access to care. Grove and Zwi advocated for public health professionals to be more proactive “by putting forward a narrative and discourse of inclusion and caring...[and] for public health to return to its social activism origins” (p. 1940).

In the health arena in general, marginalization leads to the creation of vulnerable populations who are more prone to health disparities (Vasas, 2005). Vasas explained that for marginalization to occur there must be a margin that is defined in contrast to a Center. Whether the boundaries around the Center are physical or psychological, everyone outside of the margins around the Center is therefore marginalized. Thus, there become two categories, the Center and the Other. Unfortunately, each category may seem invisible to the other. We are not sure who is in the Center and where their power resides and we also may be unaware of the needs and voices of those who are marginalized. A hope that Vasas offered as an antidote to the fact that marginalization creates vulnerable populations with greater health disparities is that marginalization is a process and processes are amenable to change. She said that recognizing and acknowledging marginalization and its effects can help to change health practice and research environments and notes the importance of giving voice to marginalized groups.

Persons with serious illness are among those who may suffer marginalization as other people may not want to be around those who remind them of their own mortality and vulnerability. People with non-visible handicaps such as diabetes, asthma, and epilepsy may suffer even more because they may be perceived as taking advantage of everything from handicapped parking spaces to special services. Persons with epilepsy are especially susceptible to being marginalized because they not only have a non-visible handicap, but they also have a condition that has a long history of stigmatization back to Biblical days and probably earlier.

People with various health problems are just one of many groups that may be marginalized in society. The same phenomenon affects people who are poor, homeless, victims of abuse, mentally ill, overweight, or unemployed (Vasas, 2005). Having characteristics that put you on the outskirts of society for whatever reason can lead to further social isolation. For example, someone who does not speak English will have trouble navigating every aspect of society from job hunting to food shopping.

Statistics tell us something about people who are marginalized, but not everything. Hearing about the percent of people who are poor, homeless, unemployed, or uninsured may have some impact, but often the story of one person's plight will have more impact, especially on an emotional level. The question is, how do the stories of people who are marginalized get told? Many of the people who are marginalized have limitations on their means of communication, either through language barriers or poor communication skills. In addition, the fact that they are marginalized puts them into a physical or social setting where their voices are less likely to be heard. In order to change the inequalities that lead to marginalization, someone needs to learn or hear about it and get interested and activated.

One of the ways of communicating the plight of the Other is to help people tell their stories. A news reporter or anthropologist may come in from outside and report on the plight of some disenfranchised group or another, but that will not necessarily be the most accurate approach. Seeing and hearing the stories of the marginalized people themselves is a much better way of communicating from the Other to the Center.

Photovoice is one such strategy that can be used to tell the stories of marginalized people. Photovoice is a participatory action research (PAR) strategy that puts cameras into

the hands of various marginalized groups to help them communicate their concerns and issues to their communities, especially policymakers (Wang & Burris, 1997). This social change strategy has been used in the United States and around the world to give voice to various marginalized groups and can be especially effective with people who may not be verbally adept or able to write their own stories.

Giving Voice Through Photovoice

“A picture is worth a thousand words” – so the old adage says. But whose picture? Whose words? Is it a picture taken by one person and interpreted by another? Or does the picture-maker do the interpreting? Who gets to take the picture? Can anyone participate in picture-taking? Or only a select few? Queries such as these represent some of the questions that participatory action researchers may have asked as they have developed photographic strategies to address social change issues. Following earlier work describing the use of photo novella as an empowerment strategy for rural Chinese women (Wang & Burris, 1994), these same researchers further refined this photographic concept, named it Photovoice, and described its methodology, use, and value for participatory needs assessment (Wang & Burris, 1997). Over the years, photo novella and Photovoice have been used with a wide variety of populations both overseas and within the United States involving such diverse community groups as rural Chinese women (Wang & Burris, 1994), homeless individuals (Wang, Cash, & Powers, 2000), youth, adults, and policymakers (Wang, Morrel-Samuels, Hutchison, Bell, & Pestronk, 2004), and older adults with chronic pain (Baker & Wang, 2006).

As a research strategy, Photovoice puts cameras in the hands, not of researchers or other experts, but of various marginalized groups, giving them an opportunity to record and describe their communities so that critical dialogue can take place. The end goal of this process is to reach policymakers about key issues (Wang & Burris, 1997). Given that such research is with marginalized groups who may also be members of vulnerable populations (Human Research Tutorial, 1998-2000), it would seem that ethical considerations in the design of Photovoice research would be paramount. Indeed, Wang and Redwood-Jones (2001) addressed ethical issues associated with the methodology based on lessons learned from a large-scale Photovoice study in Flint, Michigan, including privacy, recruitment, minimizing risks, and maximizing benefits. Yet the potential ethical issues, risks, and benefits may go beyond the methodology. Whatever the social change goal of a Photovoice project, the participants are still *individuals* who may be having their own unique experiences during the course of the project.

Why Focus on Individual Change?

An interesting layer of complexity is added when a support group whose primary purpose is to encourage and support individual change, becomes involved in a research process whose primary purpose is social change. Photovoice is a strategy involving individuals in social change processes, so even if a project affects policymakers to the point of implementing social change, there still remains the question of possible impacts of the experience on the individuals who participated in the project. The perceived success or positive community impact of a Photovoice project will not necessarily reflect the actual experiences, positive or negative, of the individuals involved in the project.

This is in fact the origin of my primary research question as I became interested in the individual experiences of participants involved in research aimed at social change. Although Photovoice is a participatory action research process whose purposes and methods should be clearly explained to prospective participants, there are still many unknowns. As in all research, potential risks and benefits can be postulated and described, but not everything can be anticipated or prevented. Thus, the researchers may explain that the process of taking and discussing photographs of certain subjects may lead to a strong emotional reaction as someone recalls a painful incident from the past. But this does not mean that the researchers know the eventual outcomes of that emotional reaction. Dealing with a past hurt may lead to an ability to see such an event in a new light. Perhaps people will feel released from something that has bothered them for many years. Perhaps they will find themselves helplessly wallowing in something they were not ready to deal with yet. Perhaps they will truly feel that they have been given a voice and are more able to move beyond their personal problems to help others. These are just some of the kinds of individual experiences that could occur as participants go through the Photovoice research experience.

In a rare description of negative impacts resulting from individual change, Carlson, Engbretson, and Chamberlain (2005) found that empowerment had unforeseen consequences, leading some “transformed” people to become more dominating and controlling over others. This phenomenon of empowerment became a key factor in the group’s resultant inability to facilitate cooperative community action, the exact opposite effect of what Photovoice aims to achieve. Thus, although the prevailing attitude may be that empowerment is “good” and “marginalization” is bad, greater consideration of potential

impacts of individual change that may occur during the implementation of a Photovoice project seems warranted.

The issue of individual impacts becomes increasingly important as the use of Photovoice expands beyond its original boundaries and researchers. In the years since its original inception, Photovoice has been combined with grounded theory methodology to explore quality of life concerns of African American breast cancer survivors (Lopez, Eng, Randall-David, & Robinson, 2005), used in a mixed methods study of childhood obesity, focus groups, and community mapping (Darbyshire, MacDougall, & Schiller, 2005), and utilized by at risk middle school students to facilitate better teacher understanding and school connections (Kroeger et al., 2004). This widening usage highlights not only the range of possible uses for Photovoice, but also the many opportunities to study its impacts. While there may be unrecognized negative impacts such as the empowerment issue previously mentioned, there might also be unrecognized positive benefits that can be capitalized upon, especially for vulnerable populations. The widening usage also raises the question of whether or not the original conceptual underpinnings of empowerment education, feminist theory, and documentary photography (Wang & Burris, 1994) should be reconsidered as Photovoice becomes used for more individual and interpersonal purposes (LeClerc, Wells, Craig, & Wilson, 2002; Lopez et al., 2005).

Thus, my goal in conducting this research was not only to identify possible individual effects of Photovoice research participation, but also to communicate them to other potential researchers. Because my nursing background has given me both individual patient care and public health experience, I came to this topic with a unique perspective that I felt could help

highlight previously unrecognized individual implications of socially oriented Photovoice research.

Purpose and Research Questions

Photovoice is a participatory action research method aimed at fostering social change through the use of photography. While the purpose of such research is to teach community members to document, reflect upon, and express community needs – with the end goal of influencing policymakers – the potentially life-changing effects on individuals, especially those from vulnerable populations, has received minimal attention.

The problem this research addressed was marginalization, especially of persons with non-visible handicaps such as epilepsy. The purpose of this study was to describe the individual experiences of support group members who had participated in a Photovoice research project, which is a participatory action research methodology for social change. Support group members with the non-visible handicap of epilepsy were the participants of interest. Due to their status as having a physical disability, they were also considered to be members of a vulnerable population.

The main research questions of this study were:

1. What are the experiences of individuals participating in a Photovoice research project aimed at social change?
2. How do members of a support group make meaning of their participation in a Photovoice project?

Conceptual Framework

In contrast to positivism, which seeks to determine the one true answer, as in scientific research, interpretivism is open to multiple views of the same situation. Thus, interpretivism became the logical choice as the conceptual framework for this research because it works well with the artistic point of view, allowing a variety of perspectives on the same subject. In the Photovoice process, participants, known as co-researchers, take photographs relating to several consecutive mutually agreed upon topics (Wang & Burris, 1997). Once the photographs have been developed, the co-researchers review the photographs and discuss them with the other group members. When they describe their photographs and the meanings to them personally, they are offering their perspectives from the ways that they see the world. Just as we have the saying “a picture is worth a thousand words,” it is also possible that a picture can have a thousand interpretations. A photograph of a car parked in a yard may mean one thing to someone who collects that brand of car and another thing to someone who used to drive the car but is no longer able to. This individual interpretation of events and experiences fits well with the interpretivist viewpoint that sees knowledge as subjective and meaning as being determined by the person experiencing it. In this view, the individual makes his or her own interpretation of events and experiences. There is no one verifiable reality, as with positivism, but multiple realities are possible (Krauss, 2005; Merriam, 1998).

Significance

In planning this dissertation research, I felt that its results had a variety of potential contributions for practice, research, and theory. Results of this study could suggest

Photovoice as a useful strategy for facilitating the mutually assistive nature of support groups that could be further studied and applied with other types of support groups. Results might also suggest other factors that need to be considered when planning for support groups, especially those that are led by lay persons with chronic illnesses who do not have program planning expertise (Caffarella, 2002). Research on persons with non-visible handicaps is less prevalent than research on persons with more obvious handicaps, so the individual changes that may occur through experiences such as Photovoice could be different between these two groups. In addition, the interpretations of individual change for persons with chronic illness may fit into several different models or theories of individual change and suggest other ways of looking at individual change that consider factors from a variety of models.

From the research perspective, greater awareness of possible individual effects of participation in Photovoice projects might help researchers to better describe potential risks and benefits to prospective participants. More importantly, study results could guide researchers in structuring Photovoice projects to include contingencies for dealing with both positive and negative individual and group effects of participation. Finally, the results may suggest changes in Photovoice's original conceptual underpinnings of empowerment education, feminist theory, and documentary photography as the method becomes increasingly used for very different purposes than it was originally conceived. The contributions of storytelling and photography may suggest the addition of presentational knowing to these conceptual underpinnings. Exploration of ways of knowing through the Photovoice process may also yield new insights about working with marginalized groups to increase their voice in the public arena.

Researcher Background

My particular interest was in support groups comprised of persons with non-visible handicaps who have participated or are participating in Photovoice research projects. According to the Rehabilitation Act of 1973, handicaps can be visible or non-visible, but must substantially limit one or more major life activities (Summary of Federal Equal Opportunity Laws, 2005). Asthma, diabetes, and epilepsy are among conditions considered as non-visible handicaps. Because of what I have observed and experienced in prior work on three Photovoice projects, one of them with an epilepsy support group, I became very interested in the individual effects of Photovoice participation that may have occurred along with the intended social change effects.

Epilepsy support group members represent not only a *marginalized* population due to issues of stigma and access, but also a *vulnerable* population because of possible cognitive impairment due to the condition and/or associated medications (Human Research Tutorial, 1998-2000). Although I had not found any published studies using Photovoice with support groups, Brown, Collins, Shepherd, Wituk, and Meissen (2003-2004), studied persons with psychiatric disabilities who used Photovoice to express the insider's view of their two consumer-run mutual support organizations. Although the title of *support group* suggests the giving of mutual support, many other tasks of consumer-run groups, such as fund-raising and public education, have potential to eclipse supportive aspects. My observations from three prior Photovoice studies have led me to believe that Photovoice is one such strategy that could enhance the mutually assistive nature of support groups by promoting individual reflection and group interaction through sharing and analyzing photographic images.

Changes in group interaction could in turn benefit the individual. For example, if a formerly reticent member began to share more with the aid of photographs, other group members might see that formerly reticent member, now an active contributor, in new ways.

Definitions

In this section, I provide definitions of commonly used terms in this research. These definitions are divided into three broad categories: adult education, health-related, and methodological, and are presented in Table 1.

Table 1

Definitions of Adult Education, Health-Related, and Methodological Terms

Adult Education Terms	Definitions
Marginalization	Process of social exclusion that relegates individuals and groups to the edges of society, often creating health disparities and vulnerable populations. Negatively viewed as Other, these people also tend to be underrepresented in research (Clandinin, 2007; Lynam & Cowley, 2007; Vasas, 2005)
Meaning making	In contrast to the empiricist view, the constructivist view that individuals and groups are involved in sense-making as a social activity that in turn shapes action (Guba & Lincoln, 2005). Also “meaning occurs in the mediation or dialogue that occurs between the action or ‘text’ to be understood and the interpreter in the context of the tradition in which the interpreter stands. Meaning thus is created or constructed each time one seeks to understand” (Schwandt, 2001, p. 154)
Voice	Concept related to who is speaking, who is heard, what is spoken, and who is given the opportunity to speak; often a concern as to which voices may be heard and which are silenced (Schwandt, 2001)

Table 1 Continued

Health-Related Terms	Definitions
Epilepsy	A brain disorder related to abnormal signaling in brain cells that results in seizures. Since there are multiple possible causes of seizures, not all seizures are a sign of epilepsy; at least two seizures are required for a diagnosis of epilepsy. Epilepsy is a highly stigmatized and often disabling condition.
Non-visible handicap	A condition or limitation that may be disabling, but that is not readily apparent, such as deafness, asthma, diabetes, or epilepsy. This would be in contrast to a visible handicap such as cerebral palsy.
Self-care	Personal care that individuals require each day to regulate their own functioning and development (Orem, 2001)
Self-efficacy	The belief that one is capable of producing a certain level of performance that in turn may influence one's decision to attempt a particular action or activity (Bandura, 1994)
Stigma	A mark, which may be physical, or related to behavior, biography, ancestry, or group membership that is discrediting and labels the individual as deviant (Jones et al., 1984)

Table 1 Continued

Health-Related Terms	Definitions
Support group	A group of individuals who have banded together because of a common life experience, condition, or problem. The group is peer-led and meets regularly to share concerns, provide mutual help, and encourage one another toward personal wholeness.
Methodological Terms	Definitions
Co-researcher	The research participant in certain types of qualitative research where the participant is either involved in the entire research project, as in participatory action research, or is otherwise considered a co-creator of knowledge.
Narrative	A presentation organized in story form; may be both a phenomenon to study and the method of study (Clandinin & Connelly, 2000; Schwandt, 2001)
Participatory action research	“The principles and values by which a community determines the research agenda and jointly shares in the planning, implementation of data collection and analysis, and dissemination of the research itself” (Wallerstein & Duran, 2003, p. 28)

Table 1 Continued

Methodological Terms	Definitions
Photovoice	A visual research methodology that puts cameras in the hands of the participants, often members of marginalized groups, to document, reflect upon, and communicate issues of concern with the goal of creating social change (Wang & Burris, 1997)
Storytelling	The process of communicating a narrative that involves an interaction between the teller and an audience in either oral or written form.
Vulnerable population	In research involving human subjects, members of a group for whom special care must be taken to assess risks and benefits of research participation, and who may be less likely to make a well-reasoned decision regarding participation, such as minors (under age 18), persons with mental, psychiatric, or emotional disabilities, persons with physical disabilities, economically or educationally disadvantaged, prisoners, the elderly, or other vulnerable populations (Human Research Tutorial, 1998-2000)

Study Overview

In this research, I studied the research experiences of individuals who had participated in the Photovoice methodology, a form of participatory action research. My specific aim was to learn about the individual experiences of members of a vulnerable population who had participated in a Photovoice research project aimed at social change. Photovoice is a methodology that puts cameras in the hands of community members who are marginalized, disenfranchised, or otherwise set aside in some way and helps them to document, reflect upon, and communicate their concerns. Participants are considered as co-researchers rather than subjects and are involved in the progression of the study from beginning to end, from determining themes of topics to be photographed, to presenting their views and interpretations of the photographs.

Participants in this study were members of an epilepsy support group who had participated in a previous Photovoice research project. In this study, participants had the opportunity to use photographs and other artifacts, along with newly taken photographs, to describe and reflect upon their prior Photovoice research experience. The methodology was visual narrative inquiry since it combines photographs with narrative inquiry. The research was accomplished in a series of three interviews with a final group interview.

Summary and Conclusions

The Photovoice technique has been introduced as a type of participatory action research that puts cameras in the hands of research participants to document community issues and stimulate social change. The original conceptual underpinnings of Photovoice were empowerment education, feminist theory, and documentary photography. Over time,

Photovoice has been used in a greater variety of ways, including combination with other methodologies, and for purposes other than it was originally conceived. With greater individual use, especially, it raises the question of whether or not the original conceptual underpinnings should be reconsidered, but more importantly, it highlights the need to understand potential individual effects of participation in Photovoice research. Despite possible benefits of research to create social change, potential individual impacts, especially on members of marginalized groups and vulnerable populations, have been minimally addressed. This research aimed to describe the individual Photovoice research experiences of a specific vulnerable population, persons with the chronic health condition of epilepsy, who were members of a support group. Interpretivism was chosen as the conceptual framework for the study because of its openness to multiple views that can arise from individual subjective perspectives of the meaning of photographs and associated stories. Results of this research have potential to impact strategies for working with support groups, suggest modifications to Photovoice research design that may improve the experiences of participants, and add to the original conceptual underpinnings of Photovoice through consideration of other ways of knowing.

The next chapter continues the explanation of the conceptual framework of interpretivism. I then discuss relevant literature areas, focusing first on the societal level, secondly on the individual level, and finally on the artistic, rather than the documentary, role of photography, with emphasis on presentational knowing through photography and storytelling.

CHAPTER TWO: LITERATURE REVIEW

This research study addressed the possible effects on individuals of their experiences with a participatory action research methodology aimed at social change. Specifically, the individual experiences of support group members with a stigmatized chronic condition who had participated in Photovoice research were the focus of this study.

Overview – The Snapshot

This chapter continues the explanation of the conceptual framework and presents the areas of literature review. Interpretivism was chosen as the conceptual framework since it is congruent with the subjective nature of meaning when people describe photographs they have taken and tell stories about their lives. The literature review has three areas. The first is the societal view that includes participatory action research and the specific methodology of Photovoice. Since this study explored the possible individual effects of Photovoice research participation, the second area of literature review is the individual with emphasis on self-care, support groups, and self-efficacy. The transtheoretical model is highlighted as a model of individual health behavior change among a range of other models of individual change. The third area of literature review is the artistic perspective of photography, in contrast to its documentary purposes in Photovoice research. Photography and storytelling are discussed as types of presentational knowing. Possible effects of engaging in the artistic process of taking and interpreting photographs are discussed in relationship to transformation and healing.

Conceptual Framework – The Filter

It's a bird. It's a plane. It's...

(From *Superman*, Salkind, Spengler, & Donner, 1978)

As discussed in the previous chapter, interpretivism provides a contrast to the single answer perspective of the scientific method by allowing multiple views of the same situation. This openness to multiple views or realities allows for the variety of perspectives I expected would occur as participants described and made meaning of their photographs and the stories that accompanied them. Interestingly enough, interpretivism not only allows multiple views and realities, but is itself viewed and conceptualized in a variety of different ways, which is the subject of the following section.

Interpretivism

Interpretivism is conceptualized in several different ways. For some, *interpretivism* is a general term used to distinguish qualitative research from the empiricist or positivist view (Schwandt, 2001). This dichotomy was evidenced by the ongoing debate between positivism and interpretivism in the literature (Fitzgerald & Howcroft, 1998; Lin, 1998; Meredith, 1998; Schwandt, 2000; Silverman, 1998). In this view, interpretivism is related to meaning making as the researcher seeks to understand the views and perspectives held by individuals about their lives and the events in them. The interpretivist view is inductive rather than deductive and is in contrast to the positivist view that there is one single verifiable truth that can be discovered and measured. In addition, the interpretivist viewpoint includes the involvement of the researcher in the research process such that he or she is part of the study and that the

ensuing meaning made involves interaction between the researcher and the individuals in the study (Baskerville, 1999; Miles & Huberman, 1994).

Another view of interpretivism is that it is one of several qualitative views. Merriam (1998) considered the interpretive orientation to be one of three views: (a) positivist, which seeks knowledge through scientific experimental research to arrive at an objective quantifiable reality; (b) interpretive, which sees knowledge as arising from an inductive rather than deductive process, and leading to the possibility of multiple socially constructed realities; and (c) critical, which sees knowledge as “an ideological critique of power, privilege, and oppression” (p. 4). Miles and Huberman (1994) divided qualitative data analysis into three categories: interpretivism, social anthropology, and collaborative research. In this conceptualization, interpretivism retains its characteristics of meaning making from the participant’s point of view, the researcher as co-elaborator, and a naturalistic setting. Semiotics, deconstructivism, aesthetic criticism, ethnomethodology, and hermeneutics are all seen as using interpretivism. In contrast to this, social anthropology, which includes life history, grounded theory, ecological psychology, narrative studies, and various applied studies, tends to be more descriptive and includes more extended contact. The third view, which is collaborative social research and includes critical ethnography and action science, is characterized by some of the same qualities of other naturalistic studies, but has the additional goal of creating change of the social environment.

While Merriam (1998) contrasted positivism with interpretivism and one other view, and Miles and Huberman (1994) contrasted positivism with interpretivism and two other views, Prasad (2005) contrasted positivism with interpretivism and three other views. He

considered the interpretive tradition to be one of four post-positivist traditions, the others being structuralist, critical, and post-traditions. The interpretive view includes symbolic interaction, hermeneutics, ethnography, ethnomethodology, and dramatism, all of which have in common similar views about subjective meaning and the socially constructed nature of reality. In contrast to the interpretive traditions, structuralism includes semiotics, the critical traditions include critical theory, feminism, structuration, and praxeology, and the post traditions include postmodernism, poststructuralism, and postcolonialism.

To round out the contrasting viewpoints about interpretivism, Schwandt (2000) offered an analysis of three epistemological stances: interpretivism, hermeneutics, and social constructionism, contrasting the philosophies, ethical issues, and methodological differences. Schwandt considered interpretivism to include three ways of defining the meaning of human action. The first was by empathic identification or intentionalism, which seeks to obtain an “inside” understanding of the intent behind a person’s actions. The second was phenomenological sociology, which seeks to understand how the intersubjective or life world is constructed. The third is what he called language games, which asserts that the system of meanings in the language is what gives meaning to human action. The commonalities of these three ways of defining human action are that they see meaning in human action, have an ethical commitment to the life world, and want to emphasize human subjectivity in an objective way. Their goal is to come to an understanding or *verstehen* of the meaning of human action. The differences among interpretivism, philosophical hermeneutics, and social constructionism are beyond the scope of this discussion of the conceptual framework. However, a key point to note is that Schwandt, after delineating and describing the

epistemological and methodological differences among the three stances, concluded that the labels are not the main point, but what “we” want to do as researchers.

That there are many conceptualizations of interpretivism is clear. For the purposes of this inquiry, interpretivism will be seen as a combination of the general characteristics of seeking to learn about meaning making and multiple realities, plus the categories proposed by Prasad (2005). Thus, interpretivism as used in this research will mean a post-positivist view in which the researcher seeks to understand the meaning of human action in a naturalistic social setting and in which the individuals participating in research may exhibit varied ways of making meaning and expressing multiply realities. In addition, the definition of interpretivism given by Schwandt (2001) will be used: “those approaches to studying social life that accord a central place to *verstehen* as a method of the human sciences, that assume that the meaning of human action is inherent in that action, and that the task of the inquirer is to unearth that meaning” (p. 234). Interpretivism is not merely the catch all phrase for any type of qualitative research but is at least to be distinguished from the critical, structural, and post traditions of qualitative inquiry. Although participatory action research, the methodology of interest for my study, is considered by some to be within the critical tradition, I was focusing on the varying ways that individuals viewed their experiences with that research. Thus, interpretivism was a good fit for the conceptual framework.

Participatory Action Research and the Societal Perspective – The Wide-Angle Lens

In contrast to positivist research, participatory action research (PAR), be it quantitative or qualitative, combines social science and social activism to create a very different way of conducting research (Minkler & Wallerstein, 2003a). Participatory action

research engages the community in the full spectrum of the research process in a collaborative approach that challenges traditional power structures and allows for a more pluralistic view of knowledge creation. Unlike traditional scientific research where the study subjects are the objects of the inquiry, PAR involves participants as co-researchers throughout the entire process in a collaborative process of action and reflection that leads to knowledge generation and increased understanding and voice of the lay people involved in the study (Kendon, Pain, & Kesby, 2007; Reason & Bradbury, 2008a). PAR most often focuses on people who are disenfranchised in some way with its ultimate goal being to effect positive social change.

Orlando Fals Borda, a Columbian sociologist, identified 32 different schools of PAR at the World Congress on Participatory Convergence in Knowledge in 1997 (Fals Borda, 1998). Kendon et al. (2007) have compiled a list of 21 current schools of PAR representing 10 different countries of origin (Australia, Austria, Canada, Columbia, Germany, India, Peru, Scandinavia, U.K., and U.S.A.). The list also included 12 names other than Participatory Action Research (Action Learning, Action Research, Community-based Research, Community-based Participatory Research (CBPR), Constructionist Research, Cooperative Research, Critical Systems Theory, Feminist Participatory Action Research, Participatory Community Research, Participatory Learning and Action, Participatory Research, and Tribal Participatory Research). This list, although long, is not all inclusive, as it does not include Participatory Rural Appraisal (PRA) (Chambers, 1994) or Chamber's own extensive list of participatory methodologies in the field of development inquiry (Chambers, 2008).

Photovoice is a specific PAR methodology (or CBPR, when applied to health issues) developed by Wang and Burris (1997) to help communities and various marginalized groups capture, reflect upon, and present findings and issues to their respective communities, with the end goal of effecting social change. Following the PAR concept of including study participants as co-researchers, Photovoice puts cameras in the hands of various marginalized groups in order to give them voice through the use of photographs.

Caroline C. Wang from the University of Michigan and Mary Ann Burris from the University of London developed the Photovoice concept, first describing its precursor strategy of photo novella, which was used by rural Chinese women to document and discuss their lives (Wang & Burris, 1994). The conceptual bases for photo novella were empowerment education, feminist theory, and documentary photography. This early work was later reconceptualized and further developed into the concept and methodology of Photovoice (Wang & Burris, 1997). As a PAR strategy, Photovoice aims to empower and create social change through reaching policymakers. Many additional Photovoice studies have followed by both the original researchers and others who have used and adapted the technique to a variety of settings and community groups.

History of PAR

In looking at this large array of PAR schools, names and countries, one might wonder if they all came from a common origin, much as a single tree trunk might grow up and branch off in many directions. Although this is possible, my exploration into the history of PAR has led me to think of it more like a bamboo shoot that shows up and starts sending out runners from various locations. When you see a new shoot, you are not sure if it was from the

original plant or if another bamboo plant has taken root and is also sending out runners. The next three sections reflect various possible tracings of the history of participatory approaches to research.

Tracing 1 – origins in action research. Action research (AR) is a practical approach to research that has its origins in the work of social psychologist Kurt Lewin in the 1940's. He is credited with developing both the term *action research* and the initial methodology of studying a social problem through a repeated cycle of planning, acting, observing, and evaluating (Bradbury, Mirvis, Neilsen, & Pasmore, 2008; Costello, 2003; Elden & Chisholm, 1993; McTaggart, 1997). Over the years, action research has been further developed and elaborated on by a variety of other researchers, both in the United States and abroad. Much of action research has been associated with business and organizational issues (Elden & Chisholm, 1993; Whyte & Hamilton, 1965) and with educational practice (Noffke & Stevenson, 1995; Schmuck, 2006). At the same time, others have taken the concepts and practice of action research and developed it into participatory action research (PAR), which is more collaborative, community-based, and oriented toward social change (Kindon et al., 2007; McTaggart, 1997). The characteristics of PAR have both similarities and differences with AR.

Tracing 2 – separate Northern and Southern traditions. According to Wallerstein and Duran (2003), there are two separate traditions of action research, the Northern tradition and the Southern tradition, with the Northern tradition being more focused on systems improvement and the Southern tradition being more focused on emancipatory research. They credited Lewin with the origins of AR, a process that involves action, research, and

education. With this distinction, AR in business and education would fall primarily within the Northern tradition, while PAR approaches such as Photovoice and community-based participatory research (CBPR) would fall within the Southern tradition. CBPR is a particular type of PAR that focuses on public health, social work, and related areas with the goal of eliminating health disparities (Minkler & Wallerstein, 2003b). Like PAR, CBPR is community-focused and aims not only to do the research with community participation, but also to effect change at the community level through action and education. Photovoice is often situated within CBPR because of its frequent focus on health issues.

Within the Northern tradition, collaborative methodologies have been developed over the years that have been used in organizations, both work sites and schools. Following in the AR tradition started by Lewin, Argyris, and Schon went on to develop the concepts of single- and double-loop learning and theory in use versus espoused theory, developing the field of action science (Argyris, Putnam, & Smith, 1985; Argyris & Schon, 1978). Within education, there is a whole stream of educational AR that focuses on research into one's own practice (Costello, 2003; Noffke & Stevenson, 1995; Schmuck, 2006).

The Southern tradition began in the early 1970's with participatory research arising in Latin America, Asia, and Africa, as a result of a variety of factors such as "the structural crises of underdevelopment, radical critiques by social scientists of existing theory, liberation theology, and the search by the adult education and development fields in how best to work with communities vulnerable to globalization by the dominant society" (Wallerstein & Duran, 2003, p. 30).

Adult education. Paulo Freire, a Brazilian philosopher and educator, was a major influence on the growth and development of PAR, especially in Latin America, through his *Pedagogy of the Oppressed* (1970) and other writings that asserted that community members were subjects of their own experience, not objects to be studied. Freire started his adult literacy work in 1961 and due to his exile, had extended it to other countries by the late 1970's as PAR was attracting interest. In his *Pedagogy of the Oppressed*, he wrote about the necessity of co-intentional education where both teachers and students are Subjects with the tasks of unveiling reality, coming to know it critically, and re-creating knowledge. In contrast to Mezirow's (2000) more individually focused transformative learning theory, Freire believed in transformation of society through both personal empowerment and social change (Merriam, Caffarella, & Baumgartner, 2007). His educational perspective demonstrated a shift from what he called banking education, where the "all knowing" teacher makes knowledge deposits into passive students, to problem-posing education where the teacher and student engage in dialogue and learn together about the situations in which they live (Freire, 1970). Another of Freire's key concepts was the process of conscientization whereby the ongoing dialogue resulting from problem-posing eventually leads the learners into the process of critical thinking as they gain awareness and begin to question oppressive forces in their lives. Note that Freire's goal of social change, with his shifting of the educational model to co-investigator status makes a natural connection of his work with the aims of PAR. His use of generative themes was another aspect of his educational strategy that had a significant influence on PAR (Torres, 1995).

Popular education. *Nonformal, community-based education, popular education, and local education* are terms often used synonymously to refer to education in the community with the underserved, disenfranchised, or oppressed, whether in this country or others (Merriam & Brockett, 1997). In popular education, strategies already common in the popular culture are used to reach and mobilize people. Especially for people with low literacy levels, art, drama, dance, song, storytelling, and other forms of expression have been used for educational purposes (Kerka, 1997). Popular education is also alternative education, representing roles the community takes on when the state is not doing it, or in contrast to what the state is doing (Jeria, 1990). According to Jeria, popular education practices were political and democratic and often arose in response to the needs of minority groups.

Freire (1973) was a key proponent of popular education through his literacy work in Latin America and many people associate popular education with Latin America. However, popular education can be conducted anywhere in the world that there are inequalities to address. Scher (2007) asked the question *Can the Arts Change the World?* in her article by the same title. One of her examples was Myles Horton's use of community arts, including music, in their organizing work with the Highlander Center. Here, the arts were useful in building relationships and mobilizing people for action and change.

Growth of PAR. Several significant organizations and events grew out of the emancipatory changes that were occurring in both education and research. These were:

- Participatory Research Group by the International Council of Adult Education in Toronto. It began in 1976 and had a network of Centers in India, Tanzania, the Netherlands, and Latin America (Hall, 2001).

- The first World Symposium of Action Research, Cartagena, Colombia. This first conference was in 1977. Twenty years later, after many other participatory conferences in other locations, the World Congress of Participatory Convergence in Knowledge, Space and Time was again held in Cartagena and attended by 1850 people from 61 countries (Fals Borda, 1998).
- Collaborative Action Research Group. This group worked with Aboriginal people in Australia. Kemmis and McTaggart were key researchers with this group (Kemmis & McTaggart, 2001, as cited in Wallerstein & Duran, 2003).
- Highlander Folk School. This adult education and social change center was started in 1932 by Myles Horton. Its participatory study on land ownership, conducted with John Gaventa, is one of the early examples of PAR challenging existing powers and oppressions (Brown & Tandon, 1983; Glen, 1996).

Fals Borda first used the term *participatory action research* in 1985, and his obituary recognized him the developer of the methodology of PAR and as the “father of participatory action research” (Gott, 2008; Gumucio-Dagron, 2008). In another example of varying views of history, Tanzanian researcher Marja-Liisa Swantz has also been credited with being the first to use the term *participatory research* (Hall, 2005, as cited in Kindon et al., 2007).

The 1980s brought a second wave of growth in PAR, particularly in community development. PRA and Rapid Rural Appraisal (RRA) were part of this wave (Chambers, 1994). PAR methodologies continue to grow and have spread around the world since the 1970s, proliferating into the myriad of schools and names mentioned previously. Ironically, as Wallerstein and Duran (2003) observed, Fals Borda did not refer to the Northern tradition

when he first wrote about participatory action research in 1985; nor did organizational development theorist William Foote Whyte in his 1991 book *Participatory Action Research* refer to the Southern tradition. Brown and Tandon (1983) reviewed a bibliography of participatory research readings and found that it did not mention AR researchers such as Lewin and Argyris. Similarly, reviews of AR literature did not cite Freire, Hall, or Swantz. And “never the twain shall meet...”

Tracing 3 – merging of disparate traditions. Tracing 1 asserted that PAR flowed out of origins that began with Kurt Lewin. Tracing 2 proposed two separate traditions, one Northern and one Southern, with AR being of the Northern tradition and PAR being of the Southern tradition. Tracing 3 now considers a third alternative. This alternative is that although AR and PAR had seemingly disparate origins, they have each developed over time and grown more similar. An obvious evidence of this phenomenon is that there have been two editions of the *Handbook of Action Research*, each of which has included a large variety of AR and PAR studies (Reason & Bradbury, 2001; Reason & Bradbury, 2008b). In addition, some books on AR now include what has traditionally been known as AR, along with PAR (Greenwood & Levin, 1998). Although acknowledging some remaining differences, Wallerstein and Duran (2003) explained that the two traditions have undergone a “rapprochement” over time. AR seems to have become more attuned and involved with social change and PAR has come to acknowledge some Lewinian connections. Kindon et al. (2007) agreed that the various strands of AR and PAR have been coming together.

Reason and Bradbury (2008a) referred to action research as a “family of approaches” and endowed it with many of the characteristics of families, sometimes arguing, ignoring, or

trying to dominate, yet pulling together in the face of the adversity, such as the common criticism of not being “objective.” By efforts such as their *Handbook of Action Research*, and other journals and forums, there is much greater awareness and exchange of ideas and strategies today that can only foster continued growth through analysis and critique. Whether or not Lewin started it all or whether the two traditions evolved separately becomes less of an issue. The issue is how to work together for the betterment of the lives of all the people touched by the various forms of participatory/action research.

Participatory Worldview

A discussion of the history and philosophy of PAR would be incomplete without considering the participatory worldview that has contributed an additional dimension to the field of participatory action research. Heron and Reason (2008) have been writing about the participatory worldview in various ways for many years, starting with their perspective on cooperative inquiry, a form of second-person action research. In contrast to the positivist worldview where the researcher is the one in control of the study and the subject is the one being studied, co-operative inquiry offers a different approach. In co-operative inquiry, the researchers become co-researchers and the subjects become co-subjects, so that they all work together throughout the entire co-operative inquiry process, co-collaborators working together to discover, or perhaps create, what is to be known. This more collaborative view of the world sets the stage for a shift in the research paradigm. Heron (1996) wrote that the co-operative inquiry model began for him in 1968-69 as he reflected on the experience of mutual gazing; this he put into a paper in 1970. His contact with experiential groups in 1970 made him think more about the fact that researchers wanting to do research on or about other

people's experiences are likely to misrepresent it. He and Reason began to work together in 1978, with Rowan, as they set up the New Paradigm Research Group in London. By 1981 they began working together on the methodology of co-operative inquiry. Heron (1996) acknowledged both commonalities and differences with both AR and PAR, but also explained that co-operative inquiry had separate origins.

Heron and Reason's (2008) work was set in what they called a fifth paradigm, the participative paradigm. The other four paradigms are positivism, postpositivism, critical theory, and constructivism. Over the years, Heron and Reason have developed an extended epistemology that extends knowing beyond the positivist world view. They asserted that although this epistemology is foundational to co-operative inquiry, it can be applied to all forms of AR. This epistemology proposed four ways of knowing: experiential, presentational, propositional, and practical (Heron & Reason, n.d., 2008). These four ways of knowing are discussed in further detail in the section *Presentational Knowing*. Co-operative inquiry, also referred to as collaborative inquiry (CI), has acquired some prominence in adult education with its use in facilitating learning from experience. Kasl and Yorks (2002) placed it within the family of experience-based action-oriented strategies, and acknowledged its origins with Reason and Heron. Unlike AR, which focuses on changing a system, CI focuses on learning and change within the inquirers, although change of the system may occur indirectly.

Wallerstein and Duran (2003) conceptualized Lewin, action science, and the problem-solving utilitarian approaches as being on one end of a continuum, with Freirean and other emancipatory PAR methods being at the opposite end. In the middle, they placed co-

operative inquiry. Another way of looking at this would be to use Reason and Bradbury's (2008a) conceptualization of first- second- and third-person research. Educational AR that looks at one's own practice would be first-person research. CI in a group would be second-person research, and PAR on a large scale would be third-person research.

Characteristics of PAR

Before proceeding to philosophies of PAR, I will provide a more thorough explanation of PAR by discussing what it is not, what it is, and finally, what it should not be.

What PAR is not. Artists often use the concept of negative space in their work, trying to cut away all that is not, in order to see that which is (Simmons & Winer, 1977). Whether it is cutting away the excess marble to reveal a finished statue or just being aware of the space around the form to be drawn, recognition of negative space can be a great help in clarifying the positive space and avoiding distortion (Parks, 2003). In a similar manner, clarifying what participatory action research is *not* can help to clarify what it is. McTaggart extrapolated from the work of Carr and Kemmis who described the minimum characteristics of critical education science, arguing that those same requirements can be applied to the social sciences, and hence, participatory action research (McTaggart, 1991; McTaggart, 1997). Thus, McTaggart provided a list of five things that participatory action research is not: (a) PAR is not what social science practitioners usually do, but is more systematic and collaborative; (b) PAR is not just problem-solving but also problem-posing and aims at improving and changing the world; (c) PAR is not research done on other people, treating them as subjects, but rather it is a collaborative process acknowledging people as knowing subjects capable of change; (d) PAR is not a method or technique for policy implementation

and it is less likely to accept outside truths than it is to help people develop their own understanding of a situation; and (e) PAR is not the scientific method applied to social sciences, but a separate, systematic, evolving process that can change both the researcher and the situation (Carr & Kemmis, 1986, as cited in McTaggart, 1997, pp. 39-40).

What PAR is. PAR involves first of all, participation, that is, having a share and taking part to the point of ownership, not just being involved, as McTaggart (1997) explained. Tandon has proposed three determinants of authentic research participation: “people’s role in setting the agenda of the inquiry, people’s participation in the data collection and analysis, and people’s control over the use of outcomes and the whole process” (Tandon, 1988, p.13, as cited in McTaggart, 1997, p. 29). Thus, in PAR, the participant co-researchers are an integral part of the study from beginning to end, not just for a specific task such as helping researchers gain access to a community or for advice on the wording of research materials to make them more “user-friendly” to potential study participants. Now that participation has been clarified, the next step is to clarify what PAR is.

The principles of PAR give a good explanation of what PAR is. These principles are best stated by the definitions produced from the first meeting of the International Participatory Research Network in 1978:

1. PR involves a whole range of powerless groups of people – the exploited, the poor, the oppressed, the marginal.
2. It involves the full and active participation of the community in the entire research process.

3. The subject of the research originates in the community itself and the problem is defined, analysed and solved by the community.
4. The ultimate goal is the radical transformation of social reality and the improvement of the lives of the people themselves. The beneficiaries of the research are the members of the community.
5. The process of participatory research can create a greater awareness in the people of their own resources and mobilize them for self-reliant development.
6. It is a more scientific method of research in that the participation of the community in the research process facilitates a more accurate and authentic analysis of social reality.
7. The researcher is a committed participant and learner in the process of research, i.e. a militant rather than a detached observer. (Hall & Kidd, 1978, p. 5, as cited in Hall, 2001, p. 171)

What PAR should not be. Despite the wonderful vision of what PAR could be, at least wonderful to its proponents, there are cautions and dangers that are best considered when embarking on a participatory research project. Even if PAR is supposed to be a good thing, empowering the oppressed and bringing about needed social change, power is still a critical issue. Kesby, Kindon, and Pain (2007) dealt with some of these cautions as they wrestled with the poststructuralist critique that even if participatory approaches are done properly, they are still a form of power that can be misapplied. These authors summarized a collection of concerns over negative power effects of participatory research drawn from eight other sources. Some of these concerns were: de-legitimizing non-participatory research

methods, romanticizing or marginalizing the production of local knowledge, legitimizing local knowledge just because it is produced through participatory processes, and re-authorizing researchers as experts in participatory approaches.

Cooke and Kothari's book *Participation: The New Tyranny* has generated much discussion and debate about the tyrannies that may arise in the participation process, particularly the tyranny of decision-making, the tyranny of the group, and the tyranny of methods (2001, as cited in Kesby et al., 2007; Wallerstein & Duran, 2003). PAR cannot just be naively implemented without looking at power relations and biases that may not be immediately apparent. Kesby et al. (2007) concluded their discussion of power issues with the comment that "We can no longer see PAR as a privileged, power-free mode of research, and must see it as a situated, contestable work in progress" (p. 25).

Moving from the philosophical issues to issues related to the conduct of research, Hagey (1997) raised other concerns about possible abuses of PAR. One of them was using the positive reputation of PAR to conduct research that is still conventional, retaining control, and being accountable to one's own bureaucracy rather than the community. Another was the use of community members as assistants or facilitators without actually getting the community into the process of owning the research. Such abuses may be intentional or unintentional, as researchers may be taking advantage of the community access that a study labeled "PAR" can provide or may truly lack the knowledge and competence to conduct this type of research. A final possible abuse of PAR was that some communities, such as First Nations who are developing their own theories and research programs, do not think that they need outside research facilitators as partners.

There are also very practical concerns from the point of view of the PAR researcher. Reflecting on a two-year participative action research study related to organizational change, Sense (2006) discussed the role of dilemmas between the ideals of PAR and one's own inclinations. Despite knowing the principles of PAR, it can be a challenge to be a participant or perhaps a facilitator on a PAR project, instead of being the one in control. Sense's reflections and discussion of the challenges bring the potential hazards down to a very practical level. Being a reflective researcher is key to the success of a PAR project as one must continually self-evaluate and determine if one is acting in accordance with the cooperative principles of PAR.

Philosophies of PAR

Every research methodology has a philosophical basis that affects how the research is conducted. In addition, every researcher has a worldview that affects what research methodologies they will choose to implement. PAR is no exception. Since the various PAR methodologies are oriented to social action and activism, it is important to consider what philosophy or philosophies underlie the methodologies and how one's personal stance may or may not fit with the methodologies. Since I was conducting an adult education research study, it was also important to consider where PAR fit within the philosophies of adult education.

Merriam and Brockett (1997) discussed three ways of categorizing the various philosophical approaches to adult education. The five philosophies proposed by Apps (1973, as cited in Merriam & Brockett, 1997) were essentialism, perennialism, progressivism, reconstructionism, and existentialism. In contrast, Elias and Merriam (1994, as cited in

Merriam & Brockett, 1997) offered the six orientations of liberal education, progressivism, humanism, behaviorism, radicalism, and philosophical analysis, discussing phenomenology, critical theory, and feminist theory under humanism and radicalism. Beder (1989, as cited in Merriam & Brockett, 1997) combined the aforementioned philosophies into three categories which he called “traditions.” These were: liberal-progressive, countercritique, and personal growth. Merriam and Brockett chose another combination of collapsed categories, liberal-progressive, behaviorist-humanist, and critical. For the purposes of my research, I situated participatory action research within one of the categories proposed by Merriam and Brockett.

Critical theory. At first glance, PAR seems to belong within the critical perspective of adult education as issues of power and oppression seem to connect PAR logically with critical theory. Critical theory arose out of the Frankfurt School of philosophy and social theory. There are a variety of lines of thought that have developed out of the Frankfurt School since different members of the school have expanded and developed their thinking over the years, changing and modifying their views over time. The principal thinkers were Horkheimer, Adorno, Benjamin, Marcuse, Fromm, and Habermas (Blake & Masschelein, 2003). Blake and Masschelein observed that it is logical for educationists interested in emancipatory education to be interested in critical theory, but that philosophers have taken much less interest in education than educationists have taken in critical theory. From their point of view, a key component of critical theory as it was originally conceived by the Frankfurt School was that while it critiqued present society and aimed to change it, the School “refused” to offer a positive ideal to aim for. Blake and Masschelein thus called critical theory a “utopian pessimism” (attributed to Gur Ze’ev, 1998).

Critical theory continues to change and evolve, however, so critical theorist and adult educator Steven Brookfield did not shy away from specifying a future ideal, a radical hope rather than a radical pessimism, that critical theory would bring about a “society of freedom and justice” (2005). Critical theory, as its name implies, is a critique, and in this case, it is a critique of capitalist society, privilege, and power, with a goal to change it.

There are five distinctive characteristics of critical theory attributed to Horkheimer (Brookfield, 2005). The first was that critical theory was grounded in a particular political analysis, that of the commodity exchange system of capitalism that determines all relationships. The second characteristic was that there was a goal of generating knowledge in order to free people from oppression. The third characteristic was that it broke down the barriers between subject and object, researcher and subject. The fourth was that the theory was normatively grounded, so that it not only critiqued current society, but also held a vision of what the world could be. Finally, the theory could not be validated until the theory it espoused was realized.

Brookfield (2005) outlined two particular elements of critical theory that related to adult learning. The first was that adults can come to question, recognize, and understand the economic (and other) disparities of the world they live in, that is, to think politically and realize that adult education is a political process. Secondly, critical theory must be critical of itself and realize that just as it challenges ways of understanding from a particular time and place, it must also realize its own origins in a particular time and place. Brookfield cautioned that we must be on guard for thinking that critical theory is the “grand theory” that will be universally applicable for all time.

Critical theory thus has close connections with PAR that seem important: contesting disparities and unjust power relationships, seeking a better life for oppressed peoples, using knowledge generation to help free people in their thinking and their daily lives, breaking down barriers between researcher and subject, and aspiring to a more just society. In addition, the first element relating to adult education was similar to the goals of conscientization (Freire, 1970) and others who have aimed to create political awareness among oppressed peoples.

Other alternatives. Despite what seems to be an obvious connection between PAR and critical theory, this connection, like the history of PAR, is not so simple. Just as critical theory asserted the need to be critical of itself and “guard against its own ossification” (Brookfield, 2005, p. 32), it is possible that other ways of thinking can also be compatible with PAR. Although Wallerstein and Duran (2003) acknowledged origins of PAR in critical theory, they also mentioned origins in liberation theology. Mayo (2000), for example, situated Freire, who had a Catholic background, within liberation theology in his arguments against “vulgar Marxism” that was too deterministic and mechanistic. McLaren (2000) further explained that Freire, in contrast to most other leftist educators, stressed the importance and power of love. In the last days of his life, he was reported to have said something like the following: “I could never think of education without love and that is why I think I am an educator, first of all because I feel love....” (McLauren, 2000, p. 19).

In addition, while PAR has answered some of the critiques of positivist research, some feminists have argued that PAR is still missing their voice, as the feminist perspective of social inequality may differ from the masculine perspective and PAR research that is not

well-done may have potentially “gendering effects” (Kindon et al., 2007). Maguire was concerned that participatory research was just “one more male monopoly” (1987, p. 48, as cited in Joyappa & Martin, 1996, p. 10). Maguire further felt that women were subsumed under terms like *community, people, and village*. Fortunately, feminist participatory research did begin to develop in the 1980s and is making inroads into the world of PAR.

Following are some of the theoretical stances held by PAR researchers: feminism, poststructuralism, Marxism and critical theory manifested through pragmatic psychology, critical thinking practices of democracy, liberationist thought, humanist and transpersonal psychology, constructionist theory, systems thinking, critical race theory, and complexity theory (Brydon-Miller, 2001; Cameron & Gibson, 2005; Fals-Borda, 2006a; Kesby, 2005, as cited in Kindon et al., 2007, p. 13). The 2001 *Handbook of Action Research* offered a similar list of theoretical stances that can be applied to all of AR, not just PAR (Reason & Bradbury, 2001): pragmatic philosophy, critical thinking, the practice of democracy, liberationist thought, humanistic and transpersonal psychology, constructionist theory, systems thinking, and complexity theory. It hardly seems to make sense that PAR could have so many different theoretical underpinnings, unless one remembers what so many researchers have said – that PAR is an approach or orientation to research and inquiry, not a specific methodology (Minkler & Wallerstein, 2003a; Reason & Bradbury, 2008a; Riecken, Strong-Wilson, Conibear, Michel, & Riecken, 2005). With this understanding then, it is entirely possible that different specific PAR methodologies could have different philosophical bases and epistemologies. Reason and Bradbury (2001) concluded that “its [action research] refusal to adopt one theoretical perspective...can be seen as an expression of a postmodern

sentiment” (p. 3). So, I must conclude, therefore, that while PAR in general seems to have close connections with critical theory, it also can be interpreted through the eyes of other perspectives.

Reconciling Framework and Philosophy

*“They went that way” said the scarecrow,
crossing his arms across his chest and
pointing in opposite directions.*

(From *The Wizard of Oz*, LeRoy & Fleming, 1939)

We have seen that PAR in its most generic sense fits within the critical tradition of adult education. We have also seen that there are many schools of PAR representing wide variations in place of origin, target populations, and specific methods (Kindon et al., 2007). In addition, PAR has a variety of epistemological sources besides critical theory, including feminism, poststructuralism, pragmatic psychology, critical thinking, practices of democracy, liberationist thought, humanist and transpersonal psychology, constructionist theory, systems thinking, critical race theory, and complexity theory (Kindon et al., 2007). Since critical theory has a specific ideological base and is a type of orientational inquiry (Patton, 2002a), it would seem that it may not be a good match with my conceptual framework of interpretivism, which although it is similarly post-positivist, is more postmodern than critical. Because critical theory has a specific orientation to research and “eschews any pretense of open-mindedness” (Patton, 2002a, p. 129), this is in contrast to the interpretivist view, which is actually more of a postmodern approach, denying objective truth and allowing for multiple realities (Kilgore, 2001). Although critical theory challenges the one true answer perspective of positivism, it has its own one true answer perspective, seeking to unmask power, confront

injustices and inequalities, and create social change. Interpretivism sees no one answer, but accepts that there may be a variety of answers from varying perspectives.

Although there also seems to be no one answer to the dilemma of reconciling critical theory with interpretivism, and thus the PAR methodology with the conceptual framework, there are some possibilities. First of all, the methodology is PAR, not critical theory. Since there are so many different ways of doing PAR, most researchers conceive of PAR as an approach to research or inquiry, rather than a specific methodology in itself (Minkler & Wallerstein, 2003a; Reason & Bradbury, 2008a). As an approach to research, PAR has some basic characteristics such as seeing participants as co-researchers and valuing local knowledge although the specifics of the methodologies can vary greatly. As mentioned previously, the specific methodologies have a variety of philosophies and epistemological stances behind them, not just critical theory. Secondly, the methodology I studied for my dissertation research was Photovoice, a form of community-based participatory research for health (CBPR) that involves the use of photography to document and create dialogue around the issues being studied (Wang & Burris, 1997). Photography is both a means of documentation and an art form (Daval, 1982; Gassan, 1972; Wang & Burris, 1994). As an art form, its products, the photographs taken by the co-researchers, may be interpreted differently by different people. The most important people engaged in interpretation are the co-researchers themselves, because it is through their eyes and voices that we begin to see and learn what may not have been evident before. Thus, although the overarching purposes of PAR may fit with critical theory in its efforts for social change and transformation, the specific methodology of Photovoice fits very well with interpretivism.

Fortunately, there is precedence for this mixing of perspectives. In reviewing the past two decades of progress in qualitative inquiry, Patton discussed a mixing of approaches that both he and Tom Barone have done, with Barone having combined “aesthetic, political (critical change), and constructivist elements” (Barone, 2000, as cited in Patton, 2002b). Just as a little tension in the muscles is good and necessary to keep the human body in balance, a little tension between overarching philosophy and conceptual framework can be functional, keeping a balance between absolutism and total uncertainty.

Summary of Framework, PAR, and Philosophies

Following a review of my chosen conceptual framework of interpretivism, I presented several alternative tracings of the history of participatory action research (PAR), demonstrating various views of the origins and development of participatory approaches to research. I then situated PAR within the adult education philosophy of critical theory, with the caveat that many types of PAR espouse different philosophies and epistemologies. Then I dealt with the tensions between the critical theory aspects of PAR and the postmodern aspects of interpretivism. I have offered some ways of reconciling the two and leave both the readers and myself to continue to wrestle with the tension.

Self-Care, Change Models, and the Individual Perspective – The Close-Up Lens

As a methodology, Photovoice engages individuals in the research process for the purpose of creating social change, but they are still individuals, subject to individual effects from the experience. Because participants in this study were support group members with a chronic health condition, the areas discussed here from the individual perspective seem most relevant. Because support groups are essentially self-help groups, consideration of how

individuals may grow and change within a support group leads naturally to the subject of self-care. People with chronic illness often have a major responsibility for the daily care and lifestyle choices that can help them to maintain or regain health. Support groups can play an important role in helping people to care for themselves as well as share with others. Within the context of a support group and also within the context of the Photovoice research experience, the individual members have the potential to experience individual change.

This section therefore will be discussing self-care and self-efficacy, defining support groups and explaining their recent history, and explaining a number of individual change models and theories. I selected one particular model, the transtheoretical model, as being potentially the most appropriate for this study, but it was also useful to consider other models as well. People do not always think or behave in ways we expect them to, which is part of the discovery aspect of qualitative research. It was important to leave open the possibility that the participants would identify with or exemplify other models or theories of change than the transtheoretical model.

Self-Care and Self-Efficacy

Nursing practice is based on theory and there are many theories that can serve as foundations for professional practice. The theory that seemed most appropriate to working with support group members who have a chronic health condition was Orem's self-care deficit theory, first developed in 1959 and more recently described in an updated version of her work (Orem, 2001). According to this theory, self-care, unlike physiological functions such as breathing, is a learned activity. When people are unable to perform self-care, they have a self-care deficit and need help to accomplish that activity. Orem saw the nurse as

“another self” who acts to do the self-care things, either temporarily or long-term, that the individual can no longer do. As the individual becomes more able to perform self-care, the nurse’s role decreases.

This theory fits well with adult education because self-care involves learning and because the self-care concept is applied to adults who are capable of self-care, as opposed to children, who generally not able to do so. Consideration of self-care would not be complete without dealing with the concept of self-efficacy. Self-efficacy has to do with one’s belief in the ability to perform an action which in turn affects one’s decision to attempt the action (Bandura, 1994). Self-efficacy can stand alone as an independent concept, but it is also a concept within the Health Belief Model (Health Belief Model, 2004) and a construct within the transtheoretical model (Prochaska & Velicer, 1997). Research on self-care is invariably linked with the issue of self-efficacy. For example, a recent study on diabetes management found that self-care agency, self-efficacy, self-care, and glycemic control were all positively related (Sousa, Zauszniewski, Musil, Lea, & Davis, 2005).

Support groups. Self-care theory also fits well with the concept of self-help or support groups where individuals struggling with common issues, including self-care, band together for mutual support and learning. The current proliferation of support groups for a variety of health conditions is partly reflective of the realization that much of the responsibility for the management of chronic conditions rests not in the physician or other health care providers, but in the patient (Clark, Gong, & Kaciroti, 2001). A prime example of the need for and benefit of support groups would be diabetes, where the patient is the one who must choose appropriate foods, take the right medications at the right time, and balance

activity with nutritional intake (Sousa & Zauszniewski, 2005/2006). A self-help group such as a diabetes support group can provide an environment in which group members share strategies and encourage one another in their necessary self-care. For example, the story of someone else's success with a particular self-care strategy could help another group member to decide what action to take.

Consideration of the development of modern day support groups, along with varying definitions of small groups for mutual aid and sharing, will be helpful for understanding the dynamics of Photovoice research within a support group. The following sections discuss such definitions and origins.

Definitions. First, some definitions are needed. There are several terms that are sometimes used interchangeably and at other times distinguished from one another. In discussing the most commonly used terms, *self-help groups*, *mutual help groups*, *support groups*, and *mutual aid self-help groups*, Lavoie, Borkman, and Gidron (1994) emphasized the importance of clarifying the meaning of "self." Using self-help books for self-improvement or engaging in political and community self-help activities such as local economic development and food banks are not what they are talking about. Engaging in social groups with peers is. They further distinguished self-help, mutual help, and mutual aid groups as being primarily "owned" by consumers, with support groups being primarily "owned" by professionals. The focus of their research was on consumer-owned groups; hence they primarily used the terms self-help and mutual aid groups, noting that there are some terminology differences internationally by culture.

In contrast, Klein (2000) used the terms support groups, self-help groups, and mutual aid groups interchangeably, noting that they basically mean the same thing: “a group of like-minded individuals who meet together regularly to share and learn from one another” (p. 9). As she said, this definition was broad enough to include many types of small groups from Bible study groups to groups that share a common life experience such as cancer, substance abuse, or domestic violence. The *Self-Help Group Sourcebook Online*, an online clearinghouse for such groups also used the three terms interchangeably on its home page (White & Madara, 2009).

A third perspective was provided by Borkman (1999) who made distinctions between support and self-help/mutual aid and further distinguished between self-help and mutual aid. In her conceptualization, support groups are groups of people with common problems that are led by professionals. Self-help is when an individual takes responsibility to help him or herself through marshalling internal resources. In contrast to Lavoie et al. (1994), she included the use of self-help books and other materials for “independent” education in this concept. Borkman further differentiated self-help from mutual aid or mutual help explaining that the latter two terms referred to individuals assisting each other emotionally, socially, or materially in a reciprocal manner. She concluded her discussion by merging the concepts of self-responsibility with interdependence and settled on the term self-help group to encompass these two concepts. She used the adage “you alone can do it but you cannot do it alone” to demonstrate this synergy (Borkman, 1999, p. 5).

A final definitional perspective was offered by Riessman and Carroll (1995) who also did not see self-help and mutual aid as synonymous. For them, self-help is the overarching

concept related to internal resources such as self-determination and self-empowerment that can be applied to individuals, groups, or communities. Within this framework, mutual aid is a particular aspect of self-help such as is present in programs like Alcoholics Anonymous (AA). Makela et al. (1996) would agree with this perspective, although calling it mutual help and emphasizing the fact, as others have, that AA eschews the term self-help because of its connotation that the individual can do it alone. Quasi-self-help refers to support groups led by professionals.

Since the self-help/mutual aid/support phenomenon is based on people coming together to share common needs and experiences, their voices need to be considered in the discussion of definitions. While professionals are holding conferences, conducting research, and writing about such groups, the everyday people are out there starting and participating in the groups. In our area, it seems that the most commonly used term is support group, referring to both professional and consumer-led groups (Support Groups, n.d.). Most importantly, the several groups I work with, including the one I studied for this dissertation research, was consumer-led but refers to itself as a support group. The term *consumer-led* would be foreign to them, but the concept of peer-led would be familiar.

Therefore, for the purposes of my research with people who have a common health concern, I use the term support group to refer to a group of individuals who have banded together because of a common life experience, condition, or problem. Such a group is peer-led and meets regularly to share concerns, provide mutual help, and encourage one another toward personal wholeness. The conduct of AA, probably the largest support group network in the world, typifies this definition.

Origins and growth of support groups. The history of support groups is by some accounts as old as history itself, and by others, a phenomenon of the 20th century. According to Moeller (1999), the history of self-help groups is rooted in group shamanism, secret brotherhoods of the sick, the guilds of the Middle Ages (which led to the Freemasons), and trade unions. Others see the history of support groups as beginning with the formation of Alcoholics Anonymous (AA) by Bill W. and Dr. Bob in 1935 (Kurtz, 1979). Although other origins are possible, I have chosen to begin my discussion of support groups with its modern day origins as this seems most relevant to my research with its focus on health-related support groups.

Bill W. and Dr. Bob, two laymen, each struggling with the life-controlling effects of alcohol, were the founding members of AA. Bill W. worked on Wall Street in New York City and Dr. Bob was a physician in Akron, Ohio. By their own accounts, they met one evening in Akron to admit and discuss their common problems with alcohol. By the next day (June 11), they had decided they needed to find another alcoholic to share with, agreeing that talking to others with the same need would be the key to continuing sobriety (Kurtz, 1979). On June 28, they found a third alcoholic to share with, and from there the membership grew to 40 in 1937 and 100 in 1939, after which growth came at an even greater rate due to the publication of their first book *Alcoholics Anonymous* that same year. Although Dr. Bob was a physician, the two men approached their respective needs as laypersons, since in the area of their common problem, neither was superior nor more “expert” than the other. In order to have a format for sharing their stories, they began holding informal meetings in one home on Saturdays and another on Wednesdays. In 1938, Bill W. began writing the story of AA which

included his initial “How it works” list of six steps, later expanded to 12. The 1939 publication of the book *Alcoholics Anonymous* under its new name marked their separation from the Oxford Group, an evangelical Protestant organization with whom they had been affiliated, and began a new era in the growth of the movement.

From the small beginning in 1935, AA has grown to be the largest mutual aid movement in the world and the prototype for many other similar programs and organizations (Makela et al., 1996; Riessman & Carroll, 1995). What began as an idea and agreement between two struggling alcoholics has now become a worldwide lay organization with an estimated 1,989,260 members and 114,561 groups worldwide as of January 1, 2007 (General Service Office of Alcoholics Anonymous, n.d.).

The origins of AA did not occur in a vacuum but in a social context. Over time there have developed many different types of support groups representing different traditions – and each tradition has its own perspective on origins, meanings, and growth. In looking back at the origins of what some now call the self-help movement (Katz, 1993), both Zola (1979) and Moeller (1999) saw self-help groups as arising in response to deficits in the healthcare system along with recognition of “expertise” on the part of patients who have “been there” (Zola, 1979, p. 454). Moeller observed that as medicine has become more technically focused, the patients have had to look elsewhere for compassionate care and they are finding it in self-help groups.

Outside of the health arena, Wuthnow (1994) saw the rise and continuing success of support groups as demonstrative of a widespread deep need for community. Wuthnow identified the 1960s as the major growth spurt in small groups, citing T-groups, encounter

groups, small groups in religious organizations, and medical and therapeutic groups as contributors to the growth. In his national representative survey, 40% of the U.S. adult population said they were involved in “a small group that meets regularly and provides caring and support for those who participate in it” (p. 45). Katz (1993) viewed the origins of the modern self-help movement starting a little earlier, in the post World War II era, with groups for “mutual support and aid by many needy, socially stigmatized, disenfranchised, and like-minded people” (p. 8) arising out of the social movements and crises of the 1950s and 1960s. The women’s movement and disability rights movement are also credited with fostering self-help groups in the 1960s and 1970s (Riessman & Carroll, 1995). They further commented that there is now a self-help group for every major disorder listed by the World Health Organization. In our era of increasing self-disclosure encouraged by the media and all of our electronic devices, along with greater and greater segmentation of society, the self-help movement shows no signs of abating.

Out of data from the national survey of small groups, Wuthnow (1994) made some conservative assumptions about the number and size of groups that 40% of the U.S. population reported participating in. From that he extrapolated that there were approximately 3 million groups at that time. This number of course included many types of small groups, a subset of which was support groups. Looking at other data from the AA Fact File (General Service Office of Alcoholics Anonymous, n.d.), the estimate of their groups in just the U.S. is 53,665. The *Self-Help Group Sourcebook Online* alone provides information on over 1,100 Mutual Aid Self-Help Support Groups, both in-person and online (White & Madara, 2009), and this is certainly just a portion of what is available.

Although I was not working with online support groups, they are a phenomenon worthy of note, offering greater possibilities of connection among people with common concerns. From the health perspective, I can see specific advantages in connecting people with rare conditions all over the world. For example, if one has a child with an unusual disease, there may be no other families struggling with the same situation in the immediate area, but there may be a family in Japan. An online support group could make that connection. Although online support groups lack some of the personal cues and face-to-face connections that in-person groups can offer, they may be more appealing to people who want to share, but also want some anonymity. A recent newspaper article on support groups reported on the possibility of virtual support groups whereby people who were hesitant to relate to other people could interact with “autonomous synthetic characters” (Miller, 2009).

My research focused on the Photovoice research experiences of members of an in-person support group with a health focus. In this type of group, as knowledge is shared and constructed, individual power increases and is no longer totally vested in the physician. Improved health could come not only as a result of medical interventions, but also as a result of improved self-care and self-efficacy enhanced by the knowledge and support shared in a support group.

Models of Individual Change

For the purposes of my dissertation research, I was looking at individual changes that may have occurred in support group members as a result of participation in the Photovoice research process. The individuals in the health-related support group were people with a chronic illness. Although, there are a myriad of theories and models describing how

individuals change, I chose to focus on the transtheoretical model developed by Prochaska and Norcross (1994). After describing the transtheoretical model, I will proceed to discuss other models of individual change. A discussion of individual change within a group context will follow.

Health professionals are acutely concerned with the problem of health behavior change because so much of what happens to people is affected by lifestyle choices. How people eat, sleep, exercise, and relate to others can all have a significant impact on health, whether for prevention of health conditions or management of chronic conditions.

One person who has a distant relative with diabetes may be concerned at a young age about preventing type 2 diabetes and work hard to eat a healthy diet and maintain a normal weight. Yet another person who already has diabetes may not be practicing the necessary self-care behaviors that can slow the progression of the disease and prevent serious complications, such as taking prescribed medications, eating a lower carbohydrate diet, and performing regular physical activity. While developing my research proposal, I spoke with a physiologist working to eliminate health disparities in the prevalence of hypertension among African-Americans as compared to other groups. After years of studying physiological measures of blood pressure and associated conditions, she is moving into the area of psychosocial factors affecting why people may or may not take care to prevent or manage high blood pressure. Why? Because, as she says, “They know what they’re supposed to do, but they’re not doing it” (M. Pointer, personal communication, February 20, 2009).

Efforts to change behaviors affecting health can be at the individual level in a clinical setting through one-on-one educational interactions between a health professional and a

patient or client. Such efforts can also be at the community level through public health measures such as media campaigns or educational programs aimed at affecting large segments of the population. Such efforts to promote health and prevent disease may also have some overlap. Vaccinating one child against measles, for example, can prevent that child from contracting measles and suffering possible serious complications of the disease, while vaccinating a sufficient portion of the population can prevent an epidemic from starting and can also eventually lead to eradication of the disease. Individual and community level efforts for health change are both needed and can be complementary.

The transtheoretical model. In their book *Systems of Psychotherapy: A Transtheoretical Analysis*, Prochaska and Norcross (1994) reviewed 13 systems of psychotherapy, each with numerous specific therapies per system. They concluded that each system had “a logical, coherent, and compelling construction, once we accept its core assumptions” (p. 453). Among the positive attributes of these systems were that they offered “brilliant” insights and could all be applied to treat the same individual whose case was used as a motif throughout the book. Disadvantages of the various systems were that most of them were not empirically tested, that they lacked predictive power regarding change, and that many of them focused more on *what* to change rather than *how* to change.

Prochaska and Norcross (1994) asserted that superiority of one system of psychotherapy over another cannot be clearly determined by empirical research (they all work in one way or another), nor can a completely rational approach to evaluating theory demonstrate such differences. Rather, they took a developmental approach in determining how to use the various psychotherapy systems. Using William Perry’s (1970) theory of

intellectual and ethical development, they applied the four main distinct stages to describe four differing intellectual stances that a therapist could take towards a psychotherapy system: dualistic, multiplistic, relativistic, and committed. Of these four options, they proposed that an ethical psychotherapist would acknowledge relativism, since there are a variety of therapies than can prove equally useful. At the same time, they recommended that therapists make a commitment to a particular system which has the potential for demonstrated validity and seek to work well within that system while continually seeking to improve and evaluate it. This is the intellectual stance they took with their own transtheoretical model. In addition, they referenced Werner's (1948) organismic-developmental theory which had three stages: seeing a global whole without individual parts, perceiving differentiation into parts but losing perspective on the whole, and finally being able to organize and integrate the parts into a new conception of the whole.

Prochaska and Norcross's (1994) lofty goal then, has been to develop a model to which therapists can make an "epistemological commitment" and which reflects both unity and complexity due to its integration of characteristics drawn from other major theories. The name of their model is "transtheoretical" because it reflects the fact that they have drawn from other major theories to develop their model. One of the appeals of this model is that although it can be used by therapists in helping clients to change, it also applies to self-change and can be useful to individuals navigating their own change processes.

Overview of transtheoretical model. The transtheoretical model is an empirically derived model of processes of individual change that has been widely used and tested since its original inception in 1979 (Prochaska & Norcross, 1994). "The transtheoretical model

acknowledges that not everyone is ready to change behavior. This model is useful in designing health programs targeted at particular stages of change or for moving individuals through different stages” (Health Behavior Models, 2000, B. Resources). Three general components of the model – processes, stages, and levels – were developed at different times, and integrated into the full model. The full model consisted of ten processes of change (how), five stages of change (when), and five levels of change (what) (Petrocelli, 2002; Prochaska & Norcross, 1994).

The transtheoretical model began with a set of theoretical processes of change that Prochaska first proposed based on his analysis of other systems of psychotherapy (Prochaska, 1979). These ten processes are consciousness raising, catharsis/dramatic relief, self-reevaluation, environmental reevaluation, self-liberation, social liberation, counterconditioning, stimulus control, contingency management, and helping relationship. These processes are considered to be the *how* of change. This current list of ten processes reflects those which have been tested over time (Prochaska & Velicer, 1997).

The five stages of change are precontemplation, contemplation, preparation, action, and maintenance. These stages are considered to be the *when* of change. What is interesting about these stages is that they arose out of research on psychotherapy patients and self-changers during a research study on the frequency with which people used the ten processes of change in either a therapy situation or on their own (Prochaska & DiClemente, 1983). This was the component of the total model most relevant to my research.

The five levels of change are symptom/situational problems, maladaptive cognitions, current interpersonal conflicts, family/systems conflicts, and intrapersonal conflicts.

These levels are considered to be the *what* of change. These levels represent a hierarchy of psychological problems from more external to more internal, and more superficial to deep, upon which therapists could intervene.

In the complete model, the ten processes may be operational at different stages, while the levels reflect points at which therapeutic intervention may occur to facilitate change. Through the years, the stages of change have become the most widely known and utilized portion of the model so that many researchers now call it the Stages of Change model (Adams & White, 2005).

Focus on stages of change. For the purposes of my dissertation research, I was most interested in the stages of change. Following are the key features of the five stages of change (Prochaska & DiClemente, 1982; Prochaska & Norcross, 1994; Sullivan, 1998) along with examples of what a person in each of the stages might say, as suggested by Westley and Briggs (2004):

1. Precontemplation – not thinking about changing behavior. People in this stage may not even think they have a problem that needs changing. Denial is another possible feature of this stage. “Huh! I don’t know what you’re talking about” (Westley & Briggs, 2004, p. 10).
2. Contemplation – thinking about changing behavior in the near future. People in this stage acknowledge there is a problem and begin to increase their awareness and knowledge about the problem. “I’m interested in knowing more” (Westley & Briggs, 2004, p. 10).

3. Preparation – making a plan to change behavior. People in this stage are developing a plan and commitment to change because they realize change is necessary. “What do I need to do?” (Westley & Briggs, 2004, p. 10).

4. Action – implementing the plan to change behavior. People in this stage make the actual behavior change or changes. “Here’s what I’ve done” (Westley & Briggs, 2004, p. 11).

5. Maintenance – maintaining the behavior. After six months in the action phase, the individual may be in the maintenance phase, where efforts are still necessary to maintain the behavior change. “Is everything OK?” (Westley & Briggs, 2004, p. 11).

The stages of change are diagramed as a spiral to indicate the fluid nature of movement from one stage to another, including backwards to a previous stage (Petrocelli, 2002; Prochaska & Norcross, 1994). This nonlinear conceptualization is one of the attractive features of the model. It acknowledges that people can be at different stages of the change process at different times and that progress is not necessarily a continually forward process. Instead of giving the individual a sense of failure, the model suggests that he or she has just moved to a prior stage and may need additional knowledge or motivation to change stages again. Forward progress is usually faster the second time due to “insights and experience” gained from prior stages (Sullivan, 1998).

Interaction of the five stages of change with other aspects of the complete model is important to note. This is because the processes of change often trigger movement from one stage to another. Of particular applicability to my dissertation research was the first process of consciousness raising. Kleinknecht (n.d.) observed that experiential procedures such as

photos, educational materials and *self-help groups* may all serve as consciousness raising activities. Although these activities usually do not lead to action, they may serve to move individuals from pre-contemplation to contemplation. Because the levels of change relate more to psychological issues upon which therapists could intervene, they were of minimal relevance to consideration of change in support group members who are not in a psychotherapeutic relationship.

Critique of transtheoretical model. Although the transtheoretical model has been widely used and applied to a variety of health behavior change issues from smoking cessation to stress management, it is not without its critics. Adams and White (2005) summarized the benefits of the transtheoretical model as being its apparent face validity, its applicability to a large number of health-related behaviors, and its practical utility. They then discussed their own “non-systematic, critical review” of 26 stage-based studies (i.e. based on the transtheoretical model) to promote physical activity (Adams & White, 2003, as cited in Adams & White, 2005). Although 73% of the studies found the model effective in promoting short-term change, only 29% of the studies that followed participants more than six months found that the stage-based interventions worked any better than the control situation. They also discussed another review of stage-based interventions conducted by Riemsma et al. (2002, as cited in Adams & White, 2005) that similarly identified the lack of long-term effectiveness related to physical activity change. Significant among Adams and White’s conclusions was that the factors affecting behavior change for physical activity were more complex than with some of the other changes, such as smoking cessation, that the

transtheoretical model had been applied to. Overall, they were discouraging about continuing to use stage-based intervention models for investigating complex behaviors.

In a reply to Adams and White's (2005) critique of the transtheoretical model, labeled as "arguably heretical" by the journal's editor, Brug et al. (2005) offered their responses. Rather than review the details of the five commentaries, let me just summarize and say that they are not for abandoning the transtheoretical model, but rather argue for continued evaluation of stage-based interventions despite problems in applying the construct to complex health behaviors. They also identified the fact that objections to the model were not only technical but ideological, since for some, the model is intuitively appealing while others just become bogged down in arguing whether it is a model or not and various other details.

I personally wonder whether changing physical activity is a more complex issue than smoking cessation, but the question raised in their title *Why Don't Stage-Based Activity Promotion Interventions Work?* (Adams & White, 2005) is an important one to consider. The concept of a "stage" is a conceptualization devised to describe a phenomenon of interest. We divide so many things into categories, intervals, and stages in order to understand and communicate about them, but the situations are often more complex than whatever the model describes. This is something to keep in mind while using the transtheoretical model or any other model with stages. A moderating factor to this dilemma is that the transtheoretical model has a recursive nature that allows for both forward and backward movement between stages, as previously discussed under *Focus on Stages of Change* (Petrocelli, 2002; Prochaska & Norcross, 1994). In addition, although the stages are labeled as discrete entities, the picture of the model is a spiral, which indicates continuity between stages.

Other models and theories of individual change. Although I chose the transtheoretical model as my framework for looking at individual change, it is just one of many ways to look at change on the individual level. A review of several texts and handbooks on psychotherapy and counseling revealed a multitude of strategies that psychotherapists and counselors use in helping individuals change. As mentioned previously, Prochaska and Norcross (1994) reviewed 13 other models besides the transtheoretical model. Dryden (2007) described 16 different therapies. Feltham and Horton (2006) discussed 23 types of therapy divided into the following categories: psychodynamic approaches, cognitive-behavioral approaches, humanistic-existential approaches, and eclectic-integrative approaches. Snyder and Ingram (2000) reviewed a multitude of psychotherapeutic approaches within the general categories of psychodynamic approaches, integrative psychotherapy, existential approaches, interpersonal psychotherapy, marital therapy, groups as change agents, constructivist and narrative psychotherapies, feminist therapy, contemporary behavior therapy, cognitive and cognitive behavioral therapies, planned short-term psychotherapies, long-term psychotherapy, and psychopharmacology in conjunction with psychotherapy. These various individual change therapies represent a wide range of treatment modalities, most of which require the intervention of a therapist or counselor, but some of which, like the transtheoretical model, may also be used in a self-directed way. The many individual change therapies discussed in these four books, although covering a wide range of approaches, is by no means inclusive as it represents just two fields of study, psychotherapy and counseling.

In addition, there are models and theories of individual change within other disciplines and traditions, such as business, health, education, and spiritual traditions, several of which I will be discussing in greater depth. In the following sections I will review several of these theories and models of individual change. The first two, field theory and the Health Belief Model (HBM), are acknowledged as foundational to action research and the study of health behavior change, respectively, and are discussed briefly. The remaining four, transformative learning, self-renewal, stages of grief, and spiritual transformation are discussed in greater depth as processes that may occur in a self-directed way within the individual or with facilitation, but do not necessarily require psychotherapy or counseling. These latter four thus seemed most relevant to my dissertation research dealing with individual change of support group members involved in the Photovoice research process.

Business and organizations – field theory. Since Kurt Lewin was also the originator of action research (Bradbury et al., 2008), I chose to include field theory as an example of an individual change theory (Lewin, 1951). Field theory is composed of a setting in which change takes place, three basic concepts, and a three stage change model. The setting or field is the “life space” which includes the individual and the environment as they see it (Neill, 2004). Two key ingredients about the environment are that the environment is whatever the individual perceives it to be regardless of how others may view it. Secondly, the present contains both the past and the future as components of that perceived environment (Daniels, 2003).

The three main concepts are driving forces, restraining forces, and equilibrium. These psychological forces are what drive change, with the driving forces promoting change and

the restraining forces hindering change (Swanson & Holton, 2001). If the driving and the restraining forces are equal, a “quasi-equilibrium” state is said to occur where there is no movement. Customs and social habits are some of the things that could keep people in equilibrium.

The process of change includes three stages: unfreezing, moving, and refreezing. If the driving forces become greater than the restraining forces, movement can occur out of the quasi-equilibrium state as changes in thoughts, feelings, and/or behavior occur. The refreezing process is then required in order to maintain the change, with the assistance of both internal and external factors.

Of particular relevance to adult education is Lewin’s view of learning, that learning can cause both changes in knowledge, which he called cognitive structure, and in motivation (Lewin, 1951). His view of knowledge was more passive than the current conceptualization many have related to knowledge construction. However, in the area of learning values such as democracy, he emphasized that “the person has to do something himself instead of being passively moved by forces imposed on him” (p. 76). Lewin’s field theory may seem highly cognitive and mechanistic compared to other present day views of change, but it is significant as a precursor to later conceptualizations of individual, organizational, and social change.

Health – Health Belief Model. The Health Belief Model (HBM) is a psychological model that focuses on individual attitudes and beliefs to explain and predict health behaviors. This model was initially developed in the 1950s by researchers with the U.S. Public Health Service and was written in book form in 1974 (Green, 2002). Social psychologists Godfrey

Hochbaum, Stephen Kegels, and Irwin Rosenstock developed the HBM, using theory from the behavioral sciences and applying it to health problems in order to study health behavior in a more systematic way (Becker, 1974; Rosenstock, 1974). Their concern as to why the public did not participate in preventive health and screening measures such as free chest x-rays for the detection of tuberculosis, led to the development of the model, as it became evident that many factors were affecting motivation and decisions to engage in health seeking-behaviors. In developing the HBM, Hochbaum, Kegels, and Rosenstock were greatly influenced by the goal setting in the level-of-aspiration component of Lewin's field theory, adopting the concept that behavior is based on "the value of an outcome to an individual and...the individual's estimate of the probability that a given action will result in that outcome" (Mikhail, 1981, p. 67).

The original HBM had three core assumptions and five key concepts. The assumptions are that an individual will take a health-related action if that person (a) feels that a negative health condition can be avoided, (b) has a positive expectation that by taking a recommended action, he or she will avoid a negative health condition, and (c) believes he or she can successfully take a recommended health action (Health Belief Model, 2004). The five key concepts are perceived susceptibility, perceived severity, perceived benefits, perceived barriers, and cues to action (Janz & Becker; 1984; Janz, Champion, & Strecher, 2002; Trammell, 2002). These five concepts relate to the perceptions, assessments, or opinions of an individual about a particular health condition and can be used to explain why this individual may or may not take preventive action. The first two concepts, perceived susceptibility and perceived severity, both relate to perceived threat. Perceived susceptibility

is the individual's assessment of the risk of getting a particular health condition. Perceived severity is the individual's assessment of how serious that condition would be and its potential consequences, including the consequence of not getting treated. The third concept is perceived benefits, which is belief in the efficacy of actions to reduce risk or seriousness of the condition. The fourth concept is perceived barriers, which are the potential negative effects, either tangible or psychological, that could result from the recommended health action. The fifth concept, cues to action, relates to external events that activate readiness and lead to actual actions toward health.

There is now a sixth concept, added to the model in 1988, which is Bandura's concept of self-efficacy, the confidence in one's ability to take action. Bandura defined perceived self-efficacy as "people's beliefs about their capabilities to produce designated levels of performance that exercise influence over events that affect their lives" (Bandura, 1994, p. 71). According to Bandura, the individuals' beliefs about whether or not they *can* change will affect their ability *to* change.

The HBM, although widely used and evaluated (Janz & Becker, 1984), has been criticized for being too cognitively focused and limited in its ability to predict complex lifestyle behaviors compared to later models that have been developed. Green (2002) noted that the transtheoretical model has now surpassed the HBM in frequency of application, but asserted that it is still useful for planning communications in health education. A fairly recent master's thesis explored just this subject, looking at Internet communication of health messages (Trammell, 2002). I believe that the basic concepts of the HBM continue to be useful and can be easily understood by anyone seeking insight into his or her personal health

choices and health behavior. In addition, the concept of self-efficacy is applicable not only to this model, but is also an independent concept with relevance to individuals dealing with self-care issues whether solo or in the context of support groups.

Adult education -- transformative learning. Merriam and Caffarella (1999) stated that “transformative learning is about change – dramatic fundamental change in the way we see ourselves and the world in which we live” (p. 318). According to Webster’s dictionary, to transform means “to radically change the outward form or inner character” or “to change in condition, nature, or character” (Costello, 1991, p. 1416).

Jack Mezirow first described his theory of transformative learning in 1978 and has continued to develop it in the years since (Merriam et al., 2007). He postulated a disorienting dilemma which challenges the individual’s view of the world and causes a reevaluation of meaning and perspective. This is accomplished in four general phases: experience, critical reflection, discourse, and action. Mezirow’s initial view of transformative learning was a very cognitive process in which reflection on one’s perspective also included rational discourse with others who could validate conclusions. The final outcome of transformative learning was action, generally more on a personal level than relating to social action. The actual model consists of ten phases:

1. A disorienting dilemma
2. Self-examination with feelings of guilt or shame
3. A critical assessment of assumptions
4. Recognition that one’s discontent and process of transformation are shared and that others have negotiated a similar change

5. Exploration of options for new roles, relationships and actions
6. Planning of a course of action
7. Acquisition of knowledge and skills for implementing one's plans
8. Provisionally trying out new roles
9. Building of competence and self-confidence in new roles and relationships
10. A reintegration into one's life on the basis of conditions dictated by one's new perspective. (Mezirow, 1995, p. 50, as cited in Taylor, 1998, p 8)

Various authors have critiqued Mezirow's theory of transformative learning over the years, leveling such criticisms as it being too focused on cognition, not dealing with social context, and in contrast to Freire's (1970) process of conscientization, not dealing enough with social change (Merriam & Caffarella, 1999).

Mezirow (2000) responded and reevaluated, with further work reflecting his developing views. He later acknowledged emotional and intuitive components of transformative learning, with recognition that learning is situated in a social context and discussion of social issues such as social justice and social democracy. He also differentiated between transformation that is dramatic and that which may occur incrementally over time. These later changes made Mezirow's theory of transformative learning not only more applicable to a variety of situations, but also more palatable to his detractors.

The streams of transformative learning have taken off in many directions since Mezirow's original conceptualization. Taylor (2005) discussed seven perspectives that have developed over the years, three of which remain more individually focused and four of which have more of a social or collective focus. In addition to Mezirow's original psychocritical

stance with its emphasis on rationality, the three other individually focused perspectives were psychoanalytic, psychodevelopmental, and neurobiological. The four perspectives with more of a view to social change were social emancipatory, cultural-spiritual, race-centric, and planetary.

Much of the change that individuals experience is a result of adversity. Sometimes that adversity can be transforming in a positive way. Lance Armstrong, seven-time winner of the Tour de France, experienced a serious health crisis, but triumphed with an experience of “meaning making and growth.”

The truth is that cancer was the best thing that ever happened to me. I don't know why I got the illness, but it did wonders for me, and I wouldn't want to walk away from it. Why would I want to change, even for a day, the most important and shaping event of my life? (Sears, Stanton, & Danoff-Burg, 2003, as cited in Park, Lechner, Antoni, & Stanton, 2009, p. 21)

Scott (1997) applied the transformative learning process to grieving and noted that both internal and external events can trigger the grieving process. In fact, she asserted that grieving is “integral” to transformation since it requires giving up old ways of seeing and taking on new ways. I see this as a link with the application of Kubler-Ross's (1969) model of the stages of grief to the losses associated with chronic illness (to be discussed under *Dealing with Loss – Stages of Grief*). Transformative learning is another model of individual change that can take place on the individual level and is appropriate for application to persons in support groups.

Adult development – self-renewal. Frederic Hudson, founding president of The Fielding Institute and co-founder of the Hudson Institute, is an educator, coach, writer, and consultant who works with both individuals and organizations on transition and change. His model of self-renewal (Hudson, 1999) is a cyclical rather than linear model of change applicable to adults. He conceived of two cycles that adults are simultaneously participating in, the life cycle, with its development stages and tasks from birth to death, and the change cycle, an ongoing cycle of internal and external change, with periods of stability (the chapters) and periods of transition.

There are four cycles in Hudson's (1999) model of self-renewal: Phase 1: Go for it, Phase 2: The doldrums, Phase 3: Cocooning, and Phase 4: Getting ready. In the first phase, people begin to envision and create their future by having a dream or a goal, imagining the steps to reach the dream, and working towards it. After achieving the goal and feeling satisfied, there may come a time of plateau when the dream no longer works. This is the entry into Phase 2, where there is a sense of distance from the dream one has been living and perhaps a disenchantment with achievements. After attempts to make changes to make the dream work again, if it cannot be repaired, the person enters a restructuring phase where an eventual disengagement or exit occurs from this chapter of life. Then Phase 3 begins, which is a season of grief and loss and inner soul searching for new direction. This period of loneliness and detachment ends with a sense of healing, renewal, and readiness to reenter the external world with new hopes and new dreams. Phase 4, then, is the phase of reentering the world with a sense of renewal, full of energy and new ideas. This is a period of engagement, learning, and eventual entry onto a new path in a new direction.

Hudson's (1999) model also included lists of behaviors that characterize each phase, along with ten life skills or competencies that can help people work through each of the phases. The model accounted for both changes by choice, such as growing dissatisfaction with a career, and unexpected changes, such as death of a child. Just as the name of the model is self-renewal, the model can also be self-taught and self-implemented. Someone could go to a seminar to learn about dealing with life transitions and change, but that same person could also read the book, identify where they were in the cycle, and use the strategies presented to gain self-awareness and assistance to work through the self-renewal process.

The model was designed to work in our present era of rapid change and uncertainty, recognizing that often life does not unfold in a predictable linear pattern, but rather is characterized by many cycles of change throughout adult life. Although life changes occur within a context of external factors and events, as a self-renewal model, this model is individually-focused, placing the burden of work (and success) on the individual. As Hudson said,

You are ultimately responsible for your own life chapters and transitions. Even if tragedy befalls you, you are the only one who can decide how to continue your story. You are a person, with a story, on a journey, weaving your way through the scenes of our life. If you do not write the script, someone else will...But if you write the script, it will be a 'life design,' an intentional plot to make your world work—the world of your own experience and imagination. (1999, p. 71-72)

Although Hudson's (1999) model of self-renewal is an individual change model, he included consideration of the world at large. He felt that self-renewed and self-renewing

adults can be leaders in society and have the characteristics to help society deal with chaos and change. Thus, he saw individual change as powering societal change.

Hudson's (1999) model of self-renewal would work well for people who are self-directed, self-motivated, and skilled at introspection. It could be more challenging to understand and work through this model for people who are less introspective, although working with a life coach could facilitate this.

Dealing with loss – stages of grief. One of the memorable lines in the movie *Zorba the Greek* was Zorba's astute comment that "Life is trouble. Only death is not" (Cacoyannis, 1964). While it may be true that death is not trouble, the process of transitioning from life to death often is, especially in the case of a prolonged terminal illness. Elizabeth Kubler-Ross, a Swiss-born psychiatrist, explained her model of the five stages of grief that terminally ill individuals experience in her landmark book *On Death and Dying* (1969). The five stages of grief describing the individual changes that may occur as someone proceeds through the dying process are denial and isolation, anger, bargaining, depression, and acceptance.

With the diagnosis of a terminal illness, the individual is often shocked and threatened by the prospective loss and may deal with the situation by trying to ignore what is happening, refusing to acknowledge the new reality of impending change. This first stage of denial can be a short-term defense to provide the individual with a way of dealing with the shock as he or she begins to process what is happening. Denial may also manifest itself as isolation since the individual may want to avoid others who remind him or her of the new reality, while others may void the ill person because they themselves are in denial and cannot deal with the situation.

Just as an individual may react to danger with “fight or flight” behaviors, he or she may either exhibit “flight” by denial or “fight” with anger against the dying process. Thus, the second stage of the grief process is anger which may be expressed as “Why me?” and involves shifting blame to others. The focus of the anger is varied, but it is usually displaced and may fall on anyone, family members, friends, or anyone else, including medical staff members, who happen to be present at the moment a grievance is felt. God may be a particular target of anger, even if the individual has had little interest in spiritual matters in the past.

The third stage is bargaining, where the individual tries to find ways to maintain things the way they were. The individual may rationalize or try to find ways to stop the changes from occurring. Bargaining with God is often a result: “God, if you will only....I will.....” This step is basically an attempt at postponement.

In the fourth stage, anger turns inward and becomes depression. The leave-taking process begins as the individual sees his or her options narrowing and realizes that the inevitable is happening no matter how they feel or what they do. Often a profound sense of loss overtakes the individual as he or she is no longer able to hold onto denial in the face of what is happening or becomes too weak to even express anger. Having the opportunity to express deep sadness in this phase is highly important and may help people transition to the last phase.

Finally, when the individual realizes there is no going backward and that all strategies of resistance have failed, he or she enters the fifth and last stage of acceptance of what originally seemed unacceptable. The individual ceases fighting against what is happening and

exhibits a peaceful acceptance of the inevitable. Persons in this phase have neither anger nor depression and in fact may be fairly devoid of feeling, as they cease the struggle and prepare for “the long journey.”

Although Kubler-Ross (1969) postulated this grieving process as a five step model, not all individuals go through all five stages; nor do they always go through them in the order she has described. In addition, time is an important factor in the process, for without sufficient time, the individual may not be able to process all the changes that are occurring and make progress from one stage to the next. Hope is an enduring theme that is present in one form or another in each stage.

Even in her initial book, Kubler-Ross (1969) noted that the process could be applied to people who were not terminally ill. She gave an example of a patient with an acute illness who achieved some resolution of grief and loss issues, stating that someday when he came to die, he would do so with greater equanimity.

Kubler-Ross's (1969) model of the stages of grief was at the beginning of a greater societal awareness and openness to dealing with issues of death and dying and much work has been done in this field since. Although many other models have been developed, her model continues to be used today. In a fairly recent article on palliative care assessing the attitudes of nurses toward caring for dying patients, Kubler-Ross's model was one of those referenced as a way of providing nursing education on end-of-life care (Wessel & Rutledge, 2005). Application of the model to nursing education is just one example of the many applications the model may have beyond the terminally ill. Most obviously, the model may be applied to families and friends of the one who is dying as they go through their own

experiences of grief and loss. Since many types of change can produce feelings of loss, the application of this model could provide a practical understanding for how an individual's behavior can change, along with the steps that others may take to help that individual progress through the change process.

Burke (2002) discussed Kubler-Ross's (1969) five stages and likened them to the stages that individual organization members go through in dealing with organizational change. Application of the model applied to organizational change, specifically resistance to change, was reported in a study by Zell (2003). In this study, forty physics professors from a large public university were interviewed several times over a two-year period as they dealt with teaching and research changes necessitated by factors in the institution and the external environment. Results of this qualitative study demonstrated that both the department and individual professors went through the five stages over time with the eventual result of organizational rebirth and a new direction for teaching and research. The generalizability of this study is certainly limited since it was only done with one particular group of professionals, but it is an interesting application of the Kubler-Ross model to the effects of change on both individuals within an organization and the organization itself. Suggestions for helping individuals in organizations through the grieving or mourning process such as providing factual information about the changing environment (to help overcome denial) and creating situations, either for individuals or groups, where such issues can be openly discussed (to bring unconscious thoughts to light), are two useful strategies that can be taken from this study.

I particularly identified with Levinson's view that all change, whether or not it is accepted, is a loss and needs to be mourned, noting that one type of loss is the loss of familiar routines (Levinson, 1976, as cited in Burke, 2002). Levinson's comment is particularly applicable to persons suffering from chronic illness, as their losses are often the loss of the ability to do the familiar things they once could do before illness began to hinder their abilities. Thus, Kubler-Ross's (1969) model is very applicable to the lives of persons with chronic illness. Chronic illness represents a lifestyle change that signifies loss and must be dealt with (Maass, 2008; Park et al., 2009). As the illness progresses, the losses progress so that individuals are often going through a repeated grief and loss process as their lives continue to change. In applying Kubler-Ross's model to persons who are living with losses, there is potential that progression through the stages will leave the person in a new place of growth and meaning once they arrive (at least temporarily) at a place of acceptance.

Some of the critiques of Kubler-Ross's (1969) stage model, summarized by Doka (2009) were that its methodology was not well-documented, that research has not supported the concept of stages, that the concepts of denial and acceptance were more complex than the way she explained them, and that it was unclear whether the stages referred to the ways that patients coped or the ways that others should help the patients progress. Nevertheless, as Doka noted, Kubler-Ross made a great contribution through her urging for humanistic care of dying patients and provided a communication tool to facilitate it.

Spiritual change – spiritual transformation. A final model of individual change is spiritual change. Just as educators talk about transformation through learning, theologians and others working in the area of spiritual growth talk about spiritual transformation. In

recent years, spirituality has started to become a topic of interest among adult educators as well, bridging the gap between the world of theology and the world of education (Tisdell, 2000). Taylor's (2005) conceptualization of the varying perspectives of transformative learning placed Tisdell in one of the four socio-cultural collective views, the cultural-spiritual view.

Since not everyone believes there is a spiritual dimension to life, a discussion of spiritual change is only applicable to those whose worldview admits the possibility of an intangible existence beyond oneself. Because of my work as a parish nurse, integrating faith and health, I have a particular interest in spiritual transformation, as it can, among many outcomes, be a precursor to other kinds of change. Since I work within the Judeo-Christian tradition, my brief discussion of spiritual transformation will be primarily within this context, although I acknowledge that spiritual transformation is a part of many spiritual traditions and belief systems.

A scripture that always make me think of change is "I do not understand my own actions. For I do not do what I want, but I do the very thing I hate" (Romans 7:15 Revised Standard Version). Feeling a desire to change without the ability to do so is one of the reasons some people turn to faith and the concept of something greater beyond themselves. Since my dissertation research included working with support groups, an example from the world of support groups may be most appropriate to illustrate spiritual transformation.

Bill W., the first of two founding members of Alcoholics Anonymous, had a transforming spiritual experience that became the beginning of his escape from alcoholism. In writing about his desperate situation years later, he said,

My depression deepened unbearably and finally it seemed to me as though I were at the bottom of the pit. I still gagged badly on the notion of a Power greater than myself, but finally, just for the moment, the last vestige of my proud obstinacy was crushed. All at once I found myself crying out, "If there is a God, let Him show Himself! I am ready to do anything, anything."

Suddenly the room lit up with a great white light. I was caught up in an ecstasy which there are no words to describe. It seemed to me, in the mind's eye, that I was on a mountain and that a wind not of air but of spirit was blowing. And then it burst upon me that I was a free man....now for a time I was in another world, a new world of consciousness. All about me and through me there was a wonderful feeling of Presence, and I thought to myself, "So this is the God of the preachers!" A great peace stole over me and I thought, "No matter how wrong things seem to be, they are all right. Things are all right with God and His world." (Wilson, 1957, p. 73, as cited in Kurtz, 1979, pp. 19-20)

Following this experience, Bill W. recalled reading Williams James's *The Varieties of Religious Experience* which helped to solidify in his mind two key concepts: the hopelessness of being an alcoholic and the necessity of spiritual conversion.

Lewin (1951) discussed conversion within the values section of his description of field theory. Although he was discussing ideological conversion rather than spiritual conversion, there is a connection between the two. In his example, significant change occurred in cognitive structure as a result of a combination of factors including motivation, need, and sensitization. Mahoney and Pargament (2004) described two theological models of

spiritual transformation, the traditional Christian view and the feminist Christian perspective, which have similarities of process but differ greatly in perspective. Other subjects in their discussion were with differences in speed of change (dramatic or gradual) and outcome (personal or empowering to social action).

Neal, Lichtenstein, and Banner (1999) discussed individual, organizational, and societal transformation, arguing that spirituality may be as much of a driving force for change as economics. The individual transformation component of this article discussed results of a qualitative study that involved both in-depth interviews and data from a three year online discussion group on spirituality in the workplace. The result of the authors' analysis was a three stage model of the integration of spiritual transformation into work life. In the first stage, *dark night of the soul*, individuals discovered that their previous life anchors no longer had any meaning. In the second stage, *spiritual searching*, individuals searched for new core spiritual principles. In the third stage, *spiritual integration*, individuals learned to apply spiritual principles to the key aspects of their lives, including work. The authors concluded that although such transformations may lead to a greater sense of meaning and fulfillment at work, other workers may find themselves in conflict with organizational culture and may choose to leave.

The examples discussed in this section are just a small sampling of the many forms and traditions in which spiritual transformation may occur; to consider more would be beyond the scope of this research. However, I have included spiritual transformation because of the fact that my research participants were people with chronic illness whose challenging lives have often "forced" them to consider their own mortality, faith, and spirituality at

unexpected times. Of additional relevance is the fact that when people experience a spiritual transformation, they often feel empowered to make other changes in their lives, as did Bill W. in his escape from alcoholism that resulted in a satisfying and meaningful life.

Summary of individual change models. The following six models of individual change have been discussed: field theory, the Health Belief Model (HBM), transformative learning, self-renewal, stages of grief, and spiritual transformation. Each of these models focuses on change within the individual, and to varying degrees, some consideration of how that change might be expressed outwardly and with continuing effects in the social context. Following is a summary of connections among the models. Although Lewin developed field theory, his work was also a significant influence on the development of the HBM, while his description of ideological conversion has relevance to the topic of spiritual conversion. Transformative learning and spiritual transformation have some common elements, especially as transformative learning comes to acknowledge the more intuitive and emotional aspects of the transformation process. The grieving process is present not only in the terminally ill, but in Phase 3 of the self-renewal process and in the spiritual transformation process described by Neal et al. (1999). Just as these models have some connections with each other, they also may have some connections with the transtheoretical model. Although I chose the transtheoretical model as my main framework for conceptualizing individual change, I knew it was entirely possible that the research participants could self-identify aspects of change within themselves that fit with one or more of the other models of individual change.

Conner (1992) stated that “micro change is when ‘I’ must change; organizational change is when ‘we’ must change; macro change is when ‘everyone’ must change” (p. 79). According to Conner’s conceptualization, this discussion of individual change has dealt with micro change, but it must be acknowledged that although one can conceptualize change in this way for the purposes of communication and discussion, the borders between categories may be more fluid and that one level of change may affect another, in either direction.

Individual Change in a Group Context

In looking at individual versus social change, the question may arise, which comes first? Do individuals change and then their individual changes interact in such a way as to create social change? Or is there a social change phenomenon that causes individuals to change? Like the question of which came first, the chicken or the egg, this is an ongoing dilemma that may never be satisfactorily resolved. However, I will proceed to discuss this question from my perspective, starting with an example from my professional practice. As a registered nurse, I have worked with both individuals and groups for many years, in hospital, clinic, organizational, and community settings. I have seen how an individual may change a behavior, such as eliminating the daily consumption of several 20 ounce sodas, which can be an effective way to jump start a weight loss program. On the other hand, I have also seen an organization change the types of food it serves at group events by offering water and other unsweetened beverages in addition to the usual sodas and other sweet drinks. In this way, people who want to cut down on their sugar consumption can easily choose such options.

How people react to such situations may be influenced by whether or not they have an internal or external locus of control. Persons with the internal locus of control are more

likely to be self-determinate and expect that their own behaviors control outcomes, whereas those with an external locus of control are more likely to be fatalistic and believe that outside factors determine outcomes (Weary, Gleicher, & Marsh, 1993). Thus, individuals who are more internally controlled may be able to make the choice to eliminate sodas regardless of environmental cues or the choices of those around them. In contrast, those who are more externally controlled may find it difficult to resist sodas when they are readily available or when the people around them are drinking sodas. Yet, if water or other sugar-free beverages are easily available, they may find it an easier choice to make. In addition, there may be an unspoken group pressure that results from being conscious that others, especially those who know they need to cut down on sugar, are watching. This in turn may influence them to choose the sugarless option. In the extreme instance of an organizational policy change which leads to serving only water and other beverages without sugar, people may have no choice at the moment but to consume a sugarless drink. However, if they have not made the internal decision, as soon as they are in another setting where sodas and other sweetened beverages are available, they may revert to their previous behaviors. My point in this story is that if an external change is imposed without the internal sanction, agreement, or commitment by the individuals involved, it is likely that the change may not endure.

To apply this line of thinking to a group context, such as a support group, I want to consider how the situation might play itself out. The Photovoice research process is a participatory action research (PAR) strategy that aims to foster social change by the use of a documentary photographic method. As it was originally conceived by Wang and Burris (1997), community members take and analyze photographs describing a particular situation,

concern or condition, and then present their results to policymakers with the end goal of effecting social change. Because PAR is a collaborative process involving the participants throughout the research process from planning to evaluation, the participants are known as co-researchers rather than subjects.

The community members involved in Photovoice research may be individuals, such as African-American breast cancer survivors, who did not previously know each other, but who were gathered together for the purposes of the study (Lopez et al., 2005). Alternatively, they could be members of an already formed group, such as clients of a mental health center (Brown et al., 2003-2004) who were asked to participate together in a Photovoice project. How individual and social factors might interact could vary by the degree to which the co-researchers knew each other previously. Since my dissertation research focused on members of an already formed group and their prior research experience, I will focus on this latter alternative.

Each person comes to the support group as an individual with a wide range of life experiences and a particular way of viewing and interacting with the world. In terms of the Photovoice research experience, they each are given cameras and each choose what photographs to take relating to the mutually agreed upon general subjects. For example, with a support group dealing with a chronic health condition, one of the topics could be “family.” After the photographs are developed, the members come to a group session prepared to describe and interpret the photographs they have taken. With the presentation and discussion of the photographs comes group interaction in which thoughts, perspectives, and ideas are exchanged, with the possibility that some or all of the group members are influenced or

affected by what has been presented and discussed. Following the group sessions, members may continue to think about and reflect upon the interactions, remaining with the views they brought to the session or modifying those views based on their experiences with the group. There is thus a complex interplay of the individual photograph-taking and analysis experience along with the group's response and interaction with those photographs. While the ultimate research goal is for the group to develop a coherent presentation and message to the community as a result of the project, there may be many other things going on within and among the group members that do not become a part of the research results, but that are nevertheless significant.

Traditionally, support groups have been developed for the purpose of individual rather than social change. Their purpose is to provide mutual help to individuals with a common problem or concern. Of course there are also groups such as political action groups that have social change as their purpose. Although such groups would fall in the general category of small groups, they would not be considered as support groups. The founders of Alcoholics Anonymous wanted to gain and maintain sobriety (Kurtz, 1979). For so many other support and self-help groups, the primary purpose has been to help individual members overcome personal difficulties such as addictions or prior traumatic experiences such as abuse. Numerous other groups have been formed to help people deal with everything from chronic illness to parenting issues to grief and loss, many of which are available through an online self-help resource (White & Madara, 2009). With the terms self-help group and support group often being used interchangeably, the focus is clearly on individuals learning to help themselves by participating in a group context (White & Madara, 2009).

It may seem paradoxical to be seeking individual change through a group setting, but this is a matter of perspective. To a sociologist, individual change within social groups may seem to be an oxymoron. However, to a social worker conducting small groups for the purpose of helping individuals change, it may seem perfectly logical. For example, Glasser, Sarri, and Vinter (1974), all professors of social work, focused on individual change through small group work. From the perspective of a social worker, the group context is an efficient way to conduct therapy, but the purpose of the group is to effect individual change within the participants. Although the facilitator and group members will undoubtedly affect each other, the primary purpose of the group is to help the individual members change. With both therapeutic groups and support groups, people live their separate lives and then come together at predetermined times, perhaps once a week or once a month, to interact and work on their individual issues. Then they can go back out and face their respective worlds with renewed strength and fortitude.

This is not to say that a support group might not also have a social change aspect, but its primary purpose is still for individual change. Many support groups, especially those associated with voluntary organizations such as the American Heart Association may also have some or all of their members involved in promoting public awareness or in fund-raising activities such as walks or runs. The caution in these situations is for the group to remember its stated mission and not get so involved in such activities that they forget to offer the necessary support to one another.

In her discussion of transformation through the grieving process, Scott (1997) discussed the differences between the social and the personal view, contrasting critical theory

and depth psychology. Critical theory takes the rational approach while depth psychology takes the extra-rational (imaginal) approach. Concluding her discussion of contrasts between the social and the personal perspective, she argued that personal work, that is, work on one's individual self is imperative: "The basic unit has to be the individual in a group...[since]...groups...are dependent on the quality of the individuals in those groups" (Scott, 1997, p. 48). For the moment, therefore, I take this perspective as at least a temporary solution to the chicken or egg dilemma in the matter of individual versus social change.

Summary of Individual Change

If you want to truly understand something, try to change it. – Kurt Lewin

(Neill, 2004, line 1)

I began this section with a discussion of individual change within the Photovoice research process. After a description of the transtheoretical model with a focus on the stages of change component, I proceeded to discuss six other models of individual change that could occur in a self-directed or facilitated way without specific or formal intervention by a professional therapist or counselor. These other models were: field theory, the Health Belief Model (HBM), transformative learning, self-renewal, stages of grief, and spiritual transformation. Following this discussion, I explained my perspective on individual change that may take place within support groups.

Just as film only shows an image after light has come through the lens, the possible changes wrought by PAR research on both society and individuals also may only manifest themselves because of some type of enlightening influence. I believe that the art of photography with the accompanying stories of photographs is just that influence that can lead

to change. In the next section, I will discuss the potential effects of the aesthetic aspects of photography with an emphasis on knowing and ways of knowing that may impact individuals in such a way as to cause transformation and healing.

Photography as Art and Art for Transformation – The Light through the Lens

Photography is essentially the recording of light.

(Gassan, 1972, p. 2)

In the following sections, I first discuss the transformative and potentially healing roles of art. Then I discuss art and knowing, with emphasis on photography and storytelling as methods of presentational knowing.

Art and Transformation

What causes change? In Mezirow's original conceptualization of transformative learning, it was critical reflection upon dialogue that could lead to perspective transformation and personal change. Mezirow's original conceptualization seemed to leave little room for anything other than rational inquiry, but his later work and the work of others who reflected upon and expanded the concept, allowed for more emotional and intuitive experiences, such as viewing a painting, to lead to transformative learning (Mezirow, 2000). In a similar manner, both photography and storytelling as art forms have the possibility of leading to transformation.

Of the various scholars studying and writing about transformation, a particular interest of mine is in the work of John Dirkx whose view was that other scholars besides Mezirow, such as Daloz, Cranton, and Freire, also had an ego-based view of transformation that was too rationally focused (Dirkx, 1997). In contrast, his interest was in Mythos rather

than Logos. By use of the term *Mythos*, Dirkx was referring to images that relate to underlying myths. These myths in turn touch the soul of the person. This would be in contrast to the term *Logos* which refers to the voice of reason. Dirkx presented ways that the soul can be guided or nourished through strategies such as story, song, myth, and poetry. These artistic strategies can help to bring about a type of transformative learning that is not rooted in rationality and reflection, but that is equally valid in helping the learner to make meaning of the connection between the inner and outer worlds. Taylor (2005) situated Dirkx within the psychoanalytic perspective of transformative learning that places emphasis on the unconscious self and the process of individuation.

In his ensuing introduction of a mytho-poetic view of transformative learning, Dirkx (1998) further discussed his alternative conception of transformative learning that uses imagination for recognizing and understanding the images that are deep within. Building on Boyd's work in depth psychology, Dirkx (2000) felt the need to further develop the emotional and spiritual aspects of transformative learning. Dirkx coined the term *mytho-poetic* to describe a way of knowing that is through images rather than concepts or rationality. It is this use of artistic methods and connection with imagination that provides one of many possible links between transformative learning and the arts.

The transforming power of art was expected to be a factor in the Photovoice research experience of the participants in this study as they both took and interpreted photographs representing their experiences and its effects on their lives. In addition, their storytelling activities in the presentation of their photographs were also expected to effect transformation. Intentional use of stories to create change or transformation may be seen in the case of

emancipatory adult educators who use stories that may lead to both individual and social change, and who are very committed to helping adult learners become instruments of social change (Wiessner, 2005). As Wiessner noted, “Through their storytelling, these women help adult learners create new knowing that leads to new action and to creating new and better worlds” (p. 115). In a related article on emancipatory learning, Wiessner and Newville (2005) combined personal perspectives, two themes from the literature (the transformative power of art and transformative and emancipatory adult education) along with a review of 25 papers from two Transformative Learning Conferences to create a collage of the emancipatory potential of the arts.

Transformative learning has already been discussed as a way of individual change under *Adult education – Transformative Learning* and is linked with various aspects of presentational knowing that will be discussed in the upcoming sections related to photography and storytelling. Taylor’s (2005) conceptualization of the seven streams of transformative learning has placed the seemingly disparate perspectives into one bigger picture allowing us to see a broader range of ways in which transformation can occur.

Art and Healing

In addition to its potential transformative role, art may have a variety of applications to health and healing. Both viewing and creating art may have deep personal impact or therapeutic effects. Art can be used for reducing stress and stimulating creativity (Siegel & Bartley, 2004), affecting patient outcomes for both disease prevention and chronic disease management (Donnelly, 2005), and promoting public awareness, lessening isolation, and creating hope (Ponto et al., 2003). In addition, various health care organizations are

recognizing the benefits of integrating art into health care. One of these is a national voluntary non-profit organization called the Society for the Arts in Healthcare (SAH) which provides education about the role of the arts in healing and sponsors an annual conference on some aspect of arts and health care (Domke, 2007). Another example is the Health Arts Network at Duke (HAND) that acknowledges the role of the arts in stress reduction and its impact on healing (“Healing Arts,” 2007).

Ulman (2001) noted that the one thing in common among all the various settings and disciplines is that “the materials of the visual arts are used in some attempt to assist integration or reintegration of personality” (p. 16). Although art therapy has traditionally been used to deal with psychological issues, more recently the spiritual dimension of art as it relates to health and healing has been highlighted. In relationship to nursing, Lane (2005) explained the link between creativity and spirituality. Lane posited that one of the ways in which this may work is through the physiological effects of “creative or spiritual acts.” Lane also cited some of the historical roots of the use of art and prayer in healing and explained how the arts can be used in nursing practice to promote healing.

Art and Knowing

“How do I love thee? Let me count the ways” wrote Elizabeth Barrett Browning in her well-known Sonnet 43, part of the collection of Sonnets from the Portuguese (Browning, 1850). When Browning wrote this sonnet, she clearly had many ways in mind, from “freely” to “purely” and with “passion” in life and even “after death.” Moving from the world of poetry to the worlds of adult education and related fields, someone among us might want to write a sonnet which starts “How do I know thee and how do I know that I know thee? Let

me count the ways.” Just as there is more than one way to love, there is more than one way to know, as the field of adult education has been recognizing more and more in recent years.

In my dissertation research, both photography and storytelling were used to present, discuss, interpret, and share research results arising from the Photovoice research experience. As previously stated, Photovoice, a participatory action research (PAR) methodology, was first developed by Wang and Burris (1997) as a way to promote social change by putting cameras in the hands of persons representing various marginalized groups. The resulting photographs of people, places, or things illustrating topics mutually chosen and agreed upon by the researchers and co-researchers, are then presented back to the group by the persons who took them. The co-researchers tell the stories behind their photographs while the group chooses some to discuss in greater depth according to a specific set of questions. Eventually, themes are generated and a photographic story is put together for presentation to policymakers and others to communicate the issue or concern that the Photovoice research addressed.

Presentational knowing. Photography and storytelling are not what most people would consider as traditional scientific research strategies, but they have gained more prominence and respectability in recent years as other noncognitive ways of knowing have begun to gain recognition. How people learn and know from art is different than how they might learn and know from other means such as reading, attending classes, or learning from others. Photography and storytelling are examples of what Heron and Reason (n.d.; 2008) call presentational knowing. Presentational knowing has nothing to do with PowerPoint and other types of academic presentations, but it does have to do with the presentation of

experiences through artistic means. Presentational knowing is part of Heron and Reason's extended epistemology that is an integral part of co-operative inquiry (2008). Although the co-operative inquiry process of action and reflection uses the four types of knowing, Heron and Reason noted that they are applicable to "everyday knowing and all forms of action research practice" (2008, p. 367).

Heron and Reason (2008) discussed four ways of knowing: experiential, presentational, propositional, and practical. Experiential knowing results from a direct face-to-face encounter with a person, place, process, or thing and is both pre-verbal and tacit. Presentational knowing, which is the type most appropriate to consider in relation to art, derives from experiential knowing and is "evident in an intuitive grasp of our resonance with and imaging of our world...symbolized in graphic, plastic, musical, vocal and verbal art-forms. It clothes our experiential knowing of the world in the metaphors of aesthetic creation" (Heron & Reason, n.d., *Critical Subjectivity and Four Ways of Knowing*, para. 3). Propositional knowing is knowing "about" and is the intellectual conceptual knowing that is expressed in ideas and theories. Finally, practical knowing is knowing "how" to do something and is demonstrated by skill or competence. Thus, it may be a manual or technical skill as well as an interpersonal or political skill. This fourth type of knowing is grounded in the three prior types and requires all three in order to demonstrate "excellent accomplishment." Heron and Reason emphasized that there is a difference between knowing and knowing about and asserted that "an experiential encounter with the presence of others and of the world is the ground of being and knowing" (2008, p. 368).

Presentational knowing is expressed in images and can be evident in both the nondiscursive arts such as the visual arts of music, dance, and movement as well as the discursive arts of poetry, drama, and storytelling. Heron and Reason (2008) explained that the cognitive world of propositional knowing can actually constrain presentational knowing through the power of language, since the processes of the imaginal mind of presentational knowing is unconscious. I believe this is why an individual may profess a particular opinion or view and yet be moved by some form of artistic expression in an entirely different direction. Both Bruner (1986) and Dirkx (2000) discussed the imaginal mind and the contrast between Mythos (comparable to presentational knowing) and Logos (comparable to propositional knowing). The goal with presentational knowing is to access and encourage that other way of knowing that offers a richness of creativity and potential for transformation of soul and spirit. Presentational knowing can be an important part of the entire co-operative inquiry process from reflection to action to outcome.

Other ways of knowing.

If the only tool you have is a hammer, everything around you looks like a nail.

(Ways of Knowing, n.d., para. 3)

The quote that begins this section, although found on the Ways of Knowing (n.d.) website, is attributed to Abraham Maslow and is also used in the world of psychotherapy to express the concern that therapists often keep using the same old approaches to new problems (Prochaska & Norcross, 1994). The concept expressed in the quote is clearly applicable to the issue of multiple ways of knowing as well. It will take a different tool of knowing to make one see that in addition to nails, there are also ropes, strings, screws, and

tape. Although Heron and Reason's (2008) classification of ways of knowing was most applicable to my dissertation research, it was only one among many classifications or conceptualizations of ways of knowing. To look at *ways* of knowing rather than *a way* of knowing is in itself a demonstration of its meaning. Although there have always been multiple ways of knowing in many places by many people around the world, it has not always been recognized in the world of science and academia. Our Western culture has tended to preference, some would say privilege, what we call logical, rational, or cognitive knowing over other types of knowing. The scientific method, which has dominated Western thinking, utilizes reason to accomplish its ends (Creswell, 2003). This positivist perspective focuses on discovery and measurement of verifiable truth seeking data that will support or refute the presupposed theory (Creswell, 2003; Merriam, 1998). Heron and Reason's propositional knowing is basically in this same category.

The range of ways of knowing. The term *ways of knowing* means different things to different people. Is it the eight ways of knowing that relate to intelligence (Gardner, 2004)? Or ways of knowing God (Danielou, 2003)? Or indigenous ways of knowing of Alaskan natives (Barnhardt & Kawagley, 2005)? The range of ways of knowing discussed in the literature of a multitude of fields is quite vast. Therefore, I will first give some examples showing the range of ways of knowing and then discuss a few of these in-depth. Table 2 gives an alphabetical list of ways of knowing with a description of the categories for each area.

Table 2

Ways of Knowing

Area	Categories
Arts	<p data-bbox="613 611 1325 646"><i>Expressive ways of knowing, knowing through the arts.</i></p> <p data-bbox="613 684 1414 940">Music, poetry, storytelling, photography, theater, and autobiographical writing. Ways of thinking and making meaning (Davis-Manigaulte, Yorks, & Kasl, 2006; Lawrence, 2005b; Yorks & Kasl, 2006)</p>
Buddhism, Japanese Zen	<p data-bbox="613 978 1268 1014"><i>The four ways of knowing of an Awakened Person.</i></p> <p data-bbox="613 1052 1414 1234">The way of knowing of the Great Perfect Mirror, the way of knowing equality, the way of knowing by differentiation, and the way of the perfection of action (Low, 2006)</p>
Catholic theology	<p data-bbox="613 1272 1143 1308"><i>Ways man comes to a knowledge of God.</i></p> <p data-bbox="613 1346 1354 1451">Religious, philosophical, revealed, and mystic (Danielou, 2003)</p>
Christian perspective	<p data-bbox="613 1488 1365 1598"><i>Two ways of knowing, differing by sources, purposes, and types.</i></p> <p data-bbox="613 1635 1127 1669">Scientific and religious (Bradley, 2004)</p>

Table 2 Continued

Area	Categories
Figuring out reality	<p data-bbox="613 575 1365 604"><i>A compass of eight ways of knowing to understand reality.</i></p> <p data-bbox="613 646 1365 827">Science, philosophy, rationalism/skepticism, religion, mysticism, esotericism, occultism, gnosis, plus interdisciplinary combinations (Kazlev, 2004)</p>
Gendered knowing	<p data-bbox="613 869 1036 898"><i>Five ways of knowing in women.</i></p> <p data-bbox="613 940 1430 1268">Silence, received knowledge, subjective knowledge, procedural knowledge, and constructed knowledge; dichotomies between connected and relational knowing versus analytic and separate knowledge (Belenky, Clinchy, Goldberger, & Tarule, 1986/1997; Harding, 1996)</p>
History of science	<p data-bbox="613 1310 1349 1415"><i>Different ways of knowing in fields of history of science, technology, and medicine.</i></p> <p data-bbox="613 1457 1349 1560">World-readings (hermeneutics), natural history, analysis, experimentalism, and technoscience (Pickstone, 2001)</p>

Table 2 Continued

Area	Categories
Multiple intelligences	<p data-bbox="618 575 915 604"><i>Eight ways of knowing.</i></p> <p data-bbox="618 646 1357 827">Linguistic, musical, logical-mathematical, spatial, bodily-kinesthetic, intrapersonal, interpersonal, and naturalistic (Gardner, 2004; Lazear, 1991)</p>
Non-Dichotomous	<p data-bbox="618 869 1421 898"><i>Two ways of knowing that overlap and may inform each other.</i></p> <p data-bbox="618 940 1398 1045">Scientific and contemplative, not scientific vs. contemplative (Hut & Tainer, 2006)</p>
Non-Western cultures	<p data-bbox="618 1087 1295 1192"><i>Indigenous ways of knowing, the example of Alaskan natives.</i></p> <p data-bbox="618 1234 1393 1339">Knowing through direct experience, interconnectedness, and holism (Barnhardt & Kawagley, 2005)</p>
Other ways of knowing	<p data-bbox="618 1381 1256 1486"><i>Any knowing obtained by alternative means to the scientific method.</i></p> <p data-bbox="618 1528 1403 1705">All other ways of knowing categorized as pseudoscience, religious, and spiritual contrasted with scientific and physical (Other Ways of Knowing, n.d.)</p>

Table 2 Continued

Area	Categories
Philosophy	<p data-bbox="618 575 1162 604"><i>Noetic (mind and intuition) consciousness.</i></p> <p data-bbox="618 646 1393 676">Intuition, reason, and sensory perception (may be combined)</p> <p data-bbox="618 718 979 747">(Noetic consciousness, n.d.)</p>
Philosophy of education	<p data-bbox="618 793 816 823"><i>Process theory.</i></p> <p data-bbox="618 865 1393 970">Technical versus grounded (ontological) knowing (Oliver & Gershman, 1989)</p>
Psychology	<p data-bbox="618 1012 1419 1117"><i>Four ways of ascertaining truth, a “flawed” model, and a new conceptualization.</i></p> <p data-bbox="618 1159 1419 1411">Trust the source, intuition or personal inspiration, personal experience, use reason to think critically about ways one, two, and three; alternatively look at experience, intuition, religion, philosophy, and science (Huitt, 1998)</p>
Psychology, Indian	<p data-bbox="618 1453 919 1482"><i>Three ways of knowing.</i></p> <p data-bbox="618 1524 1317 1629">Scientific, phenomenological, and spiritual; potential integration through Indian psychology (Salmon, 2007)</p>

Table 2 Continued

Area	Categories
Spirituality	<p data-bbox="618 573 834 602"><i>Spiritual growth.</i></p> <p data-bbox="618 646 1432 825">Dark night of the soul, spiritual searching, and spiritual integration. Knowing and growing, not necessarily in a specific tradition (Neal et al., 1999; Tisdell, 2000)</p>
Transformative learning	<p data-bbox="618 869 906 898"><i>Unconscious knowing.</i></p> <p data-bbox="618 942 1432 1045">Unconscious or implicit knowing and emotions relating to rationality (Taylor, 2001)</p>

In reviewing this diverse list of ways of knowing, which is by no means inclusive of all possible ways of knowing, a few themes emerge:

- Categorizations range from dichotomous to multiple options.
- Some categorizations are field specific while others try to categorize all possible ways of knowing that could comprise reality.
- Some categorizations are only spiritual while others are only tangible.
- Some categorizations include both tangible and spiritual ways of knowing.

How do Heron and Reason's ways of knowing (2008) fit into this array of ways of knowing? Using the above categorization, Heron and Reason's four ways of knowing have multiple options, can be used in a variety of fields, including education, do not claim to

account for all of reality, and are tangible and imaginal, but not necessarily spiritual. Their categorization thus has some overlap with Gardner's multiple intelligences (2004), while presentational knowing itself is comparable to expressive ways of knowing (Davis-Manigaulte et al., 2006).

Narrowing the focus. This next section focuses more in depth on several ways of knowing. The first is Gardner's theory of multiple intelligences. Gardner first proposed his theory of multiple intelligences in 1983 and provided a new introduction in the 20th anniversary edition of his book (Gardner, 2004). His list of types of intelligence continues to be: linguistic, musical, logical-mathematical, spatial, bodily-kinesthetic, intrapersonal, interpersonal, and naturalistic. These are briefly explained below by linking each type with a colloquial phrase along with a strategy that could be used to facilitate learning using each of these intelligences:

- Linguistic – word smart, use words
- Musical – music smart, use music
- Logical-mathematical – number/reasoning smart, use numbers or logic
- Spatial – picture smart, use pictures
- Bodily-kinesthetic – body smart, use a physical experience
- Intrapersonal – self smart, use self-reflection
- Interpersonal – people smart, use a social experience
- Naturalistic – nature smart, use an experience in the natural world. (Armstrong, 2011, para. 1, 4)

Gardner noted that he extended his theory to include naturalistic intelligence in 1994-95 for which he felt there was “ample” evidence. In addition, he was considering the possibility of an existential intelligence. Before reading of his changes and reconsiderations over the years, my critique of Gardner’s theory would have been that it was totally based in the material world and left out the possibility of spirituality. Therefore, I was most interested to find in the latest version of his book (2004), that although he chose not to “tamper” with his original list, he had been considering that spiritual intelligence may exist. Thus, although he focused on the first seven types of intelligence in his book, he also acknowledged that there were eight or nine, and if he later chooses to add spiritual intelligence, there will be ten.

Gardner’s theory of multiple intelligences grew out of his years of experience in developmental psychology, including work with both gifted and brain injured persons, along with his recognition that intelligence quotient (IQ) tests only measured mental abilities (verbal and logical-mathematical). He realized that the IQ tests did not come close to accounting for the myriad of talents and abilities that human beings possess. The question may arise here of how multiple intelligences relate to ways of knowing. As Gardner puts it, multiple intelligence theory “seeks to underscore the extent to which ways of knowing – forms of knowledge – are present in virtually every realm of human existence” (Gardner, 2004, p. 285). If one has a particular type of intelligence, he or she will learn in a way that matches that type of intelligence. For example, a person with an interpersonal intelligence will learn well through social interactions. Once the person has learned the thing, whatever that thing is, he or she then knows it. Therefore, that type of intelligence becomes a way of knowing. Gardner’s musical, spatial, and bodily-kinesthetic intelligences are most

comparable to presentational knowing. Many educators since the 1980s have gravitated to the concept of multiple intelligences and developed strategies and methods for teaching both children and adults using multiple ways of knowing based on Gardner's work (2004) and others (Berghoff, Egawa, Harste, & Hoonan, 2000; Lazear, 1991).

The next area of focus is dichotomies and trichotomies. In reviewing the large number of ways of knowing, I observed that several of them were dichotomies or trichotomies that basically contrasted some form of logical-rational knowing and some form of intuitive, emotional, or spiritual knowing. Table 3 compares seven such dichotomies/trichotomies.

Table 3

Ways of Knowing: Dichotomies and Trichotomies

Author, date	Way of Knowing 1	Way of Knowing 2	Way of Knowing 3	Comment
Bradley, 2004	Scientific	---	Religious	---
Bruner, 1986	Paradigmatic	Narrative	---	---
Dirkx, 2000	Logos/Reason	Mythos/Mytho-poetic	---	---
Hut and Tainer, 2006	Scientific	---	Contemplative	May overlap and inform each other
Noetic consciousness, n.d.	Reason	Intuition	(Sensory perception)	Sensory may be combined with Reason
Oliver and Gershman, 1989	Technical	Grounded (Ontological)	---	---
Salmon, 2007	Scientific	Phenomenological	Spiritual	May be combined

Five of these ways of knowing are from the prior listing in Table 2 while Bruner (1986) and Dirks (2000) were discussed previously under *Presentational Knowing*. The dichotomies remind me of the right brain/left brain duality that portrays the verbal and rational left brain in contrast to the nonverbal and intuitive right brain (Bergland, 1985, as cited in Schneider & Ingram, 2007).

The final area of focus is Bruner's (1986) conceptualization of paradigmatic versus narrative knowing, which was particularly relevant to my research. Rather than conceptualize all the arts as opposite to the propositional side, as does presentational knowing, he situated narrative knowing in contrast to the logico-scientific mode. In one sense, it is less useful to my research, since I am also dealing with the art form of photography, but in another sense, it is useful because the development and comprehension of stories is exactly what is done with the photographs in a Photovoice project. Although Bruner acknowledged the value of the paradigmatic mode in developing good theory, sound arguments, etc., he extolled the joys of the narrative mode over the "heartlessness" of logic, emphasizing its importance in culture making through the use of language. Fals-Borda (1987) corroborated this value of narrative knowing as he described the importance of storytelling to the peasant cultures of Latin America. "Story-telling and other expressions of oral tradition are among the most effective ways for keeping alive the people's culture and their core values. Story-telling refuses to die because, if it did, the peasant people would die with it" (p. 343).

Reflections on multiple ways of knowing. Multiple ways of knowing seems to be a popular concept that is attracting authors in fields as diverse as math education (Coomes & McDuffie, 2007) and public policy (Schneider & Ingram, 2007). It seems everyone has a

categorization, whether it is two, three, four, or eight ways of knowing. The irony of categorization is that multiple ways of knowing has developed out of a dissatisfaction with the predominant Western emphasis on reason and logic and finding the one “true” answer. Once one opens up the possibility that there is more than one way of knowing, who is to say that the next author has found the definitive number of categories? If the whole point of considering other ways of knowing is to say that knowledge may be gained in a variety of ways, then are we just creating a new positivism by saying that we have determined the new “true” number of ways of knowing?

A dichotomous categorization, if indeed any such categorization is warranted, may be better because it leaves open the possibility that any new ways can be added to one side or the other. Since I am in the health field, I think of the example of hepatitis. Once hepatitis had been differentiated into types A and type B, a third kind of hepatitis was discovered in the 1970s that did not fit the characteristics of either A or B. Since medical scientists were not exactly sure what this new virus was, they called it non-A, non-B. Finally, in 1987, the organism was discovered, and in 1989 the condition was renamed hepatitis C (Hepatitis C, 2009). In the same manner, I would propose that it is better to categorize ways of knowing by dichotomies such as cognitive versus non-cognitive, dominant versus non-dominant, Western versus non-Western (or indigenous versus non-indigenous), and then one by one add the ways of knowing that we discover, recognize or create, naming them as we go. Gardner said, “I am confident that if there are eight intelligences, there must be more. My goal is to convince readers of the plurality of intelligence and to offer a reasonable list of what the several intelligences might be” (Lazear, 1991, p. viii).

Photography and storytelling. My dissertation research included two types of presentational knowing, photography and storytelling. These presentational methods were particularly useful in achieving the aims of the Photovoice research methodology. Following a discussion of photography and storytelling, I will proceed to connect these two types of presentational knowing to PAR in general and my dissertation research specifically.

Photography. In the conceptual underpinnings of Photovoice, the use of photography was taken from documentary photography and as such was seen as a research tool (Wang & Burris, 1994). Photographs can be used to document what is going on with people, places, and events, as in documentary photography and photojournalism. Yet this is only one possible view of photography. Photography may also be seen as an art form, specifically a visual art as is reflected in such books as *A Chronology of Photography: A Critical Survey of the History of Photography as a Medium of Art* (Gassan, 1972) and *Photography: History of An Art* (Daval, 1982). As an art form, photography can have an aesthetic effect that moves people in some intangible way, reaching deep inside to touch their heart or spirit. In looking at the individual experiences of Photovoice research participants, it was also useful to consider the possible effects of taking and viewing photographs from the artistic point of view as opposed to a purely documentary purpose.

Storytelling. In addition to visual or graphic art, storytelling also belongs to the category of presentational knowing. Thus, when Photovoice participants tell the stories associated with their photographs, they are actually engaging in two types of presentational knowing. Providing participants the opportunity to tell the stories behind their photographs opens up an additional way of communicating about their life experiences. Although many

stories are also put in written narrative form, Photovoice participants engage in oral storytelling, with their photographs serving as visual aids and cues to the stories. Clark (2001) offered narrative learning (i.e. learning through story) as a significant way of meaning making that was connected with self-understanding and identity, and explained the potential of personal change to occur through the telling and retelling of our stories and the hearing of other's stories with which we can identify.

The art of art and the story behind story. Since learning is connected with knowing, exploration of the association between knowing and the arts was also important to consider. While the creation or experiencing of various art forms may have deep emotional and spiritual effects, the artistic process also has effects due to the involvement of the body. Somatic or embodied learning comes about through involvement of the body and occurs during the experience rather than as a result of reflection about the experience after it has occurred (Clark, 2001; Merriam et al., 2007). Thus, somatic learning can be due to a physical or emotional reaction rather than a cognitive process. This type of learning seems to be somewhat of a latecomer to the world of adult education, but its benefits have long been known in the artistic world. Cameron (2002), writing in *The Artists' Way*, talked about the inspirational aspect of art as a spiritual experience due to the connection of creativity with the mystical. Yet the activities she prescribed for unlocking one's creativity are tasks, activities, or actions that involve the body as a way of unlocking the creativity within. Part of that doing seems to be a way of bypassing the negative thinking that says the doing will be impossible.

Whether one's involvement with art is in the creation of it or the experiencing of it, or both, "making and finding meaning through art is a transformative experience. Once we have

encountered seeing and thinking in the aesthetic realm, our ability to think and see more generally is altered” (Lawrence-Lightfoot & Davis, 1997, p. 35). Lawrence (2005a) noted that the transformative power of art may have its effects on a variety of levels. It can have inner personal effects on self-awareness, interpersonal effects on awareness of others, and can also promote community building and social action. The kind of knowing that leads to such transformation is called expressive ways of knowing (Davis-Manigaulte et al., 2006) and, as was mentioned previously, is comparable to presentational knowing (Heron & Reason, n.d., 2008).

Webster’s dictionary defined a story as “a narrative, either true or fictitious, in prose or verse; tale” (Costello, 1991, p. 1319). The National Storytelling Network defined storytelling as “the interactive art of using words and actions to reveal the elements and images of a story while encouraging the listener’s imagination” (“What is Storytelling,” 2006). Thursby (2006) defined storytelling as follows:

Storytelling, whether it be traditional, nontraditional, anecdotal, gossip, rumor, didactic, or for entertainment, is something in which all cultures engage. It is an exchange of information from the teller to the hearer, and in many cases, this is the way cultural values and taboos are shared. (p. 167)

Storytelling is thus the process of communicating a narrative that involves an interaction between the teller and an audience. Even when the storytelling is a performance, there is always an interaction with the audience. Entertainment, transmitting traditions, and honoring culture may be traditional purposes of storytelling, but there are many other purposes as well. In relaying the story of *Ten Traditional Tellers*, MacDonald (2006) noted

that in addition to the sheer entertainment value, storytelling also functions to inspire and educate. A story may share moral values and inspire the hearer to action. A story may teach about current situations or offer a vision of what could be.

Everyone has a story. Stories help define who we are and indeed may be part of the formation of one's identity (Rossiter, 2002). Storytelling can also be taken out of the realm of entertainment and cultural transmission and used purposefully for adult education from the individual to the group level. Related forms of the use of story for case studies, critical incidents, role-playing, and simulations (Rossiter, 2002), along with autobiographical writing, are other ways that story can be used, although they were not part of my dissertation research.

Education is about change. Although one may learn something without it having an impact on one's life, more often, learning affects attitudes, beliefs, and behaviors, so that change can be internal, external, or a combination of both. Whether or not learning should result in social action is a debatable topic and part of the ongoing discourse about individual versus social transformation (Merriam & Caffarella, 1999). Although storytelling may have individual, organizational, and societal effects, my focus was on the individual effects. Note that this is somewhat of an artificial demarcation for the purposes of discussion, however, since the effects of storytelling at one level may certainly impact another level.

Galbraith referred to the process of helping adults learn as a "transformational journey" (Galbraith, 1990, p.3) implying that both the educator and the adult student will change as a result of the educational journey. Although there are many theories of individual change, the theory of transformative learning was a relevant context in which to situate

storytelling as a teaching strategy for individual change. Transformative learning, as originally conceptualized by Mezirow, postulated a disorienting dilemma that challenged the individual's view of the world and caused a reevaluation of meaning and perspective (Merriam & Caffarella, 1999). The process of transformative learning was primarily cognitive, needing rational discussion with others who could validate one's reflections. Individual rather than social action was the expected outcome. Although Mezirow originally conceived of this transformation as occurring as a result of a single event, a disorientating dilemma, he later acknowledged that a gradual or epochal change was also possible. In addition, he came to see the possibility of transformative learning through other experiences, such as art, that were not purely rational (Mezirow, 2000). Simultaneous with his own development, many others, such as Cranton (2006) have critiqued and further developed the theory of transformative learning. It is important to note that the concept of transformative learning raises ethical issues, which the educator must consider when designing educational experiences attempting to change an individual's perspective or worldview (Merriam & Caffarella, 1999).

Teachers who use transformative learning are teaching for change. Their goal is to bring about a change in perspective or belief in the students. Davis-Manigaulte et al. (2006) provided an example of fostering transformative learning through expressive ways of knowing, "those forms of expression that engage the learner's imagination and intuition" which can include "music...dance...mime, as well as all forms of myth, fable, allegory, story, and drama" (p. 27). Using storytelling and other creative strategies can tap into the more nonrational parts of the learner and help to draw out untapped inner resources and

perspectives that the learner may not have even been aware of. These authors provided examples of individuals acting in new and unexpected ways in their daily lives after having had the experience of learning through expressive ways of knowing such as storytelling.

An example of the use of storytelling in adult education was relayed by Higgins (2004) who used a narrative approach for the teaching of sociology to women in prison. Believing that narrative would be the most effective way to reach the diverse population of incarcerated women with such a wide variety of educational experiences, the educator presented the topics in lecture format in which each lecture was actually a self-contained story constructed about some sociological topic or issue, such as women in the workforce. Although the educator was initially the teller, subsequent discussion sessions allowed the women to relate their stories as well. Of particular relevance to my research was the finding that older women, especially, benefited from this educational approach and gained new knowledge about themselves by being able to situate their stories in the context of the larger public story. The possibility of transformative learning in an incremental or epochal way (Mezirow, 2000) was demonstrated by this approach.

Considering another educational arena, the experience of illness is often in itself a transforming experience and one that may be shared through storytelling both to encourage others with similar challenges and to educate health care professionals about the patient's perspective. In *The Wounded Storyteller*, Frank (1995) discussed storytelling about illness as an attempt, among other things, to give voice to the person having the experience (the wounded storyteller) and to share that testimony of suffering. He offered an interesting perspective that we should not just think *about* stories, but that we should think *with* them. In

thinking with a story rather than about it, one can be affected by it and find the truth for one's own life.

In another example of the use of story with illness, Basting (2006) described the use of the arts, including storytelling, as a means of expression and connection for dementia patients. One storytelling technique called TimeSlips was used to help dementia patients construct a new story based on a visual image, rather than expecting them to remember a story. In order to implement this strategy, staff members were taught the TimeSlips technique and they in turn implemented it with the dementia patients. This storytelling strategy was found to improve both the communication skills of residents and the job satisfaction of staff. Dementia care can be a very challenging and discouraging area of practice, since treatment is not that effective and mental decline continues relentlessly. The small victories associated with storytelling in this type of setting may not be on the magnitude of transformative learning, but do suggest the possibility of positive changes in both residents and staff. The use of storytelling with illness was particularly relevant to the stories of persons with chronic illness that were explored in this dissertation research.

Although storytelling has been discussed in relationship to change in the individual, effects on other levels are certainly possible. For example, the story of an illness may be shared one-on-one, such as in a support group and may help another individual to know what to expect in his or her own future life experience. Yet that same story might mobilize the medical community to make a change of practice. An example of this is the National Family Caregiver Story Project, an online space created by the National Family Caregivers Association (NFCA) where individuals can share stories of family caregiving (“The NFCA

Story Project,” n.d.). On the one hand, the sharing of stories may be instructive to other caregivers in similar circumstances, a sort of one-on-one virtual support group that also helps to decrease the sense of isolation caregivers often feel. On the other hand, the Story Project serves a larger purpose of giving voice and increasing community awareness in order to produce changes in the ways that caregivers and their families are perceived and served by the medical profession and others in their respective communities.

Storytelling is one of many art forms, such as music, photography, theater, poetry, and autobiographical writing that can be used as an educational tool. Lawrence (2005a), in summarizing a series of articles on *Artistic Ways of Knowing*, noted that in addition to art being a context for learning, the use of artistic expression can lead to greater awareness of self, deepen awareness and knowledge of others, build community through creating collective knowledge and solidarity, and foster social change through transformative and emancipatory learning. Indeed, storytelling has great potential to affect learning on many levels. As Haitch and Miller (2006) wrote, “The ability to construct the world linguistically empowers people to initiate change” (p. 397).

Thus, we have a continuing story of transformative learning and its intersection with the arts that includes cognition, the soul, imagination, emotions, the body, spirituality, and creativity. The effects of this intersection can range from individual to community to societal.

Value of presentational knowing. Although Photovoice is a type of participatory action research (PAR) based on documentary photography, it also has artistic components that can arise from the combination of photography and storytelling (Clark, 2001; Daval, 1982; Gassan, 1972; Wang & Burris, 1994; Wang & Burris, 1997). PAR is an approach to

inquiry, not a specific method (Minkler & Wallerstein, 2003a; Reason & Bradbury, 2008a; Riecken et al., 2005) that seeks to engage participants as co-researchers in the process of identifying and solving community issues. One problem with traditional scientific research has been that it sets up the researcher as the expert and the research subject as the object of the research. Without active participation of the persons being studied in the research process, the entire conceptualization, conduct, and outcome of the research is based on the knowledge of the researchers – and that knowledge may be very limited, particularly when it comes to the culture and social context of those being studied. Photovoice and other PAR research strategies often deal with issues of oppression, inequalities, disparities, and marginalization (Hall, 2001; Minkler & Wallerstein, 2003a; Torres, 1995) so that part of the problem may be to discover what the issues really are from the point of view of the people who are actually experiencing them. Seeking their participation in communicating the issues and possible solutions then becomes of critical importance.

Asking persons with disabilities to rate their life satisfaction on a five point Likert scale from “A” very satisfied to “E” very dissatisfied, yields only one thin data point. Giving those same persons cameras and asking them to take photographs of what their daily lives are like will yield a wealth of information from both the photographs that are taken and the stories that they tell about those photographs.

This is just one example of how presentational knowing could become a bridge between the researcher and the co-researcher to create richer communication, better understanding, and more effective solution-seeking. Utilizing a noncognitive way of knowing such as presentational knowing can help participants express what they might not have

otherwise been able to express. This in turn opens up the culture to the researchers who are trying to get a better understanding of the problems in order to foster change. The research process thus becomes a cooperative exchange between the researchers who want to learn and understand and the co-researchers who want to be understood and empowered.

Application to research. Following are some examples of the application of presentational knowing in PAR and other participatory practices.

The accidental storyteller. Little did the researchers know when they planned to use storytelling with diabetes support groups that the stories would take on a life of their own. Greenhalgh, Collard, and Begum (2005) wanted to provide diabetes support and education to Bangladeshis and other minorities in inner city London. Based on previous success with storytelling and smoking cessation, they planned the diabetes intervention and trained a group of bilingual health advocates using the course they developed, “Storytelling for Group Learning in Health and Care.” The researchers had chosen what they thought would be an appropriate strategy for reaching their target population, but unfortunately, their advanced planning did not go far enough. They gave the example of one of their diabetes storytelling groups where stories were indeed shared, but not in the organized and structured way they had planned. The researchers learned that the participants would do things their way, which was not to take turns, but talk all at once, move around a lot instead of sitting still, and have friends and family members wander in and out at will. It was sort of a half-success story. The presentational knowing strategy of storytelling was planned as a culturally appropriate way to reach the Bangladeshis and other minorities with health information, but the researchers had not really done their “homework.” The research used the action research cycle, but because it

was not a *participatory* action research study, the participants, who could have helped the researchers understand in advance what would work and what would not work, were not involved as co-researchers in any aspect of planning or evaluating the project. Instead, the program was planned without their participation and delivered to them. Overall, the storytelling groups were successful and well-received, but it was more due to the fact that the participants made the groups culturally relevant than that the researchers planned it that way.

The Elders versus the IRB. What do you do when the Institutional Review Board (IRB) insists on the destruction of tapes after interviews and the Elders say they will not participate if their stories on tape are destroyed? This was just one of the dilemmas faced in the development and implementation of a PAR study on sobriety with Alaskan Natives (Mohatt et al., 2004). Following an unsuccessful conference on alcoholism that was researcher-controlled and offended the Alaskan Natives, a coordinating council was formed consisting of both Euro-American and Alaskan Natives and the mutual process of defining a research agenda began. The part of the study that relates to presentational knowing was that instead of using a questionnaire, participants were asked to tell their stories “in their own way” which included choice of location (anywhere from the kitchen to a motel room) and choice of type of person they would talk to (male, female, member of their own culture, or not). This approach worked well, yielding life histories that council members, once trained, were able to code together. In this study, storytelling was a culturally accepted way for the Alaskan Natives to communicate about sobriety. The researchers were aware of the participants’ differing ways of knowing from the onset of the research and were able to successfully negotiate the potential communication hazards that occurred along the way. As

for the IRB, the procedure was modified and a method for preserving the tapes was developed, along with a plan for donating the honoraria to charity since the Elders had said their stories were not for sale.

Entering the flow, like salmon. Traditional Pathways to Health was a PAR project that conducted research about health and wellness and injury prevention. It was a joint project between faculty researchers and Aboriginal teachers and youth in western Canada (Riecken et al., 2005). In this project, the students used digital video technology to develop short videos about health and wellness topics. Interviews, images, songs, or text were all options for the students to use in making their videos. This openness to arts-based modes (i.e. presentational knowing) allowed for new knowledge creation and gave the students a wider vision of what could be accomplished through a cooperative research process. In addition to the actual production of the videos, the study participants created a dialogue composed of interview segments, field notes, and reflective writing in order to capture the essence of the research process. The dialogue of voices was first done in a conference format and then incorporated into an article. Thus, the article itself was like a play with dialogue that went back and forth from student to teacher to researcher, giving the reader an inside view of what the experience was like for each of the participants. One of the students said,

Culture keeps us alive. I knew it [culture] was there but I just never had it reflected back to me. My mother's in there [the video] and I can see myself being like her 20 years from now and I can see myself doing the same, passing it on. Culture keeps us alive. (Riecken et al., 2005, PAR with Indigenous Participants, para. 25).

A teacher said, “The dialogue that occurred in the research is bigger than the research” (Riecken et al., 2005, PAR with Indigenous Participants, para. 55) and was especially appreciative of all the connections that were made. A researcher said “the journey that is PAR is one that is taken side by side rather than with leaders and followers, researchers and subjects, or marginalized and mainstream” (para. 52). These few quotes provide a brief glimpse of the deep and meaningful experiences that were created by the use of presentational knowing in the PAR process.

There is a long tradition of use of presentational knowing in popular education (Kerka, 1997; Merriam & Brockett, 1997) and throughout the history of PAR. The roots of both popular education and PAR are embedded in presentational knowing. Freire used stories and drawings in his literacy work, especially for generating dialogue to awaken consciousness (Freire, 1970, 1973). Fals-Borda (1987) recounted a variety of ways that the use of presentational knowing was crucial in their PAR work in Mexico, Nicaragua, and Colombia. They took advantage of elements of the folk culture such as art, music, drama, sports, beliefs, myths, and especially storytelling to engage people in “action through research.” The three examples I have discussed in detail have just been a sampling of more current applications of presentational knowing in PAR that continue a long tradition.

Application to my research. How does one really learn about the world in which another dwells? When we look, we see through our own eyes. When we assume, we often assume wrong. When they look, they can help us see through their eyes. The difference between the impact of a traditional research method and the Photovoice method may be illustrated by an experience we had presenting the results of a Photovoice research project to

a group composed largely of medical students at a nearby university. They had all read about, studied, and perhaps even seen patients with the particular medical condition being presented, but when they saw the photographs, heard the stories, and met the people, they were greatly impacted. “I had no idea that...” and “We never learned any of this in med school” were typical comments we heard. This is just another example of how using presentational knowing can open up new doors of understanding to other worlds of experience, or as Bruner would say, “possible worlds” (1986).

Based on the history of the use of presentational knowing in PAR research, along with my own experience, I expected to find a tremendous benefit of using presentational knowing to learn about the individual experiences of support group members who had engaged in Photovoice research. Earlier in this chapter I discussed transformative learning and its intersection with the arts. There is much yet to be explored and I hoped that the two presentational art forms used in this research, photography and storytelling, would have their own intersection with transformative learning and change.

Summary of presentational knowing. I discussed presentational knowing as one of four types of knowing described by Heron and Reason (n.d., 2008). I then reviewed a wide range of ways of knowing and discussed several categorizations in depth. I discussed photography and storytelling as two types of presentational knowing that I used in my research. I then gave several examples of PAR research that used presentational knowing and explained the importance of using presentational knowing to access the culture and exhibit cultural competence during the research process.

Ways of knowing may be categorized in so many ways: by gender, culture, spirituality, discipline, etc. No doubt, this multiplicity of ways of knowing will continue to grow as further research explores and discovers additional ways of knowing. One notable characteristic of presentational knowing is that it is not gender specific, culture specific, or specific to a particular tradition or discipline. Therefore, it can be used by so many different individuals and groups seeking to access or express aesthetic and imaginal knowledge. Now that the cognitive door has cracked, so to speak, to allow in other ways of knowing, a multitude of knowing contenders are pressing in and seeking a place at the table. There is room for them all.

Summary and Conclusions

The conceptual framework and literature review comprised this chapter. Interpretivism was described as the conceptual framework since it is a subjective perspective that allows for a variety of ways of meaning making along with multiple realities. Just as different filters on a camera lens can change the view and final outcome of a photograph, individuals may have different interpretations of their experiences based on the ways they see the world. Interpretivism offers an openness to the variety of perspectives that research participants could have had about their photographs and related research experiences. Three literature areas have been reviewed. The first was from the societal perspective and included participatory action research (PAR) and Photovoice. The analogy of a wide-angle lens was used because PAR is community-focused and aims at social change for groups and communities. However, the group of co-researchers participating in Photovoice was composed of individuals, each of whom had his or her own experience while also being a

member of the research group. Thus, it was important to consider the individual perspective as well, using the analogy of the close-up lens. Within the individual perspective, Orem's self-care deficit theory was used to explain how persons with chronic conditions need to focus on self-care and take personal responsibility for it in order to maintain as much health as possible. The concept of self-efficacy was included in the individual perspective because belief in one's ability to change is a necessary component in the change process. Support or self-help groups can assist greatly in the self-care process by providing shared knowledge and social support. The transtheoretical model of health behavior change was a way to view individual changes that may occur as people make choices about self-care and other health matters. The Photovoice process may have particular impact in the consciousness raising component of this model. Six other models of individual change have also been reviewed that reflected other ways that persons with chronic illness could perceive prospective and actual changes in their lives. The third area of literature was the medium of photography as art, with the analogy of the light that comes through the lens from the prior two perspectives, societal and individual. Here, photography was considered as an art form, not just a means of documentation for research. The potential of art to transform, play a role in healing, and provide presentational knowing through photography and storytelling opens up new ways for learning about individual experiences of Photovoice participation. My expectation was that as individuals shared their respective stories of Photovoice research participation, enhanced by additional photographs they had taken, their stories would emerge to provide new insights as to the individual experience of engagement in research aimed at social change.

In the next chapter, I present the methodology for this study. I provide the rationale for the selection of visual narrative inquiry as the qualitative methodology. Details of the research process from initial preparation to implementation to analysis are discussed in detail, including changes that evolved during the research process.

CHAPTER THREE: METHODOLOGY

Photovoice is a participatory action research method aimed at producing social change by putting cameras in the hands of various marginalized groups to photograph issues of concern (Wang & Burris, 1997). While the purpose of such research is to teach community members to document, reflect upon, and express community needs, with the end goal of influencing policymakers, the potentially life-changing effects on individuals, especially those from vulnerable populations, has been minimally addressed. The purpose of this study was to describe the individual Photovoice experiences of support group members from a vulnerable population who had been involved in such research aimed at social change. The research questions that guided this study were:

1. What are the experiences of individuals participating in a Photovoice research project aimed at social change?
2. How do members of a support group make meaning of their participation in a Photovoice project?

Thus, the individual experiences of Photovoice research participation were foregrounded, while the results of the Photovoice project itself were in the background.

The structure of this chapter is as follows. First, I provide rationale for the use of qualitative methodology and narrative inquiry specifically. I then discuss data collection methods, which included interviews, photographs, documents and artifacts, and the research journal and field notes. Explanation of data analysis and data display follows. Finally, I conclude with study limitations, researcher bias and assumptions, trustworthiness and veracity, followed by a summary and conclusions for the chapter.

Rationale for Qualitative Study

This research study did not seek to survey, assess, or measure a large sample of Photovoice research participants in order to determine common or causative factors of their research experiences. Rather, the study goal was to explore and describe the Photovoice research experience through photograph-enhanced stories of Photovoice research participants in order to gain an in-depth view of the meaning of the research experience and its effects on these specific people.

Creswell categorized research into three possible approaches: quantitative, qualitative, and mixed methods (Creswell, 2003). Quantitative approaches are within the positivist tradition and involve deductive reasoning, hypothesis testing, experiments and surveys, and the use of numerical and statistical data for theory testing. In contrast, qualitative approaches are inductive, seeking to learn about individually and socially constructed meaning by developing themes from open-ended data that is verbal or textual rather than numeric. Mixed methods use pragmatic assumptions and result in a combination of both numeric and textual data.

The four main characteristics of qualitative research are (a) it aims to understand how people make meaning of both their experiences and their world; (b) the researcher is the human instrument, rather than a mechanical instrument, for data collection and analysis; (c) the research process is inductive rather than deductive so that themes, and eventually theories, are built based on the data that has been collected; and (d) the end product of the research is “richly descriptive” through words, pictures, and all the means through which data was obtained (Merriam & Associates, 2002). There are many types of qualitative

research and a variety of ways of conducting it, but there are also commonalities. Following are general characteristics of qualitative research and qualitative researchers. The five characteristics of qualitative research are that it

(a) is naturalistic, (b) draws on multiple methods that respect the humanity of participants in the study, (c) focuses on context, (d) is emergent and evolving, and (e) is fundamentally interpretive. Qualitative researchers... (a) view social worlds as holistic, (b) engage in systematic reflection on the conduct of the research, (c) remain sensitive to their own biographies/social identities and how these shape the study, and (d) rely on complex reasoning that moves dialectically between deduction and induction. (Rossman & Rallis, 2003, as cited in Marshall & Rossman, 2006, p. 2)

The appropriate methodology for my study was qualitative research because it fulfilled the characteristics just described as it sought to discover the meaning of the Photovoice research experience to a small group of individuals who had varying interpretations of both their photographs and the research process. The study was inductive and developed themes based on the narrative and visual data collected, along with the field notes and reflective journal of the human instrument researcher, myself. Further illustration of the qualitative nature of this research is evident throughout the following sections that describe narrative inquiry, interviewing, photographs, research journal and field notes, data analysis, data display, and positionality.

Learning about the views, experiences, and ideas of the study participants can best be accomplished through qualitative exploration of the subject, since this strategy does not have a preset agenda, but is open to new directions and ideas so that themes can emerge from the

data. Determination of causation and the ability to generalize would be characteristics of a quantitative study (Maxwell, 2005), whereas this qualitative study sought more to understand meaning on an in-depth level than to summarize or predict (Denzin & Lincoln, 2003). The subjective viewpoint of the interpretivist conceptual framework points logically to the qualitative approach, as does the acceptance of multiple co-researcher perspectives characteristic of participatory action research and multiple ways of knowing (Hall, 2001; Heron & Reason, n.d., 2008; Krauss, 2005; Merriam, 1998).

Method Used and Rationale

The qualitative approach used was visual narrative inquiry (Bach, 2001; Bach, 2007). This approach to narrative inquiry adds photography to the storytelling process. Narrative inquiry itself encompasses a variety of ways in which stories or descriptions of a series of events, i.e. narratives, are studied and analyzed (Clandinin, 2007). Narrative inquiry can use written or oral accounts by which stories may be told and retold as the narrator makes meaning out of life experiences (Marshall & Rossman, 2006). My research was an exploration of the experiences of Photovoice research participants through the stories they told about their lives with epilepsy and their participation in Photovoice research. I wanted to learn about their experiences through their stories and this was accomplished by eliciting their stories through narrative inquiry. Thus, the stories told of the Photovoice experience became the data for the narrative inquiry methodology of this study. As Clandinin (2007) said, “narrative inquiry embraces narrative as both the method and phenomena of study” (p. 5). Although narrative inquiry has been criticized because of its focus on the individual (Marshall & Rossman, 2006), it is precisely the individual perspective that was sought in this

study. Marshall and Rossman also noted that a benefit of narrative inquiry is its power to elicit voice and it is the voices of persons from a vulnerable population who have participated in a particular research methodology that was the subject of interest for this research. I also wanted to incorporate the photographs taken during the original Photovoice project along with new photographs the participants took to further illustrate their research experiences. One of the ways that Photovoice gives voice is by providing an aid to the storytelling process, since photographs can serve as a guide or a memory trigger (Bach, 2001; Clandinin & Connelly, 2000). Thus, the use of photographs was expected to facilitate storytelling as well as to add a visual dimension to the stories that were told. In addition, it makes logical sense to study the photographic research process of Photovoice by using photographs.

Daniels (2005) studied the meaning making process in adult women through the use of credible still photographs. In this study, the photographs were taken by the researcher and interpreted by the study participants. This process is what Taylor (2002) referred to as photo-elicitation, where photographs taken by someone other than the study participants are used to stimulate the interview process. In contrast, the Photovoice research process uses photographs that are both taken and interpreted by the research participants. Participants take photographs of themes chosen by the group and then discuss those photographs according to specific questions developed for the methodology. In a similar manner, this study involved the use of photographs taken by the participants to depict their respective research experiences. The participants discussed these photographs to tell the story of their experiences. Thus, the use of story makes the process narrative inquiry while the addition of photographs makes it visual narrative inquiry, “an intentional, reflective, active human

process in which researchers and participants explore and make meaning of experience both visually and narratively” (Bach, 2007, p. 281).

Both a stepwise outline and a narrative description of the original Photovoice project are provided in Appendix A, the *Photovoice Research Process Outline and Narrative*. In planning this retrospective dissertation research on the Photovoice research experience, I chose a few elements similar to the original Photovoice project: use of disposable cameras, photographs developed in duplicate so participants would have a copy to keep, and a final group meeting, in this case an interview. However, because my research was not a Photovoice project, but a narrative study of individual Photovoice research experiences, there were several study design differences. These were: individual rather than group interviews, three interviews rather than three group meetings, interview questions and probes developed by the researcher rather than themes developed by the group, one roll of film (rather than three) to depict the Photovoice research experience, and the option to bring photographs from the original Photovoice project and any other artifacts to the interviews.

Study Population – Sampling and Justification

When a population is large, a sample must be taken in order to have a manageable number of subjects or participants in terms of research resources. In order for statistical inference to be made, as in a quantitative study, the sample must be representative of the population by some criteria, such as random sampling (Maxwell, 2005). My study was interested in persons with non-visible handicaps, specifically those with epilepsy, and more specifically those with epilepsy who were members of a support group. However, this study did not aim to produce inferences about a population, but rather to provide an in-depth look

at individuals in a specific support group. In a qualitative study, where inference is not necessary, purposeful sampling may be done as a deliberate choice in order to provide the information sought by the study (Maxwell, 2005). The purposeful sample for this qualitative study was actually more like a complete enumeration, as all support group members from a specific epilepsy support group who had participated in Photovoice research were invited to join the study.

Pseudonyms rather than actual names were used in the write-up of the research. This was especially important for maintaining confidentiality since there were a small number of participants. In my proposal, I left open the possibility of using actual names if a participant would have specifically requested it, which was a possibility since some of them are strong advocates for epilepsy and might have seen this research participation as another way of “getting the word out.” However, during the data collection process, I decided to hold to the original plan of pseudonyms for all, as revealing one participant name could have compromised the confidentiality of the others. Pseudonyms were also used for cities, towns, and institutions.

Contact with the potential participants began once IRB approval was obtained. The *Informed Consent Form for Research* (Appendix B) was completed by each of the study participants after the study was explained to them and before any data collection began.

Data Collection

Interviewing was the main data collection method used in this study, supplemented by photographs and accompanied by the research journal and field notes. Next, I discuss the

general purposes of these methods along with their specific relationship to narrative inquiry and visual narrative inquiry.

Interviewing

Interviewing, especially in-depth interviewing, is one of the four main methods of data collection described by Marshall and Rossman (2006). According to Marshall and Rossman, whether the interview is totally open-ended or somewhat systematized, its purpose is to obtain the participant's view and perspective. Among the advantages of the interviewing method given by Seidman (2006) are its ability to provide insight through understanding the experiences of those interviewed, its congruence with the fact that most people make meaning through language, and its affirmation of the individual while still allowing for the possibility of collaboration. Interviewing allows people to tell their stories and gives the researcher the opportunity to understand the lived experience and meaning of that experience as expressed by the interviewee (Seidman, 2006). A one-time interview is unlikely to provide sufficient opportunity for the interviewee to express and the researcher to understand the experience of interest. Nor does it allow time for one to become comfortable with the other or for the interviewee to reflect upon the stories and add to them (Clandinin & Connelly, 2000; Seidman, 2006).

The interview methodology chosen for this study was the three interview series described by Seidman (2006). The plan was for interviews to be spaced several days to a week apart and last about 90 minutes each. The first interview was to provide context as the participant gave a focused life history. Of particular interest was the participant's illness story, how and when the epilepsy began, and its effects on the person's life. In the second

interview, the participant was to give the details of his or her Photovoice research experience. The third interview was to provide opportunity for the participant to reflect on his or her sense and understanding of the Photovoice research experience, with an emphasis on making meaning. The *Interview Guide* (Appendix C) consisted of background information, with open-ended questions and prompts for each of the three interviews and the group interview. After all the individual interviews were completed, there was a group interview with an opportunity for group sharing, reflection, and summary comments about the Photovoice research experience. The rationale for having the group interview as the last interview was that a group setting may not be conducive to deep personal sharing and in addition, members of a group can influence one another so that a non-representative consensus could be developed (Taylor & Bogdan, 1998). All interviews were tape-recorded and written transcripts were subsequently made.

In contrast to standard interviews for survey purposes or those with a question-answer format, the in-depth interview of narrative inquiry seeks deep information and understanding (Johnson, 2002) and therefore needs a different approach. The narrative inquiry approach is a much more unstructured and open-ended approach and uses instead an elicitation technique to draw out the story and keep it going (Javchelovitch & Bauer, 2000). Javchelovitch and Bauer suggested a four-stage process for this elicitation process: preparation, main narration, the questioning phase, and concluding talk. The key factor in this process was to allow the participant to tell the story or narration without interruption other than non-verbal signs and encouragement to continue (Javchelovitch & Bauer, 2000; Mishler, 1986). Questions to fill in the gaps should not be asked until it is clear that the main narrative has ended.

Photographs

Interviews were photo-enhanced, with the participants providing photographs that demonstrated or typified aspects of their experiences during the Photovoice research process. In order to have the photographs available for the interviews, I contacted each of the potential participants and met with them separately to explain the purpose of the study and obtain consent. At this time, I also reviewed instructions about the process of taking photographs, having photographs developed, and the subsequent individual and group interviews. The chosen theme for their photographs was “My Photovoice Research Experience.” The process was as follows. First, each participant was given a disposable flash camera in order to take photographs to go with the subsequent interviews. Next, participants had one to several weeks to take the photographs depending on their estimates of how long they would need to get them done. I had originally planned for participants to return the cameras to a central location, but ended up using my proposed alternate plan if they were unable to do so. Thus, I made arrangements to pick up the cameras at a location convenient for the participants, which in the case of three of them was at their homes and the fourth was my place of employment. In planning the study, I had considered the use of disposable digital cameras, which would have eliminated development time, but in the end, I decided to remain with regular disposable cameras so they would be the same type as in the original Photovoice project. Thirdly, participants also had the option of including any of the photographs from the original Photovoice project in the interview process. Finally, following development of the photographs, the series of interviews began, with at least several days between interviews to allow time for review and making notes on each interview.

The use of photographs as secondary data or part of a multiple methods approach can be part of a general qualitative approach (Marshall & Rossman, 2006), while the use of photographs as field texts that can be used to trigger or unfreeze memories and enhance the telling of stories is also specifically associated with narrative inquiry (Clandinin & Connelly, 2000) and visual narrative inquiry (Bach, 2001). Because photographs taken by the research participants are the primary data collection method of Photovoice (Wang & Burris, 1997), it seemed logical to continue the use of photographs in the narrative inquiry process of this research study. Bach (2007) emphasized the importance of the visual in knowledge construction and therefore the ability to add another layer of meaning when the visual aspect is added to narrative inquiry. Field texts such as photographs not only trigger memory but also supplement those memories with details that aid in the retelling (Bach, 2001; Clandinin & Connelly, 2000; Taylor, 2002).

Documents and Artifacts

Interviews are one of the major sources of data for qualitative research. The other two are documents and observations, according to Merriam and Associates (2002). Creswell (2003) cited four data sources: interviews, observation, documents, and audio and visual material. Marshall and Rossman (2006) categorized data sources as primary and secondary, with primary being interviews and observations, and secondary being documents. I planned to include photographs from the original Photovoice project that participants chose to discuss as part of their recounting of the Photovoice research experience. These photographs were considered as visual documents (Merriam & Associates, 2002), visual material (Creswell, 2003), or other forms of communication/historical data/visual anthropology (Marshall &

Rossman, 2006). These photographs had been given to each participant at the conclusion of the original project and thus became the personal property of each participant. Therefore no consent was required to include them in the study. Participants were also invited to bring other documents or objects, often referred to as physical material or cultural artifacts (Merriam & Associates, 2002), to help tell their stories. In addition, the original Photovoice project was on a CD and had been presented two times. Each potential participant also had a copy of this CD, so I had considered the possibility that one or more of them might refer to it during either the interviews or the final group meeting. As it turned out, none of them did refer to the CD.

Documents and artifacts can be useful additions to a qualitative study for several reasons. According to Merriam and Associates (2002), the fact that they are preexisting means that they do not intrude upon a situation the way a researcher would as in participant observation. As an additional source beyond interviews, they can also help in triangulation of data to establish validity (Creswell, 2003; Marshall & Rossman, 2006). Finally, they can be a component of the data for narrative inquiry that accompanies storytelling (Marshall & Rossman, 2006).

Research Journal and Field Notes

Additional data for this study included the field notes made after each interview and a research journal of notes, ideas, and reflections kept throughout the research process. Both the research journal and field notes became an important aid to the quality of wakefulness that Clandinin and Connelly (2000) presented as a necessary reflective tool throughout the narrative inquiry process. Field notes are the usual way of recording observations, but are

also important for recording the observational aspects of interviews (Marshall & Rossman, 2006). In addition, these field notes become field texts and are part of the total data gathered (Clandinin & Connelly, 2000). Ongoing field notes and reflective journaling are both important parts of the total research process that add to the rich data gathered for continuing reflection and subsequent analysis.

Data Analysis

Riessman said that storytelling “is what we do with our research materials and what informants do with us. The story metaphor emphasizes that we create order, construct texts in particular contexts” (1993, p. 1). Thus, the storytelling of the research participants becomes the narrative that is analyzed. Mishler (1986) described three different approaches to narrative analysis. The first was functional analysis, which focused on clauses and how they related to each other. The second approach focused on coherence and how themes related to each other. The third approach looked more specifically at stories told in the context of interviews. This third approach was the most appropriate for the purposes of this study as it considered the co-creative nature of the story in the interplay between interviewer and respondent. In this co-creative process, the researcher and participant each affect each other in the process of telling, discussing, and retelling the stories (Mishler, 1986; Riessman, 1993).

A variety of strategies comprised the data analysis phase. Both data reduction in terms of coding (Miles & Huberman, 1994) and data synthesis in terms of creation of profiles and a meta-story or metanarrative were involved (Chase, 2005; Lawrence-Lightfoot & Davis, 1997). Some initial codes were developed before the data collection phase. These provisional

codes were based on the literature or “conceptual framework, list of research questions ... problem areas” (Miles & Huberman, 1994, p. 58). For example, some codes relating to stigma and marginalization were developed. I also used the themes developed from the original Photovoice research project.

The data collection and data analysis phases overlapped. Entries in the research journal were ongoing, while field notes were written in association with each interview in order to keep track of observation, thoughts, insights, and reflections. Interview tapes were reviewed and the transcription process began in between interviews so that insights and ideas gained could be applied to subsequent interviews.

Completed transcripts were reviewed and analyzed for significant stories and themes linking those stories. In addition to coding based on provisional codes, inductive or open coding was also done since themes emerged from the data that were not anticipated (Miles & Huberman, 1994; Strauss & Corbin, 1998). Included in the open coding were *in vivo* codes in the words of the participants, such as “isolation” (Saldaña, 2009). As each transcript was reviewed, associated photographs were also reviewed. However, unlike the visual narrative inquiry process described by Bach (2007), the field text was not composed in advance of interviews as an imagining or anticipation of what they might mean, but only after the interview process in which the participants discussed and described the meaning of the photographs to themselves. Individual interviews and the group interview were coded for common themes, looking for themes first within each participant’s story and then across participants.

Riessman (1993) described Bell's strategy for reducing a story to its core narrative. This process allowed a clearer view of the story without all of the details and also permitted recognition of commonalities among stories of the various participants. A strategy that helped me to do something comparable was compiling a chart of the stories each participant told, categorizing them by whether the stories related to their own new photographs, their own prior Photovoice photographs, Photovoice photographs taken by others, or were unrelated to a photograph. In a final column I made annotations, referenced key quotes, and noted repeat references to the stories and/or photographs in other interviews.

The process of data reduction and data synthesis was a multi-layered process that looked at smaller units within stories, the various stories told by each individual about each photograph, the overall life story of each individual, and the composite story of the members of the support group. Individual profiles and specific stories of both individuals and the group were developed and are discussed further in the next section.

Data Display

In keeping with the methodology of narrative inquiry, one of the main methods of data display is stories. First, profiles were developed of each individual participant. I tried to write them in a more artistic way that portrayed a sense of each person's unique life story and gave a more emotional sense of his or her life with chronic illness than a standard biography. My idea for the development of these profiles came from the work of Lawrence-Lightfoot and Davis (1997) who explained how qualitative researchers can use portraits to "record and interpret the perspectives and experience of the people they are studying, documenting their

voices and their visions” (p. xv). For each participant, I chose one photograph to accompany the profile that I felt exemplified the story of his or her life with epilepsy.

I organized the findings by research question in chronological order to reflect the overall story of the research experience from beginning to end. Within this chronological story, the individual participants had their own stories and interpretations of the experiences, which were presented along with photographs depicting key features of the experiences and feelings that they wanted to share. Data from the group interview helped to clarify the commonalities so that the meta-story could be constructed. Rather than one metanarrative, I ended up with a poem, a diagram, and a summary photograph that together provide complementary aspects of the meta-story of the Photovoice research experience and its meaning to the participants. The collective story of the Photovoice experience of this group of individuals was more of a meta-story than a grand metanarrative describing an era or phenomenon (Chase, 2005).

Study Limitations

As qualitative research, this study makes no claims as to generalizability to all persons with epilepsy, all support groups or all persons with non-visible handicaps since it pertained to only one support group and one particular chronic illness. A potential limitation, which was also simultaneously a benefit, was that I already knew the prospective research participants due to my prior work with the group and the prior Photovoice project. Because I am not in a leadership or power position with the participants, but rather in a background advisory role with the support group, I did not think my position with the group would exert undue influence on the participants. I expected that since they had all been very enthusiastic

about the Photovoice project that they would be willing to participate in this study and was gratified that they were all very eager to participate. If one or more of them had chosen not to participate, I was prepared to stop coming to the monthly support group meetings during the data collection time to avoid making them feel uncomfortable. I had also considered missing the monthly meetings even if all the potential participants chose to participate since they might have been more likely to discuss the project during a meeting. This could have potentially compromised the group meeting planned for the end of the data collection period. However, I had also considered that missing meetings might be perceived that I was valuing my research above my role with the support group and abandoning them, so I made the decision not to miss any meetings.

Another potential limitation was that it may seem incongruent that the research was from the individual perspective within a collective methodology. However, this was intentional because the individual perspective of what may happen to individuals participating in a collective methodology is precisely what this research addressed. The individual perspective is what has been missing from the total picture of the Photovoice research process.

My positionality as a nurse might have been a limitation because I have a health care perspective when I look at the issues surrounding chronic illness. Thus, although I am also an educator, I may not see the same things as someone from a social science background, for example. However, this difference of perspective is part of the very nature of qualitative research – there is a particular lens through which the research is seen and interpreted (Chase,

2005). The key point is to acknowledge it and be aware of its potential impacts, which is what I have attempted to do.

Researcher Bias and Assumptions

I have been practicing and teaching nursing for many years, working in both academic and community settings. My original nursing education was in an unusual program that allowed specialization at the baccalaureate level. Because I already knew that I was more interested in health promotion and disease prevention, I specialized in primary care and have spent most of my career in positions that focused on prevention rather than acute care. As such, I tend to look at the beginning of the health spectrum in regard to illness, trying to prevent it, or in the case of chronic illness, trying to help people get back to or maintain as much health and independence as possible. Most of my work has been in public health or community health so I have also tended to work with disenfranchised or marginalized populations and their many health-related needs. Thus, I am not unbiased when it comes to issues of prevention, access to care, adequate care, or marginalization.

In addition, my professional practice for the past ten years has been in parish nursing, a specialty area that combines faith and health. I am thus very attuned to spiritual issues related to health and illness and could have been more likely to notice and follow up on photographs or stories that related to spirituality than someone who did not have this perspective.

Positionality

Although I hold a peripheral role of advisor and resource person for the support group, I am also welcomed by the group, even though I am not an official member due to the

fact that I do not suffer from epilepsy. The advantage of my work with the group was that it has given me some knowledge about the group members and also gave me access to the group. Yet my long-term involvement with them may have meant that I would have a different perspective than someone who is more of an outsider would have. I may thus have seen some things due to my longevity with them and missed others because of things I have become accustomed to. My goal was to continue to tread the fine line between insider and outsider, working with them as a sort of honorary member who can be trusted as a respectful and understanding researcher. I feel that I accomplished this.

Trustworthiness and Veracity

Trustworthiness and veracity was addressed according to the eight strategies compiled by Creswell from several other sources (2003):

- Triangulate different data sources. Using different sources of information such as individual interview data and photographs, along with group interview data, served as a triangulation strategy. The specific interview question about observation of changes in others elicited responses in both the individual interviews and the group interview that confirmed what other participants (and/or the researcher) had observed or surmised.
- Use member checking. I provided copies of the transcripts back to each participant and received confirmatory feedback from two of them.
- Use rich, thick description. Rich, thick description was used to describe the findings, especially in profiles and stories that were compiled and presented, with detailed quotations in the words of the participants.

- Clarify researcher bias. Potential bias has been described under *Researcher Bias and Assumptions* and was monitored throughout the study.
- Present negative or discrepant information. Negative experiences and perceptions are included in the findings of the following chapter as participants discussed such aspects of the Photovoice research experience. Unexpected findings are also included in the next chapter, while differences between expected matches of the data to the literature are addressed in the final chapter. I did not expect that participants with such different backgrounds and life experiences would necessarily have the same types of stories and responses, but was surprised to discover how many similarities there were.
- Spend prolonged time in the field. The study itself did not take place over a prolonged time period, but there were repeated contacts with participants because of the three interview series plus a group interview over a period of several months, rather than a single interview. In addition, because I have worked with the participants over the period of several years, even though this time was outside of the actual study, it had value for establishing rapport and a basis for relationship.
- Use peer debriefing to enhance accuracy. Since this was dissertation research, I was the sole researcher and did not have a co-researcher to serve as a peer debriefer per se. However, as a member of two different dissertation support groups, I had opportunity for review and questions from colleagues within the limits of confidentiality that were promised to the participants.

- Use an external auditor. My dissertation co-chairs have served as external auditors of the research.

Along with these general strategies for validity in qualitative research, other strategies specific to narrative inquiry were considered. Clandinin and Connelly (2000) viewed wakefulness as the most important criteria for assessing narrative inquiry. By wakefulness, they meant ongoing reflection and thoughtfulness about all of the decisions in the narrative inquiry process. This approach highlights the importance of thorough field notes to document research events and activities and an ongoing research journal for thoughts, insights, and reflections. To fulfill this criterion, I wrote extensive field notes and continued the research journal throughout the data analysis process and on through the process of writing the dissertation. Because Clandinin and Connelly described narrative inquiry as a “kind of fluid inquiry,” other evaluative criteria seemed to vary depending upon the setting and the specific researcher. Of the criteria they discussed, ones that seemed most relevant to this research were transferability (rather than generalizability), having an explanatory invitational quality, having authenticity, and having adequacy and plausibility.

Regarding the photographic aspect of the research, Loizos (2000) provided insight into the evaluation of photographs, noting first the fallacy of “the camera cannot lie.” Some of the concerns with photographs such as doctored negatives or electronic manipulation were irrelevant since all photographs in this study were taken by the participants using disposable cameras and I was the one who transported the cameras to a commercial vendor for development. Manipulation of images by the photographer for the purpose of influencing the viewer in a particular way, such as in photographs taken for a specific ideological effect, was

also not a concern, since the research participants took and interpreted their own photographs to explain their own realities. What was relevant to this study was consideration of not only what was in the photographs, but also what was not in the photographs, along with what was photographed and what was not photographed at all. What was absent in a particular photograph and what was not even photographed can be very telling and thus suggests the importance of including these questions in the interview process.

According to Loizos (2000), the following four ways in which a photograph may arise may be helpful in the discussion and interpretation of photographs.

- The subjects can be caught off guard, behaving informally, by a photographer.
- A group of subjects, hearing that there is to be a photograph taken, may position themselves in a way they consider to be appropriate.
- A photographer may take the initiative to place subjects in a specific composition, and they may passively accept direction.
- Some collusion or negotiation between photographer and subjects may take place.

(p. 99)

I had expected that discussion of how photographs came to be taken would arise during the interviews and this was the case. As will be discussed in the following chapter, participants described the various ways that their photographs were composed and this proved to be helpful in understanding the meaning and interpretation of their photographs.

Summary and Conclusions

The individual experiences of Photovoice research participants were explored using the qualitative methodology of visual narrative inquiry. The qualitative approach allowed for

an in-depth exploration of the meaning and effects of Photovoice research participation. The use of visual narrative inquiry as the methodology was a logical outcome of the use of storytelling by participants to describe their respective research experiences, enhanced by photographs from the prior Photovoice project with additional photographs newly taken to illustrate the research experience. A series of three tape-recorded individual interviews and a final group interview comprised the data collection process.

Study participants were members of an epilepsy support group who had participated in Photovoice research. The issue of potential individual effects of research participation took on even greater importance since the individuals were members of a vulnerable population as was the case with persons with epilepsy. Specific care was taken in the planning of the research and was so documented in the IRB application and consent form. Strategies for assuring trustworthiness and veracity were followed with the end goal of producing credible results and conclusions.

I was aware of both the benefits and possible detriments of my status as a health professional who acts as a resource person to the epilepsy support group. Although gaining entry was a benefit, I made sure that the option not to participate was clearly given in the consent form and the verbal explanation of the study, and had plans for dealing with a declination if it had occurred.

Data collected included individual and group interview results, photographs, documents and artifacts, the research journal, and field notes. Profiles, stories, and three types of meta-story were the major means of data display following analysis of themes and stories.

The next chapter introduces the study findings, beginning with the context of the support group and participant profiles and proceeding to the context of the research and research findings. Findings are presented by research question in three major sections, accompanied by quotations and photographs to tell the chronological story of the Photovoice research experience.

CHAPTER FOUR: FINDINGS

Photovoice is a participatory action research method aimed at producing social change by putting cameras in the hands of various marginalized groups to photograph, document, and express community issues of concern (Wang & Burris, 1997). The problem this research addressed was the marginalization of persons with the non-visible but highly stigmatized condition of epilepsy. The purpose of this study was to describe the individual experiences of support group members who had participated in a Photovoice research project. Members of an epilepsy support group were the participants. Since epilepsy is a physical disability that may also have cognitive and/or medication effects, the participants in the study were also considered to be part of a vulnerable population.

The main research questions of this study were:

1. What are the experiences of individuals participating in a Photovoice research project aimed at social change?
2. How do members of a support group make meaning of their participation in a Photovoice project?

Members of an epilepsy support group were invited to participate in this study investigating the possible individual effects of their prior Photovoice research participation. All four individuals who had participated in the original Photovoice project agreed to participate. Visual narrative inquiry was the methodology which allowed participants to tell their epilepsy and research stories with the aid of photographs and other artifacts.

Photographs were from two sources: those they took for the original Photovoice project along new photographs they took for this study depicting their respective Photovoice

research experiences. Three interviews were conducted with the participants, the first, a focused life history of their epilepsy stories and the remaining two about their Photovoice research experiences. A group interview with all the participants concluded the research process.

This chapter presents the findings of the study starting with participant profiles and proceeding to the findings related to the two research questions. While some stories begin in the past and then go back to the beginning, I felt that this story would best be told in chronological order. Therefore, it begins with a description of each of the support group members and who they were at the time of the original Photovoice project. The story continues with a description of how participants entered the research process and adapted to it, followed by how the experience affected them at that time and over time.

Thus, the chapter is structured into three major sections: *What They Brought to the Table*, *What They Found at the Table*, and *What They Took Away from the Table*. *What They Brought to the Table* describes the context of the support group and the research participants. *What They Found at the Table* provides the findings for the first research question regarding participant experiences, while *What They Took Away from the Table* presents the finding for the second research question on meaning making. I chose this metaphor based on the use of the expression “being at the table” or having a “seat at the table” that usually refers to having equal access or equal treatment. My use of this metaphor was also supported by the participants’ photographs and discussions of tables and who was there and who was not there.

In keeping with my original plan to use pseudonyms for the study participants, they will be referred to hereafter as Yvonda, Alice, Cary, and Eagle. Other pseudonyms that will be used in this chapter are Wheatville, a city where two of the participants live, and Valleyview, a town visited by participants. The university where the Photovoice presentation was given will be referred to as UXE (the University of Excellent Education). A newer and occasional participant in the epilepsy support group is Brian. In presenting longer quotations from participants, I have italicized quotes that seemed particularly notable.

What They Brought to the Table

Epilepsy is not an Alaskan cruise. – Yvonda

In order to understand the possible impacts of the Photovoice research experience on members of an epilepsy support group, it is important to know first about both the group and its members. Therefore this section provides a discussion of the context of the support group along with an introduction to each person through the use of profiles. My aim is to clarify the status of the group and life situation of its members at the time the Photovoice research opportunity was presented to them.

Support Group Context

The epilepsy support group, which members refer to as the Wheatville Epilepsy Support Team (WEST), was initiated in 2004 by Yvonda and Alice. As persons with epilepsy who had both achieved some progress in managing their respective conditions, they felt ready and able to reach out to others to provide a safe setting in which people could share their concerns, struggles and triumphs. They began by offering a physician-led informational session through the community outreach program of a local hospital. From contacts at that

session and other community contacts, they proceeded to meet on a monthly basis in a conference room at the local public library. The state's epilepsy foundation served as a resource, providing informational materials and referrals, but was not involved in guidance or oversight of the group.

I first became aware of the WEST through my work as a parish nurse in the same community. As a health professional operating at the intersection of faith and health, my overall ministry goal is to help congregation members understand the relationship between faith and health and to facilitate the adoption of healthy lifestyles based on that understanding. One of the many roles of the parish nurse is to work with support groups, so when I met Yvonda, I was interested in learning more about her community-based support group and seeing how I might assist her in her efforts. The support group had only been operating a short time when we met and I began attending the monthly meetings. As a peer-led group, meetings were often informal without a preset agenda. After introductions, members would share current concerns or triumphs. If a new person was attending for the first time, the current members would share their respective epilepsy stories for the benefit of the new person, who might or might not choose to share his or her story at that time. Then the meeting would proceed to individual sharing. Sometimes an item shared would end up being the topic for the entire meeting. For example, if one person talked about a new medication his or her physician had just prescribed, then others would share their experiences with that medication or what they had heard from other friends or family members who had tried that medication. In addition to the support group aspect of the WEST, the group also began to plan and participate in an annual fundraiser which was a 5K walk. In the months

preceding the walk, the group focus became more task-oriented, often had an agenda, and had decreased time for personal sharing. This became a yearly cycle for the group.

When I first began attending the group, a neurology nurse from one of the local hospitals had a close association with the support group and attended the meetings when possible. Shortly after I became connected with the group, this nurse left for another position, so I began to serve as an advisor and resource person to the group. Although my specialty was not neurology, I had a variety of personal and professional experiences with persons who had seizures, along with other support group experiences. I shared from my experience on several occasions during initial introductions to help group members understand my empathy and solidarity with their struggles. However, because of my commitment to the peer-led support group model, I endeavored to keep myself in a background role and support Yvonda's leadership of the group.

The design of this research study included the opportunity for each participant to bring photographs from the original Photovoice project and any other artifacts to any of the interviews. Yvonda brought several samples of flyers, agendas, and other handouts from the support group which helped to convey the purpose and attitudes of the group. Artifacts shared by other participants were personal in nature, such as awards or art work, but were not specifically related to the support group.

Support group members were from three different cities, so although most meetings were in Wheatville, the group occasionally rotated to the other two cities which also opened up opportunities for new people from those communities to attend. By the time of the

Photovoice project, the group had relocated its meeting place to a private dining room at a local restaurant.

Support Group Members

Since this research study explored individual Photovoice research experiences, it was important to first learn about the individuals who had those experiences. Thus, the first interview of the three part interview series was a focused life history that asked about each person's life with epilepsy. Profiles of the research participants are provided along with a representative photograph to serve as a lens through which to view how they subsequently interpreted and reflected upon their respective Photovoice research experiences. Documents and artifacts that they shared during the interviews are also discussed at this time.

The participants each had a potential of four rolls of film, over 125 photographs, to use to describe their Photovoice research experience. I chose one photograph for each of them to illustrate their profiles. Without intending to choose the same type of photograph for each person, I ended up with four photographs relating to support: family support (Yvonda), spiritual support (Alice), medical support (Cary), and non-human support (Eagle).

Yvonda. Yvonda and I met in the library conference room at her church for our three interviews. The room had a large table where she could spread out the various documents and artifacts she brought to share. These items included some related specifically to the Photovoice project, some related to her epilepsy and the epilepsy support group, and a personal item. For Photovoice, she brought a copy of the letter she had written to the professor who had invited them to present to the medical students. She also referred to but was unable to find at the time of our interviews, some thank you letters she received from the

medical students (which she called fan letters), the thank you letter she wrote to the Photovoice researchers, and a newsletter article she wrote for the women's ministry at her church. General epilepsy information included sample flyers about the support group, a notebook of memorabilia from various epilepsy-related events such as the annual 5K walk, and some copies of the magazine *Epilepsy Advocate*. In addition, she brought several bottles of medications which she set out on the table at the end of one of our interviews to photograph. She also wanted to show and have me photograph the location of her vagal nerve stimulator (VNS), a device which has given her great confidence and freedom now that she knows she has an implant and wand she can pass over it to ward off a seizure. Finally, she shared a poem she had written about a very special giving and helpful neighbor. It was during our discussion of all these documents and artifacts that I was able to clarify her art form, which is her way with words. In speaking, she has a variety of sayings that she has developed that she often shares in meeting or on flyers. She also likes to write, has written more than the one poem she shared, and has aspirations of writing a book.

“ASK ME” says her license plate. “Epilepsy Advocate” says her business card. Yvonda had her first seizure at work, although it was unrecognized as such. That night she had a major grand mal seizure that resulted in two broken shoulders, a long hospital stay, and an even longer nursing home stay to recuperate. She went from being an active, independent worker, wife and mother, to a dependent person on disability, unable to drive and at times having so much trouble with seizures and the medications to treat them that “there were many, many down times when I didn't even know who I was.”

But Yvonda was not a quitter and she had prior experience with other health challenges, so she knew something about overcoming obstacles. She is a breast cancer survivor of over 30 years, having been first diagnosed at age 29. She is also a heart disease survivor. Active in both organizations that fight cancer and heart disease, her “favorite” disease, if a disease could be a “favorite,” is epilepsy, and that is the cause to which she dedicates the majority of her efforts.

Yvonda was very fortunate to have a supportive family, especially her husband, along with many friends who helped her along the way. A key photograph for her was an empty armchair (Figure 1). She tears up when she describes how if she woke up and saw her husband sitting in that chair, she knew she had had another seizure.



Figure 1. The chair.

Not everyone in her circle of family and friends was as supportive or understanding, however, and she often faced lack of understanding and negative comments about her condition.

As her condition stabilized and she regained some of the independence she had lost, including her driver's license that was finally reinstated after 12 years, Yvonda found herself wanting to reach out to others suffering from the same condition. Thus, it was about 14 years after being diagnosed with epilepsy, that she and Alice began to work together to start a support group.

Alice. Alice and I met in her home at her lonely kitchen table for our three interviews, the same table pictured in Figure 2. The one document she wanted to share was a copy of Psalm 139 which had come out blurry in her photograph. Without a close-up lens it had not been possible to get a readable photograph of the scripture. Her artifacts were her garden, which we walked through, looking at the various plants she has, some of which she had photographed, and her present car which she is now able to drive. She showed me the spot in the back yard where the car she had been unable to drive for so many years used to be parked.

From her discussions over the years about her delight in clowning, I knew that clowning was an art form for her. One of her photographs was a self-portrait of herself as a clown. When she later showed her photographs of her garden with the butterflies, I also sensed that she had a special appreciation of beauty and that the beauty of her garden was a source of joy for her.



Figure 2. Alone at the table.

Alice's story is a little bit like *Alice in Wonderland*. One day she was a nurse on a neurology floor taking care of patients with seizures and the next day she was one of them. Down the rabbit hole she went into a confusing world of uncontrollable seizures and years of ineffective treatments. And every day she would look out in back of the house at the car she could no longer drive. Nothing in the story of *Alice in Wonderland* seemed right. Both people and animals looked different than expected and acted differently than expected. And so it was with the Alice in this study. One would expect that her family would be understanding and sympathetic, but they were not. It seemed they never really understood or believed the problem she had and kept expecting her to do the things she could no longer do, such as

working. The invisible nature of the handicap (when you're not having a seizure, you appear to be just fine) may have contributed to this phenomenon. But whatever the reason, she felt alone in her struggles, alone in her home, just alone in the world. A key photograph for her was the empty table shown in Figure 2 with one place setting where she does her daily Bible study. The isolation and rejection she felt pushed her to rely more on her faith. When she felt rejected by her family, she still felt accepted and loved by God.

Several years after being diagnosed with epilepsy, Alice was diagnosed with breast cancer and went through a long series of treatments for that disease. Then on top of the side effects of the epilepsy medications, she had the added effects of chemotherapy on both brain and body which took a while to recede. She then contracted *Mycobacterium avium*, a form of avian (bird) tuberculosis that has damaged her respiratory system and leaves her chronically on antibiotics and daily breathing treatments.

However, when you meet Alice, you would never know of any of her personal or medical trials. Though very quiet, she is a perpetually cheery and smiling person.

Cary. Cary and I met in his home for the three interviews and sat at the dining room table, looking out on the back deck with his larger than life wire sculptures looking back in at us. He also showed me his studio where he has various other sculpture projects he was working on, along with his calligraphy work. He had used calligraphy to make a sign for a prior 5K walk and had also drawn and taken a photograph of a sign representing the North Carolina Eugenics Board for the original Photovoice project. I had known of his work in these two mediums of art since the time of the Photovoice project. His artistic bent was also evident in the way he staged and arranged objects for his various photographs.

Wired. That is the word I chose to describe Cary. He is wired. His short cropped whitish gray wiry hair stands straight up at varying angles almost as a symbol of the fact that he is always on high alert. As caregiver to his wife of close to 20 years, he is the hyper-vigilant protector, always on the alert for sights, sounds, or experiences that may trigger her seizures. It could be the motion of windshield wipers on a rainy day, a loud noise (even our conversation during the interviews in the dining room had to be kept low), or the flicker of fluorescent lights during a trip to the mall. At the time of the interview, he said he had seen “thousands of seizures from her just through the years” and he can tell you all about the different kinds and their manifestations. He is also an expert on the wonders of Diastat, the only medication that can stop her current grand mal seizures, which he has administered over 500 times. This medication has averted “hundreds” of trips to the emergency room. He says he would have been “crazy” without it. A key photograph for him is a ready syringe of Diastat shown in Figure 3.



Figure 3. Diastat, a lifesaver.

Although Cary is the caregiver, he has also been the one in need of care. He has several medical conditions that have hindered his own health, the after effects of an injury that crushed his hip and pelvis, narcolepsy, central apnea, and congestive heart failure. Yet he is always on guard and always on duty and has not been able to leave the house for even one night for the past three years, as of the time of our first interview. His wife's severely constricted life means that his is constricted as well, but he deals with it with a sense of grace, because he feels his difficulties are not as bad as what his wife has had to go through. She is unfortunately in the 10% of patients with epilepsy who cannot be adequately medicated and has daily seizures.

While most support groups are for the person with the condition, unless it is specifically a support group for family members, such as Al-Anon, Cary has been a consistent member of the epilepsy support group on behalf of both himself and his wife. Since she has never been able to attend, he comes for her, for himself, and for us, adding an additional perspective on life with epilepsy.

Cary was pleased with the pseudonym I suggested for him because although it could refer to his caregiver role, it immediately reminded him of Cary Grant, and he is happy to be associated with that debonair actor. In discussing how one sometimes sees something in a photograph that was not previously noticed, he said that once “someone took a picture of me and there’s like rays of light above me or something like a saint or something. I’m no saint [laughing]. But it was interesting to see that effect.” Cary is also the name of a 16th century Irish saint and many who know him would agree that his devotion to his wife is indeed saintly despite his protestations.

Eagle. Eagle and I met in her home at her dining room table, with an abundance of natural light streaming in through the windows. This was the location for our three interviews as well as the group interview once all the individual interviews had been completed. Documents and artifacts she shared were related to her life with epilepsy and other personal matters, but not specifically about Photovoice. She shared some books she had on disability and a copy of her medical records documenting her various medical conditions. She also showed me a disability article she wrote called “A Taste of a Nightmare” about another medical condition that she had, along with some of the items she had photographed for this study, the photograph of her father’s last Valentine rose for her mother, a community service

award, and a clear glass friendship ball. Another personal item she shared was a photograph of two angels that reminded her of a dear friend with a disability that she had lost.

Eagle was the one participant for whom I did not have a prior conception about a preferred art form. When I started asking about photography as art, however, she replied, “How did you know?” and revealed her actual background in graphic arts and photography. Ironically, her visual limitations had given her a special appreciation for the visual arts and for the value of light.

Eagle chose her own pseudonym, not a typical female name, but a name that had meaning to her. In her spirit, she longs to soar like an eagle, but in reality, she is confined to a very narrow world. Because of multiple chemical sensitivities, late term neurological effects of Lyme disease, photosensitivity epilepsy, and a long list of other medical conditions, her life outside her home is severely limited. Exposure to fluorescent lights can trigger seizures, so this eliminates being in most public settings. Even finding a restaurant where she can meet with the support group is a challenge.

Walking around her home itself was an illustration of how she has had to adjust her environment to accommodate her seizures. For example, she works from home where she has a custom made wall unit desk of real wood since the offgasses from composite boards and other treated wood and wood-like products cause her brain to shut down. Her desk is in the light airy dining room and whenever possible she works in natural light.

Eagle has struggled through many difficult years following abandonment by her husband after she initially became ill. Out of the poverty and despair into which she was thrust when her husband left her, she emerged with a plan and a goal: to get a professional

degree in order to help other persons with disabilities. Four years and many challenges and accommodations later, she graduated and eventually became qualified to do disability work as an attorney-mediator.

A key photograph that symbolizes her life is that of her little dog who has a heart shaped patch on his forehead and came to her on Valentine's Day (Figure 4). Although she has wonderful family support from her current husband and her mother, who also lives with them, Eagle feels a special support from her little dog, who loves unconditionally and who she feels really understands, although in an unspoken way, as he also has suffered from seizures.



Figure 4. A special dog.

“The *Eagle* has landed.” These are the words spoken by astronaut Neil Armstrong in 1969 when Apollo 11 touched down on the moon (“Apollo 11,” n.d., “Lunar Descent,” para. 9). With the bald eagle being the national symbol of the United States, this statement at the occasion of the successful lunar landing became an expression of triumph. The Eagle of this

study does not want to land triumphantly; she wants to soar triumphantly. And occasionally in her spirit, she sees herself soaring like an eagle.

The Photographs

In addition to bringing themselves and their life stories to the table, they also brought their documents, artifacts, and photographs. Documents and artifacts have already been discussed along with each of the profiles. With so many available photographs, I needed to be selective in choosing those most appropriate to represent the findings. Among the photographs I chose for inclusion in the dissertation, a few of them had identifying information that needed to be removed or modified to maintain confidentiality. Figures 7, 25, and 27 were photoshopped for this purpose.

Although only a small portion of the photographs could be included in the dissertation, I felt it would be useful to present the range and breadth of photographs taken by the participants to represent their lives with epilepsy and their Photovoice experiences. Thus, I themed the photographs into eight categories, providing descriptions of photographs pertaining to each category. Most of the photographs were of things, some were of places, and few were of people. Almost all of the photographs were of what most people would call *ordinary things* such as chairs, tables, stoves, cars, shopping malls, etc. The difference is that to these persons with epilepsy often what appears to be an ordinary thing can represent a danger, precaution, or source of emotional pain. Many of the items photographed retained the meaning of the item, such as a table where one would sit alone, or a pet dog who served as a support. Yet many others items photographed were symbols to represent feelings and situations, such as a photograph of hurdles to represent the continuing challenges of life.

Following are the eight categories along with descriptions:

1. Ordinary things of daily life at home, excluding dangers or precautions. These were photographs of household objects, memorabilia, people, and pets. Note that the fact that so many photographs were taken in the home reflects the constricted and isolated life that persons with epilepsy often experience. Example photographs were of an empty chair where a spouse would sit when his wife had had a seizure, a table with one place setting symbolizing how alone the person felt within the family, framed pictures, objects, and awards symbolic of happier moments from the past, family and friends who have been supportive, self-portraits, and pets that have been a special support.
2. Ordinary things both in the home and outside the home that represent dangers and precautions. These photographs were of things that could cause a seizure, such as the motion of a ceiling fan, or places one cannot go, such as the mall, because of the flicker of fluorescent lights and other stimuli. These photographs were also of things a person with epilepsy should not do, such as handle knives or cook on the front eye of the stove. Example photographs of seizure inducing situations were ceiling fans, windshield wipers, and shopping malls. Example photographs of things to take precautions with were knives, swimming pools, showers, stoves, and locked bathroom doors in public restrooms.
3. Signs of illness, treatment, and management. These photographs were of things representing seizures, medications, devices to prevent seizures, and emergency services that are often necessary. Example photographs were of a spouse in bed,

various collections of epilepsy medications, the scar where a VNS was implanted, the wand for activating the VNS, a syringe of Diastat (an emergency seizure medication), a phone on the counter with a hand drawn 911 sign next to it, ambulances, hospital exit signs at night, and emergency hospital entrances.

4. Symbols of the constricted life. These photographs were of ordinary household objects used to symbolize loneliness and isolation, along with other photographic reminders of the challenges of daily life for someone who has epilepsy. Example photographs were hurdles, metal railings that look like prison bars, a tangle of weights in a corner, lights narrowing to a pinpoint, a room divider signifying separation from others, a car in the back yard that cannot be driven, and busses that someone who cannot drive might need to use for transportation.

5. Stigmas and barriers imposed by society. These photographs were of institutions that symbolized the stigma of seizures and their connection in many people's minds with mental deficiency and the power of state agencies and organizations to significantly affect one's life. Example photographs were mental hospitals, photo ID cards instead of driver's licenses, the Department of Motor Vehicles (DMV) office door, the glare of lights one might be under when applying for driver's license reinstatement, and a handmade sign for the North Carolina Eugenics Board, reminding us of how persons with epilepsy were treated in the past.

6. Places of pain, places of triumph. These were photographs of places that were a reminder of bad experiences from the past, either personally or for other persons with disabilities; yet some of these same places came to acquire a more positive meaning

in retrospect. Example photographs were a medical center, the meeting place where the Photovoice project was conducted, historic markers for the North Carolina Eugenics Board that no longer exists, disability laws books someone can now use to help others, and the university campus where Photovoice results were presented.

7. New options and opportunities. These were photographs of an improved quality of life or new opportunities that occurred with health changes or following the Photovoice experience. Example photographs were a car that can now be driven, someone sitting in the car with keys and a driver's license, a trunk full of groceries now that one can now drive to get, a stove that one can now cook on, a graduation photograph, a driver's license plate promoting advocacy, epilepsy education brochures, and a front yard garden that one now has the motivation and interest to cultivate.

8. Light and thumbs. These were a variety of photographs of light, along with some photographs with quality issues. Examples were photographs of indoor lights, outdoor lights, objects with reflected light, barren trees outlined against the sky, the sun shining in and through clouds, and the sun shining without clouds. There were also several photographs with thumbs obscuring the view, either because of trying to use the camera without having a seizure or just the occasional problem of one's thumb getting in the way.

The Group Story

Because my research methodology was narrative inquiry, my focus was on stories. Thus, although I did an initial coding using some a priori codes, and added codes that

emerged from the data, my actual goal was to find the stories and the themes that emerged from the stories. For example, all the participants experienced losses due to the onset of epilepsy in their lives. These could be varyingly coded as loss of job, loss of income, loss of relationships, loss of mobility, loss of independence, loss of identify. These codes could then be grouped together under the theme of Grief and Loss. From a narrative perspective, however, it seemed more appropriate to identify stories rather than statements of loss and to note themes across stories.

Stories identified from the first interview on stories of life with epilepsy were about loss, isolation, perseverance, and new directions. Each participant experienced these types of stories to some degree, perhaps more of one type than another, depending on the individual. But they were all “knocked off course,” so to speak, by the onset of epilepsy and began to find a new way of being over time. Since each person’s life with epilepsy story was different, with one of the participants having a combined story of his caregiving role and his wife’s epilepsy, it would be difficult to make one single story out of all the variations. So to express the overall essence of their lives with epilepsy, I have chosen to paraphrase and generalize the varied experiences in order to communicate one unified expression and set the stage for the addition of the Photovoice research experience to their fractured lives. The following free verse poem “My Life with Epilepsy – The Unfinished Story” provides this summary.

My Life with Epilepsy – The Unfinished Story

I had a life and it was a good life. It wasn't a great life or a perfect life, but it was *my* life. I was married and had a career and satisfying relationships with friends and family.

And then one day it all changed.

I had a seizure, and then another, and another and it wouldn't stop. It didn't matter where I was. I couldn't stop it and the doctors couldn't stop it. My life was out of control. It was confusing and disorienting. I was injured, body, mind, and spirit.

Why this? Why me?

It wasn't just one isolated seizure from a known source. Like a child with a febrile seizure. Stop the fever and stop the seizure. It was epilepsy and it jumped into my life and disrupted everything.

The seizures left me foggy-brained. The medications left me foggy-brained.

I couldn't do for myself. I couldn't go where I wanted to go when I wanted to go. I couldn't work. I couldn't drive. *Sometimes I didn't even know who I was.*

And worst of all, it was invisible. If I broke a leg, people would give me sympathy.

But between seizures, no one could see the "it."

So maybe I didn't really have a problem. Maybe I just didn't want to work or take care of the house. Maybe there wasn't really anything wrong with me.

Get over it, they said.

But worse than the worst, it was scary and threatening. Specters from ancient history. Myths and misconceptions. Did I have supernatural powers? Or was I doomed by some great unknown sin?

Don't tell the neighbors. Don't tell the family. Don't tell anyone! Keep the secret. So much stigma and so much shame.

The truth is, I wouldn't have gone anywhere even if I could have gone.

Some left me alone. Some abandoned me. And even when I was with others, I was still alone, because no one really knew what it was like.

It's not as though epilepsy is a popular disease...like high blood pressure or toe fungus.

I lost my moorings. Adrift in an unfriendly sea. Or marooned on a lonely island. Or stuck in a long earthquake where the shaking ground never stops.

And no one understood.

Well I could have given up. I thought of it. But I didn't.

I kept living one way or another. Try this, try that. Maybe a little better. Maybe a little worse. Days became weeks; then months and years. If I hold on long enough, maybe something will work for me. A new medicine. A surgery. Something.

Perhaps one of the good things about a good but not perfect life was that I had endured some difficulties in the past. Maybe I could get through this. Maybe what worked

for someone else would work for me. Or maybe I would be the one to find something new
that worked just for me.

They say there are no atheists in foxholes. I'm glad I already wasn't one before I fell
into *this* hole. My faith sustained me, kept me going on the darkest days. Just the smallest
glimmer of hope could lift me up. A verse of scripture, a little prop to my sagging spirit.

Some little bright moment or event in a day.

Then, after a while, out of all the things I couldn't do, there were things I could do. I
could make others laugh; I could make a beautiful object; I could reach out to someone who
had just started the struggle; I could be a voice to those with less of a voice than even I had.

Timid steps at first in new directions, then more boldly pursuing new dreams and ideas. I
can't do this, but I can do this. It seemed my body crumbled daily but my spirit
soared.

Or if it didn't soar, I could always hope it would.

The title of the poem is "My Life with Epilepsy – The Unfinished Story" because it
represents the story of the support group members at a particular point in time. This is who
they were when presented with the option and opportunity to participate in a Photovoice
research project. Who they were and where they were in their individual epilepsy journeys
affected their decisions to participate and their subsequent experiences and outcomes
resulting from participation. *What They Found at the Table* is thus the next section of the
research story.

What They Found at the Table

I photographed ordinary objects, but in Photovoice they had an entirely different meaning.

– Cary

This section presents three findings related to the first research question: What are the experiences of individuals participating in a Photovoice research project aimed at social change? These findings arise from the reported experiences of the participants from their decisions to participate through project completion and also include reactions to a subsequent presentation of the project to a group of medical students. Since the experience was a choice (unlike the illness), the experience only occurred because each individual chose to participate. Therefore the decision to participate is included as part of the research experience. In a similar manner, since the ultimate purpose of Photovoice is to present the findings to policymakers and others with the goal of creating social change, the presentation to the medical students is also included as part of the total research experience. Although the presentation to the medical students took place months after the completion of the project, it was a very significant experience for the participants and represented the completion of the Photovoice process.

The previous section began with the context of the support group before proceeding to participant profiles. This section begins with the context of the research before proceeding to the findings.

Research Context

At the time of the original Photovoice research project, I had been working with the WEST for about a year. The group was still in its formative stages, but had a small core of

regular attendees. The Photovoice research project was conducted as described in Appendix A, *Photovoice Research Process Outline and Narrative*, with four of the original support group members. It seemed that every few months after the Photovoice project, a recollection about Photovoice would come up in conversation either among the group members, or in discussion with new members. It was very gratifying to finally be able to follow up on these informal comments in the form of this dissertation research that looked back on the experience and its meaning to the participants. The initial meeting to describe the Photovoice study and obtain informed consent had been at the public library, but by the time we began to meet to discuss the photographs, we were meeting at a local restaurant with a private dining room, since scheduling at the library had become too difficult. This setting remained as the location for our weekly support group meetings. A photograph of “where we started our project” shown in Figure 5, was important to Yvonda.



Figure 5. The meeting place.

Finding 1: Choices and Challenges

You've got to go through the rough edges to get to the smooth part. – Yvonda

The Photovoice research experience began with the choice to become involved in the project and was followed by a variety of challenges as participants began to understand and adapt to the research process. Early challenges eventually led to progress and a commitment to continue. Once engaged in the research process, the research experience itself became a challenge as the unexpected strength of painful memories and emotions threatened to outweigh the potential benefits of the study. For each of the following sections, I discuss the problems and then the progress.

Research process. In order to participate in the Photovoice research project, the participants had to make a decision to participate. This decision was primarily affected by prior research experience, prior experience with photography, and understanding of the purpose and value of the research. Aspects of the process which became potential problems once participants were engaged in the research process were technology, understanding of the SHOWeD technique of analyzing photographs (Wang et al., 2004), which will be discussed in the section *Understanding the SHOWeD Technique*, and a role conflict that led to a difficult decision for the group leader.

Deciding to participate. The decision to participate was a different process for each person. The process was influenced by their familiarity with research studies in general, their comfort in taking photographs, and their understanding of what this particular study entailed.

Prior research experience. Three of the four study participants had prior research experience and all of them understood the importance and benefits of research. Cary had been involved in a longitudinal Alumni Heart Study for about 20 years that was mostly survey research. He felt that his prior experience made him more willing to participate in this study because “these things are useful. I used to be involved in them when I was a graduate student in Sociology a hundred years ago.”

“Oh yes. I had been involved in a research program before,” offered Yvonda. It was a breast cancer study looking at family history since she was a breast cancer survivor. Between the time of the Photovoice project and the interviews for this study, she had also participated in a lupus study, but had declined participation in a randomized clinical trial that her physician offered. “I never chose to do that because I wanted to know what I was taking.”

Alice had been in a breast cancer study testing various chemotherapy drugs during her treatment process. In that study, she had been in the control group. More recently, she had been in an epilepsy clinical trial where she eventually realized she was on the experimental drug due to “very many reactions” that necessitated lowering the dose of her other medication. It was near the end of the Photovoice project that her seizures finally stopped and she has been seizure free on the once experimental, now approved, medication ever since.

Eagle knew other people who were in research studies and said that “they were doing some research studies when I first got sick, but I don’t know if they used any of my blood in any of that or not.” Because of her numerous medical problems and history of adverse reactions, she felt she would probably not have been a good candidate for an interventional study. However, she understood the importance of such research to advance knowledge and treatment options and was very willing to participate in this study that did not include experimental medications or treatments.

Prior photography experience. The participants’ prior photography experience ranged from having a collection of photographs taken by others to having taken photography courses. Eagle had a significant amount of prior photography experience. Because she was legally blind in one eye, her fifth grade teacher had suggested she go into art to learn how to compensate for lack of depth perception. She found that she greatly enjoyed art, so later in community college she earned her Associate Degree in Graphic Arts and Advertising Design. She described her experiences as follows:

We had two photography classes there where they taught us...and I loved photography because it was like...with the vision I had, it was a *whole new way of seeing*. And so I worked with black and white and we worked with this...the old 35 mm cameras and I did I think a couple of color slide things and I...had a dark room so I worked with some of those chemicals....So...if you just have vision in one eye, it kind of gives you [laughing]...like a picture of that. Not mono – monocular picture anyway. So they taught you how to...what you were thinking about you could focus in on it. Plus I had a creative problem solving class and that taught me...kind of how to mix that in with...looking at things. And they taught you how to frame something in a...an art piece that...where you had the most impact on what you wanted...to say...and that was all before I got sick. [laughing]...I won...an honorable mention with a photograph that I did during college....It was my dad's last roses to my mom...[showing me the photograph seen in Figure 6].



Figure 6. Last roses.

Since her college experience, Eagle maintained her interest in art and photography but never worked in the field professionally. She took family photographs and would also photograph drawings and other art work she had done.

Alice said she always took a lot of photographs “especially when we were on vacation. Probably too many...[laughing]” and that she was basically the family photographer. She has photographs of children, grandchildren, and pets and on holidays would “always take pictures of the parents and my sisters....We have a big get-together on Thanksgiving and we have about 60 people there.”

Cary, always self-deprecating, said that he always took a lot of photographs but “I was a lousy photographer and not smart enough to use a digital camera.” He would carry a

camera with him in case he saw something he wanted to photograph. “I’m not very... accomplished technically but I can...take a picture.”

Yvonda, in contrast to the others, always had a flash camera, but did not take a lot of photographs herself. The large collection of photographs she has were taken by other people, part of the reason being “because my husband was ...he never says ‘I’m disabled,’ because he was vision impaired.” She was also influenced not to take photographs because their family home had burned down and her mother said what hurt her the most was that she “lost all our pictures. And...I think it kind of made it a negative thing for me because I was afraid I would lose my pictures.” So because of this fear, she ended up just not taking photographs even though she liked having them.

Understanding the purpose and value of the research. Eagle understood the purpose of the research immediately and was very articulate about what she thought about it.

[Ever] since I had this illness, it just seems like *it tries to take your voice away* and isolate you and it was really important. I just saw this [Photovoice] as a tool because I’m really big as far as advocacy...for other people with disabilities and it gives you a voice to do that. Especially for the audience that’s viewing it if it’s in a research setting or medical setting...a social worker, whoever, whatever views this. I think it’s really important that they know they have a visual picture of what people are going through and you never know how things will filter down.

Because she understood the purpose of the research, she decided she “wanted to be a part of it.” She continued her description of why she decided to participate.

Plus I respected the people I was working with and I felt comfortable enough to...to be able to share in...in the context that we were in, just...and I also felt supported and it felt like something we could all do together to make a difference.

Cary thought the project would be a helpful and informative in addition to the “obvious” value of using photographs.

Oh, it sounded like a good idea for many obvious reasons. A picture’s worth a thousand words, of course, and when you are deciding which pictures to take, you think about things that you would not have thought about necessarily otherwise.

When you’ve taken the picture and look at the picture, sometimes you see things that you didn’t see when you took the picture. Sometimes it’s almost like *revelation*. You see something in the finished picture that you didn’t see at the time and you’re amazed....And so the project sounded interesting from the beginning, and so I was ready and willing to do it. And I thought it would be helpful. I knew it would be helpful...I knew it would be to caregivers, to people with epilepsy, to people who are none of the above so that they can understand a life with epilepsy better because many people have never seen a seizure, don’t know anyone with epilepsy. They actually do but they don’t know.

Alice stated very simply, “It was just something that I wanted to do...I thought ...very interesting...Photovoice was very...I thought very uplifting and something I wanted to do...it was like it was something that would help people.”

In contrast to the other three, Yvonda was cautious about the decision to participate. “I’d never heard of Photovoice. It sounded like Greek to me.” Because she was also the leader of the group, she was in a dual role of being both leader and member and felt a very strong responsibility for the welfare of the group. The support group was in the early stages of development and she did not want to do anything that would jeopardize its success.

And I really didn’t want to...we were a group...new group starting out and I didn’t want to put us in something that we may not benefit from or for the fact that we ...that would cause us to regress.

In the end, her main reason for agreeing to participate was because of me, since I had been working with them as an advisor and she saw me as a “faithful person” coming to their meetings.

I saw you reaching out to us and I wanted to return that favor to you. That was the main reason...I know that I didn’t know where we were going but I was willing to...because it was you, I was willing to get on board.

It was only later that she began to value the Photovoice research experience and see its benefits to the group and beyond.

It was one of the greater experiences that I’ve had with epilepsy and I hope that it’s something that we can continue to do in some way....As I listened to the group...being excited about it, they gained so much from it too.

While Yvonda had initial reservations about participating in the Photovoice project, due at least partly to her leadership role with the group, the others had a more immediate

positive response to the opportunity. In the end, they were all very enthused about having been involved with Photovoice.

Adapting to the process. Once the participants had made the decision to enter the research process, there were still some initial adjustments to be made. These adjustments related to use of technology, the technique for analysis of photographs, and the perceived attitudes of one of the researchers.

A problem with technology. When the Photovoice process was initially developed, disposable cameras were chosen as the instrument because it was felt that they could be used by almost anyone anywhere in the world. Both the cost and the ease of operation were factors in this decision. Yet even the point and shoot simplicity of a disposable camera proved to be a problem for one of the participants. Eagle, who had studied photography in the past, became unable to use a camera with manual settings after she started having seizures, late stage Lyme disease, and multiple chemical sensitivities that all affected brain processing. “Yeah...I started having the difficulty after I got sick...I couldn’t multitask so I couldn’t...use the [regular] manual one....I could not respond quickly enough to get the subjects and stuff.”

She had not expected to have any problems using a disposable camera, but the flickering red light of the flash was a problem for her because of her photosensitivity epilepsy. The only way she could take a photograph without being at risk for a seizure was to try to cover the flashing light with her thumb while taking the photograph. “Then the one you gave me, there’s not a lot...you don’t have to do anything but push. Now, I will say there’s a

flickering light on there that I had to cover up to take my pictures.” We had a lengthy discussion about the design of the camera and the thumb problem.

That’s a no-no, a big no-no in photography. You don’t stick your thumb in front of...[laughing]. That’s not normally what I would have a problem with...I think of strobe lights and I think I learned about the visual...visual fire alarms, they trigger it but I didn’t think about [laughing] the little camera [light] right in the field of vision. If that was on the other side, it wouldn’t bother me ‘cause I wouldn’t be looking at it.

She explained the problem as follows:

Anyway I see out of this eye...my vision that’s left, so I had to cover up my...put my thumb on that light and then still try to look through the viewfinder and then [laughing] anyway, that was...that side. You know, when it’s flickering up that way it wasn’t bothering me but it was flickering right in my eye.

Covering the flickering light with her thumb was a temporary fix and helped most of the photographs to turn out without the intrusive thumb. Still, it was a problem for her and something to consider in working with people with this kind of seizure. Figure 7 is one of the photographs taken for this study that illustrates her problem, a sharp contrast to the photograph of roses in Figure 6 that was taken years earlier before her seizures and other problems began.



Figure 7. Cover the flicker.

Although Yvonda had no difficulty with the cameras in the Photovoice project, she seemed to be having difficulty for this study. During the consent session, I reviewed operation of the camera in detail, but later she said she was having problems with it. I just took it back and gave her another one since there was a possibility it was defective. I also helped her stage some of the photographs that were taken during and after our interview times.

Understanding the SHOWeD technique. Analysis of photographs taken for a Photovoice research project is done in a particular manner and in a particular order. The technique is called the SHOWeD technique (Wang et al., 2004) and involves five different steps to discuss each photograph, as shown in Figure 8. The process starts with a purely

objective question, “What do you **See** here?” and progresses through the other questions to elicit analysis, application, and promotion of activism. This is the way each selected photograph is discussed by the group during the Photovoice process.

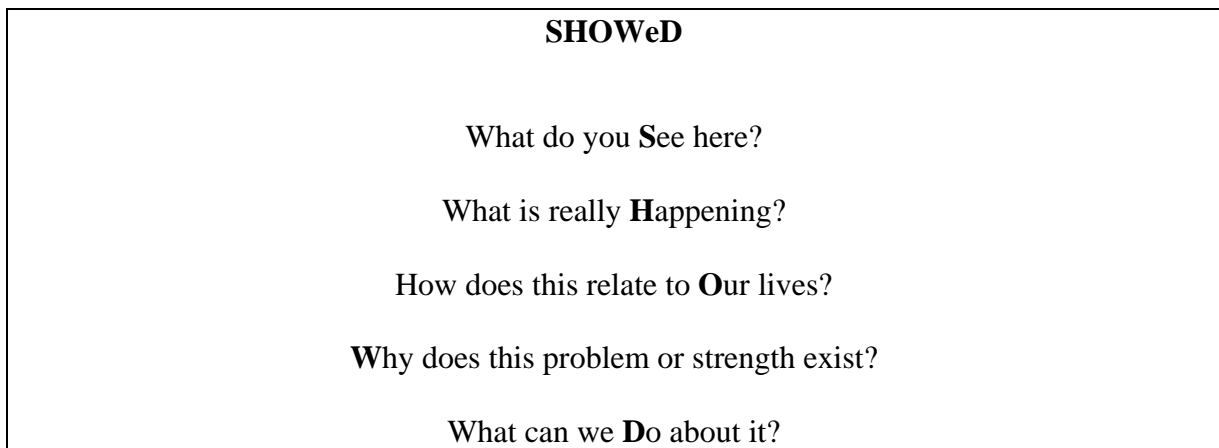


Figure 8. The SHOWeD technique.

I recall this process of analysis being particularly challenging for some members of the group during the Photovoice project. Part of the reason may have been that participants were so excited to be able to present and discuss their photographs that they wanted to get right to the meaning of each one and skip the prior steps. However, I also believe that this may have been conceptually difficult for some of them. After three rounds of discussing photographs, they certainly became better able to use the SHOWeD technique. Yet difficulty with understanding the purpose of each step and how to do it was still evident during the group interview for this study where we used the SHOWeD technique on one particular photograph that seemed to summarize the Photovoice research experience.

In addition, the need to use the technique appropriately led to some tension between one of the researchers and the respondents. This is discussed in the next section.

A conflicted choice. Yvonda had some particularly negative memories of the Photovoice project due to her perception of how one of the two other researchers treated her and other members of the group. She felt that the researcher was not sensitive enough or sufficiently aware of the epilepsy brain and its limitations in comprehension, memory, and reaction time due to the condition itself or the effects of the medications. She revealed that she felt so strongly about this negative experience that she had considered dropping out of the study. “There was a couple of times that I wanted to hang up....I probably was as...as upset probably more than anyone else because I was not only thinking about me, I was thinking about the group.”

One of her photographs of the research experience depicted this feeling by showing members of the group walking out the door of the actual room where the project had been conducted (Figure 9).



Figure 9. Leaving.

Yvonda and I discussed her feelings at length both during the interview and at a time when she asked me to turn off the tape recorder. I understood that she felt demeaned during the Photovoice project because she felt that one of the researchers was pushing them hard to follow the SHOWeD technique exactly. I remember that incident from the research although I had no idea until the time of the interview that Yvonda had felt so strongly about it and had even considered leaving the project. I saw it as a conflict between the research agenda and the needs of the participants; that is, the researcher wanted to proceed on the project, follow the protocol, and get things done in a timely manner. Yet Yvonda felt that they were being asked to do things that they really could not do at the speed they were being asked to do them.

Sometimes things would be said and it wasn't because I was illiterate or anything. It's because you have epilepsy and that was one of the things that the young lady that was with you gave me the impression that she thought we were illiterate....Because you don't...because you don't respond. I may not respond to everything you say at the moment you [ask]...And we may have responded slowly or we may not have responded in the order that it should have been.

We both remembered when she spoke up and said "We have epilepsy." We also discussed the fact that it seemed ironic that in a research project trying to combat stigma that she as a participant felt that a researcher was putting stigma on her.

In the end, she decided not to withdraw, as her commitment to the group overruled her personal feelings. This is because she saw the positive experiences that other group members were having and the potential benefit beyond the group.

Yes. Yes, I did [think about leaving] but I had to think about more than me. I had to think, "Yvonda, this is a group that you want to...get going and there are a lot of people that may be depending on this" so I couldn't just think about myself at that time....And I felt being the leader of the group, I needed to say what I felt. But as we were getting into it, I saw it was something that we could grow from, we could learn from...and I thought at that point, "Well we've helped someone else".... As I listened to the group...being excited about it, they gained so much from it too.

This was a deeply emotional incident for her and she had many feelings to work through. She felt bad that what she took as stigmatization and criticisms affected her so deeply because of memories of other past hurts, but she also eventually came to see the

situation in a more positive light and felt better equipped to deal with similar situations in the future.

There were a couple of times when I was in tears and I was in tears and I don't think that I would let it do it then...I was hurt because I did regress. I didn't know that those feelings were still there so I did have to go beyond those feelings again but I had to reach the point where I can say, "Oh well they didn't know any better." And for me, I had to realize that as I said, that this is not what I...this is not who I am. If I said ten times, that's what I had to learn from it myself...I would have to evaluate me as it turning out to be a positive thing for me because I think I had suppressed some of the feelings and when I was first able to talk about 'em, I think some of it I think because of the criticism. But even now I think I could take some of the criticisms because I would know how to brush them off even better...I wouldn't let it affect me like I don't think I would let it affect me like it did.

In reflecting further on the incident, Yvonda took on a more philosophical and less personal view of the situation and was able to be more gracious about the researcher whom she felt lacked understanding.

I think the positive part about that I had...that I had to realize is that...that everyone don't understand and even though they may be doing this project, that they don't understand that this is a situation that is sensitive to us. But I had to rise above that in order to...to continue to be in a positive...in a positive way. Not suppress my feelings. I think I need to talk about 'em. I think I could talk about 'em in a positive...more positive way. I could say, "Hmm, they don't know any better."

Once participants had worked through the adaptations to the process by dealing with a flickering camera, trying to learn an analytic technique for discussing photographs, and working through negative feelings of being stigmatized, they still had more challenges to face. These were from the early stages of the research experience itself as they shared photographs and discussed the stories behind them.

Research experience. Even when there are no expected physical health risks to a research study, psychological effects are often a possibility. To alert potential study participants of this possibility, the following statement was in the RISKS section of the *Informed Consent Form for Research* (Appendix B):

Recalling and talking about your Photovoice research experience may bring up memories or feelings related to epilepsy and its effects that you find discomforting. You will have the option during the interviews of ceasing to talk about any subject that you find particularly distressing.

The participants all read and signed this consent before beginning the interview process. However, the extent to which their memories would challenge them did not become apparent until they began to talk about their photographs in the first group meeting of the Photovoice project.

Painful memories, difficult emotions. At the first Photovoice meeting after the first round of photographs had been developed, participants had the opportunity to share and discuss the photographs they had taken. This process was repeated two more times with additional sets of photographs. Looking back on that process in the interviews for this study, participants revealed the largely unexpected challenges they faced as painful memories

surfaced. Yvonda especially said that there were many things from the past she thought she had gotten over, but when she went to take photographs symbolizing those past events and started to talk about them, she realized that the past was very present. This was an upsetting experience for her as she had to remember and review past hurts all over again. “I had to relive a lot of...of the agony that had happened.” She continued,

It was the photographs were...photographs really took me back....Even this morning when I woke up and my husband was sitting at the foot of the bed, I don't know what it was. It was just...it was just something about it. And that couch...and that chair.

[Shown in Figure 1.] I guess that's why we won't get rid of the raggedy thing but....Truly, I believe probably I regress more than anyone....Reliving....I was upset that I was upset but I was upset because I feel like I was reliving what had happened.

In another example, Yvonda also clarified how taking photographs illustrating precautions for epilepsy patients, such as for cooking on a stove (Figure 10), was also painful to remember.

What I was saying to you was when I took the picture knowing that, that took me back to a time when I had the seizure and it was traumatizing for me of the things that I couldn't do....When I took that picture...it made me think about “Oh I could have a seizure at the stove,” because that was the purpose of it....[And] when I saw the pictures, it made me think that, “Oh I could have fallen on that stove. I could have scald myself.”... Yes, I did know I wasn't supposed to do it but it still was traumatizing and...I cook anywhere I want to now, front, back, anywhere, but when I looked at those pictures, that took me back. There was a time when I wasn't supposed

to do that. As I say, I'm still not supposed to do that but it was just reliving what I knew I was not supposed to do, if that makes any sense to you....



Figure 10. Precautions with a stove.

In response to a question about changes observed in others, Eagle also recalled Yvonda's distress over memories of the past, yet it was less of a problem for her because she felt she had already worked through those things.

I did see one of the participants become more emotional as far as the sadness just reflecting over the losses....I think maybe it telescoped it all into one thing for her. What balanced that out for me, I mean I'd already pretty much knew all that, [laughing] but was just being able to put a...have sort of a mission with it and

that's...when you put things in that context, or doing something positive with a negative.

Eagle acknowledged feeling emotional pain as well, but she had already worked through many of the issues in her own mind. "I mean there were times it was painful to think about some things that happened, but I was already dealing with that anyway." She realized the healing benefit to herself and others of telling stories and using cognitive methods to see things as "half full" rather than "half empty."

Alice recalled that some of her photographs made her feel sad and others made her angry. At the time of the Photovoice project, she had been unable to drive for 14 years, so one of her photographs that made her both sad and angry was of her car sitting in the backyard (Figure 11).



Figure 11. The undriven car.

In addition, her lack of family support left her feeling alone and isolated. Her photograph to express that was of a single place setting at the kitchen table (Figure 2). “I was angry about...let’s see. I think...I took a picture of the table with one place mat. That was a little anger too and sad and alone.”

Cary said that he did not have negative reactions to taking the photographs because “anything I remembered in the past, it wasn’t new and wasn’t...no, there was no...no problem like that at all.” He did however emphasize the lasting impact of the photographs in general which caused him to remember the pain that others experienced, “Like that ID card,

I...I think of that a lot. And yes, some of the pictures are sort of *burned into my brain forever*. Like the eugenics thing.”

In our discussion of the resurfacing of painful memories, Yvonda brought up an incident regarding someone who had been to the group several times but no longer attended. She connected it with the Photovoice project by saying that in a support group, painful topics may be discussed and not everyone is able to handle them.

I even saw that in Brian, and when his mother said, “I hate so much that he doesn’t come back to the group,” but I saw exactly what she was saying is...is that reliving it is just not a pretty thing.

The participants felt that once they dealt with the painful memories and difficult emotions that arose, they would be better able to deal with them in the future, and that overall the positives of the Photovoice experience outweighed the negatives. The next finding continues the story of painful memories as it discusses how participants worked through and resolved painful memories to emerge from the process having experienced growth and learning.

Finding 2: Growth and Learning

But for me, reliving it, it was not a pretty thing but I learned this is what the group goes through. But that was part of growth too. – Yvonda

The *Choices and Challenges* section described the process of how participants decided to participate in the research, challenges they had adapting to the research process, and the initial negative reactions to past hurtful memories that emerged. This was just the

beginning of what they found at the table. They may not have liked the appetizers, but the main course was about to begin, and with it a rich feast of experience.

Participants detailed a variety of experiences during the Photovoice project that promoted and enhanced personal growth and learning. Areas of growth will be discussed first, followed by dimensions of learning.

Areas of growth. Five areas of personal growth were identified during data analysis: emotional, social, artistic, spiritual, and intellectual. These areas have some overlap; for example, artistic growth could have a spiritual component. However, this categorization is helpful for the purposes of discussion and grouping similar incidents and accounts.

Emotional. The emergence of painful memories and difficult emotions as participants began to share photographs and stories could have caused them to withdraw from the project or to shut down emotionally and not deal with their feelings. Fortunately, neither of these things occurred, and participants persevered to work through the challenges and emerge feeling triumphant. With increased emotional strength, they became better able to continue the lifelong challenge of living with a chronic illness. Yvonda and Alice spoke the most about the emotional aspects of the experience.

Yvonda gave a great deal of thought to why she “regressed” as she put it, what it meant, and how she got through it. For her, the experience “really did bring back a whole lot of feelings that I thought were dead” and that was what was so difficult for her. She further explained how the process of reliving the past eventually ended as a positive outcome for her.

I would think that it helped me to capture some of my sensitivities and to...to be more aware that they are there, but that my projection is that I have passed that. And even

though I relived it, I know you can't go forward until you know where you've come from.

Alice also found a way to deal with memories that brought up difficult emotions as the project progressed. While Yvonda's resolution of painful memories had to do with the confidence that she could react differently to a similar situation in the future, Alice's resolution had more to do with breaking through the self-described denial she had been in for so long. Alice felt that she did not tend to think about things saying, "I think I stuff things a lot. And I know that's not good." She felt that the Photovoice project forced her to deal with issues she had been avoiding.

It helped me realize what my life was like, what it's been like....[I] think I didn't realize, like I said, how much things...how many things I don't think about, talk about and it brought out a lot of feelings like that from that. Photovoice brought out a lot of feelings, a lot of knowledge that I hadn't thought about before. Knowledge of the way I was feeling and...and I'm thankful for that. I was just thinking, "This is really like it is and was" and a lot of times we're in denial about things I think sometimes and it was just....I think it was very helpful for things like that...It was very, very beneficial. Yes, because it helped me, like I said, get in touch with my feelings and my...things I hadn't realized that were...that I felt.

Her emotional growth as she became better able to face things as they were also ties in with *Learning About Oneself* and will be discussed in greater detail in that section.

Social. While the focus of this study was on possible individual effects of Photovoice research participation, the individual effects became intermingled with group effects because

the individual participants were part of an ongoing support group in the early phases of formation. In addition, the research was conducted in a group setting where each individual participant discussed photographs and stories and interacted with other members of the group during these discussions. When the group had to pick one photograph to discuss in depth, members had to work together to both choose and discuss the photograph. Because Yvonda was the leader of the group, she probably had the most to say about the social aspect of growth. She explained how every time a new person participates in the support group, whether in a regular meeting or while having outside researchers work with them, new things arise that people have to deal with. In the case of Brian, discussed earlier, hearing the epilepsy stories of others was more than he could handle at the particular place he was in his own journey, so he stopped coming. With the incidents she experienced feeling stigmatized and also remembering past hurtful experiences of life with epilepsy, she felt it was all part of what a group goes through developmentally.

...it was not a pretty thing but I learned this is what the group goes through....Reliving was growth because you've got to know where you came from before you know where you're going.

Eagle commented that the Photovoice project helped accelerate the learning about each other and particularly to connect with Cary's wife who was unable to attend due to her condition. The project helped her to better understand his situation and get to know his wife in absentia.

We heard more about everyday lives in a little capsule that really brought it out...in the pictures. 'Cause like...I hadn't seen your wife, I hadn't got that privilege and

so...when I got to see her picture and her in the bed and...that...for me, that...I'm a visual learner so it helped me connect with the words, both of those together.

The Photovoice project also provided a forum for a depth of sharing that was beyond the way most support groups normally function. According to Yvonda, it provided an unusual experience that would not have happened otherwise, especially without the photographs, because "as many epilepsy meetings I've been in, I've never known anybody to talk about it like that."

The interactive group process promoted by the Photovoice project helped to form a cohesive supportive group that continues to this day. Eagle summarized her feelings about the group, linking its social and spiritual aspects, during the final group interview. "I think God anointed this group to come together anyway because everybody had their own part in this group but yet they became one."

Artistic. Because consents would have to be obtained from anyone whose photograph was taken for the Photovoice project, participants were both encouraged and motivated to take photographs not involving people. While several of them took photographs of family members who were supportive, the only other photograph of a person was of one of the researchers. This meant that participants had to find ways to photograph non-humans (i.e. pets) or inanimate objects to express the stories they wanted to tell. This in turn meant that they had to be more creative in determining the content and composition of photographs.

Cary was very aware of the artistic aspects of taking photographs and felt that it enhanced the storytelling process.

I have a story to tell and I can tell it face to face or in a group. I think everyone does...either who has epilepsy or is a caretaker or caregiver to someone that has it. And...my story I can tell...Photovoice can tell it to many more people potentially.

When he described his photographs, he talked about how he chose the topics, what he had to do to take the photographs, what the challenges were, and how he framed the items in the photographs.

You know I'm the most amateur photographer. I compose. My wife says it takes me...fifteen minutes to take a picture. I compose...the thing. I...I crop the thing. You can do it with...the computer if you're set up to do it, but I wasn't so I sort of was cropping it by how far away I was, how close I was, what I wanted...I wanted to get extraneous things out of the photograph. *I didn't want to photograph any recognizable people because I didn't want to go have them sign the form.*

[laughing]....So they were either like unrecognizable or...but mostly there weren't people in them. Yeah. And...what else? Well I took several pictures of a theme, like in the mall. I just wanted...to get several pictures so I could choose the best one, sort of, for its purpose, what I wanted to show. And like you could say artistically, I didn't want my thumb over the thing, as an example, which I sometimes do. So I just wanted to choose the best picture and the...the one that was...had the imp...had the most impact that I wanted it to have. So I did a lot of thinking about my pictures that I took. It took me, oh I didn't just go take 'em in half an hour. I took them...in some I had to wait until the right time. Like my photographs that I took...the last photographs over at [the medical center]. I wanted to show a bus and a bus stop but I

wanted to show it with no people in it. And the bus was stopped there and you couldn't see any people and the bus said [medical center] and there was a bus stop and that sort of conveyed a lot about how a lot of people with epilepsy can't drive and how...so they need other means to get around.

Eagle spoke in praise of the value of photography as art to “*vocalize what you were seeing.*” She stated that “*Photographs is an art form not usually combined with the words,*” but the “*words added to the photos...painted that picture.*” She saw the value of the arts for promoting disability awareness and spoke of several examples she was aware of including giving cameras to children who had experienced traumatic life events, a tactile art project at the university hospital eye center, and a disability group that used drama and had performed at the Kennedy Center. She explained that “the emphasis on that as an art form is empowering to the folks that probably take the pictures too, once they've done it. But it's a combination of voice and pictures I think.”

She also recognized the effect of needing to take non-human photographs, as Cary had discussed, but her perspective was that of the use of symbols to convey meaning.

Yeah. And the symbolism is real important...in art or whatever. I think symbols...are ways that will...well in the Christian world, Christ related to people through...parables and there were a lot of symbols in there that people could relate to. *So when you're painting a picture of a feeling that someone else has not experienced, you have those symbols and those ways that they can say, “Oh this is like that.”* I've had that experience. So it's the transition really...and as far as a process of *education*, it's the transition point 'cause you're helping them to identify and see that picture that

you're painting for them that's not a visible thing always, unless you're there...in their environment.

She concluded by summarizing the range of art forms and the connection with Photovoice.

So I think that's...and that's...art has a lot of different forms. It has word, it has speech, it has drama, it has photography, it has... You've just got all types of ways of expressing it and there's multimedia so...[laughing] the voice and the...and the photo...graphic experience were both...both great.

She was also very articulate about the use of photographic images to represent and convey feelings.

And I...just suggestions when you're making creative suggestions...you can think about things outside. You can think about things inside. You can think about...once you think about your feelings....Then just find something maybe to symbolize that, maybe something actually that does. And like the table in our house or just...the things like when I went to the op...my optician's place....From the outside...you could see all that reflected all at one time. And I wasn't expecting it to be, it was just there....So sometimes things will just be there and you're just in the moment and you just get 'em. [laughing] You know, it just all comes together and all the pictures aren't always gonna be what you want to say but don't get down on yourself about that. Just...keep...keep looking for the next. Just let yourself brainstorm....And brainstorming, there's no rights or wrongs so...you just come up with ideas, just they come to you. Some of 'em are more helpful than others, but that's...really not the

purpose of it. So you can come up with more creative *things*, I think, when you do that. So I think that's it.

She further linked symbols with creativity and explained how this worked in the examples of some of the photographs she took.

Oh with photography? If you look through that lens, it's a way of seeing life just as it's a metaphor for seeing life. So there's your lens and it's...and even if you only have one eye that works like I do, it's...it's a metaphor for seeing life through that little lens. *So what you put in that lens is your statement about whatever it is you're taking a picture of and how it relates to your life with epilepsy.* So, and the creativity again is just not just putting yourself in a box...but just allowing your mind to...to put symbols and things together and see...things that "*This is like that. This is like that.*" What I'm taking a picture of is...'cause I was...you mentioned to me one other participant was sad so I was thinking, "What can I take a picture of that reminds me of sadness?" 'Cause there's only a brief...some of that. And then I thought about the puppy when she was down like that [laughing] and that was just, [laughing]...the look on her face. So...that was...that was the analogy there....And if you can't take a picture of a person...there's plenty of animals around [laughing] that don't require informed consent or signed consent forms or something....And so, you...that looked like bars so you can think those shapes, that's what that looked like, even if they weren't bars. It was just a patio thing. But it was...*it symbolized for me that was a way to say what I had wanted to say about isolation and being kept out of a lot of the main things that I used to be able to do...because of lack of accessibility.* And... it

was...lack of understanding, education and things like that. So you've really got to allow your...and you can't be...you've got to just...I guess you have to explore those feelings.

Yvonda also saw photography as art but further connected it with healing, saying "Art is a part of healing now and so being able to put our pictures on the table, put 'em on a screen, is saying, 'I'm healing. Hey that's me. Look where I was.'" She felt that the impact would not have been the same if they had just spoken without having the photographs. In discussing memories of different photographs she had taken, she observed,

So you see, that's a positive thing. In the bathroom, even though I was reluctant just last week, at least I went in there and things...and I was fine. And I saw it on a picture and seeing that picture let me know "Well you can go in a locked bathroom" and I think it would be...I think it would be a tool for others to know that it's healing. I can't think of a better word to say than healing.

Alice saw the value of photography as a means of expressing her feelings if she could not or did not write about them. She took photographs of "things that made me feel real lonely or not supported in and left out." She, like Eagle, was aware of the use of symbol to express feelings. One of her examples was the photograph she took of groceries in the back of her car now that she is finally able to drive again. "Well the groceries. I had a picture of them because it helped explain my freedom I guess you might say that I can go get groceries by myself and take all the time I want and just enjoy it." Alice probably spoke less than anyone else, yet her photographs spoke volumes, as others frequently talked about the lasting

impact of her photographs on them, such as the picture ID and the single place setting and Bible at the kitchen table.

Overall, all of the participants had a perspective on photography as an art form, whether related to creativity, symbolism, healing, or a means of expression. Eagle used to see art as a “finite thing,” such as graphic art, photography, telling people’s stories, etc., but over time she has come to a broader understanding of art because she “see[s] creativity in a more holistic way now....So, I guess *I see life as an art form in how it’s lived...and how it’s survived sometimes.*”

Spiritual. None of the participants expected to have lives circumscribed by the chronic condition of epilepsy, but they all found that their faith sustained them through epilepsy and their other health challenges. As often happens with persons dealing with a chronic illness, they turned more to their spiritual resources for strength and endurance. Participants frequently referred to faith issues during the interviews for this study although no questions about faith or spirituality were asked. Yvonda expressed a positive outcome following the misery of remembering past hurts. After she said “I had to relive a lot of...of the agony that had happened,” she continued the thought with “but that was good too because it let me know look where He’s [God] brought me from.” She later added that “if I didn’t take my medicine, Janet, I would still have seizures. I am seizure-controlled because the Lord let...let them find the right medicine.”

Alice referred several times to the photograph she took of a single place setting at the table in her kitchen that symbolized how alone she felt in her family situation due to lack of

understanding of her condition (Figure 12). Spiritual solace then became her intangible support. “And then when I had the picture of the Bible, it was...my hope was in the Lord.”



Figure 12. Not alone.

She also took several photographs of a favorite scripture passage which unfortunately was not readable. The passage was from Psalm 139 and provided a sense of hope to her.

It meant to me that God's in control and He knows us before we're born and He has a plan for us for our lives and He's real special to me. And for me it meant...now especially, He knew I was gonna go through these things and things would be better later on.

Alice continued to explain how her faith was beneficial to her in her view of both her own life and those around her.

My faith is what got me through and got me...gave me hope....Gave me somewhat understanding and gave me patience and endurance and I just never...I never did feel like I was the only one and it gave me more empathy for others in the same situation.

Eagle recounted her story of loneliness and isolation that she felt after being abandoned by her husband when she became ill and shared about a non-human support she received in the absence of family support. It was her little dog, shown in Figure 13, who also had seizures.

He had seizures and then we stopped giving him those pesticides and things on him and those have stopped. But he was with me from...from when my husband left me....He was with me there, that day, came on Valentine's Day and he had a heart on his head and he's always with me. He's always following me around....So...So I'd have something to hold...when I didn't...'cause y'all...your families are supportive and we've been through some things that....God knows if he has to make a little dog with a heart on its head and send it on Valentine's, then He can do it....That was God's...God's gift to me.



Figure 13. Dog with a heart/Epilepsy dog.

Cary shared a photograph of the medication (Diastat) that he considers to be a lifeline in stopping grand mal seizures, saving hundreds of trips to the emergency room (Figure 14).

And some people have mixed feelings about chemicals and drugs and...and I know one medication almost killed my wife but this is the lifeline. I have a neurological problem, a different one. I take a very powerful medication and without that, my life would be gone. So, I regard these as a gift of God.



Figure 14. Diastat, a gift of God.

Faith was a continuing topic of discussion during the Photovoice project and during the interviews for this study which gave opportunity for sharing and encouragement of one another. During the final group interview for this study, Eagle made a series of statements about the faith context of the group, to which other members nodded and agreed as she spoke. “I think the presence of the Lord was with us. And I felt that in everybody...in this group. That gave it another dimension I think. Faith was expressed quite often.”

As was mentioned earlier, the five areas of growth were separated for the purposes of discussion, but had some overlap. Eagle, for example, linked the social and the spiritual and also saw a strong link between the artistic and the spiritual.

And the things that we talked about in Photovoice, a lot of the pain and loss, God has made a way for us to be where we are right now....And so to me, that just...just opened up to me that...that creative part and so I take that creative part 'cause it's kind of like a different experience with art. *It was a spiritual, artistic experience.* [laughing] And it's the same way with music. That's the context that I've worked in there and those were the happiest contexts because God is the creator. He creates everything so everything can be a form of...art.

Intellectual. At the beginning of each subsequent interview after the first for this study, I asked the participants if they had thought of anything else they would like to add since the prior interview. I also asked a similar question at the end of each interview. While not everyone had something to add each time, there were several extended comments from participants, particularly Eagle and Cary, which reflected their thinking and analysis on topics that seemed to have been stimulated by the Photovoice project.

Eagle felt that the experience of hearing other people's stories had both an emotional and intellectual impact, observing, "You know it gives you more resources to help other people and to understand, to be kind. [And] it educates you emotionally as well as intellectually and there needs to be a lot more of that going on."

Cary also felt that the photographs had both intellectual and emotional impact, citing the example of Alice's photographs of the undriven car and the ID card that communicated the message about being disenfranchised. "They had the greatest...intellectual and emotional impact because they...they summed up so many things."

At the third interview, Cary provided a detailed analysis of his thoughts about the value of using still photographs over motion pictures. He had been watching some documentaries that week and given much thought to the merits of still photographs versus motion pictures.

Somehow in documentary, when you have motion pictures, that has its advantages and you pick up a lot. But *having still pictures, is a way...an advantage in itself because you can focus on one picture and then talk about that picture in the background, think about that picture, just that one picture.* Whereas when it's in motion, you...your thoughts are flowing and you might forget an image.

And...usually with motion, people are talking and so there's less of a chance to narrate them and less of a chance to discuss them and the...with Photo...Photovoice, you can...you can have the voice with the [photograph] plus you can discuss it at the same time and there's no time limit exactly....You think that...you think just the still photos might not have what the motion picture has but they actually have things that the motion pictures don't have, good things they don't have. So it has some advantages actually. They both have their advantages but still...still Photovoice...Photovoice has its advantages, important advantages.

In the group interview especially, Eagle continually brought up disability dilemmas and issues, referring to current situations that people with disabilities must deal with. She and Cary, particularly, were concerned about disability-related civil rights issues and the importance of vigilance against restigmatization in the future. Although these topics were beyond the scope of the original Photovoice project, I felt that it indicated the ongoing impact

of the project as participants continued to think about, discuss, and analyze disability issues. Eagle also provided a detailed analysis of the relationship of Kubler-Ross's model on the stages of grief and loss (Kubler-Ross, 1969) to Photovoice, which is another example of intellectual growth and will be discussed further under *Learning About and Exemplifying the Methodology*.

Dimensions of learning. Photovoice was not designed as a formal education project, but it engendered much learning. Learning involved people, as participants learned more about themselves and others in the group. Participants also reported learning more about photography and the research methodology itself. Finally, participants were most excited about being able to share their epilepsy stories to influence the learning of others.

Learning about oneself. Participants learned more about themselves through both negative and positive experiences during the Photovoice research project. As was discussed at length in the *Emotional* section under *Areas of Growth*, Yvonda learned a great deal about her own sensitivities. Through her dealing with past painful memories, she subsequently felt better able to deal with them in the future.

Alice had the most to say about what she learned about herself through the Photovoice experience. She gained in self-awareness as the research process pushed her into unplanned introspection. As she began to take photographs, she was aware of the feelings she had associated with them, both positive and negative.

Sometimes when I was taking pictures I'd be real sad and sometimes I would be hopeful. Like the picture I took of the car made me sad and hopeful that I would be able to drive again. And then a picture I had...some of the pictures made me hope my

family would be more considerate and understand a little bit more and be more caring....

As she went along in the project, Alice began to realize that not only had she been in denial about her feelings, as previous discussed in the *Emotional* section of *Areas of Growth*, but that she actually wanted to get in touch with them. As she described the newness of the project and how it affected her, she continued onto the topic of feelings.

It was very...it was very...something that I have never done before. It was very...I thought the three different areas, three different subjects, was very enlightening and made me really think about how things were at that time and made me just get in touch with my feelings...which I don't do very easy sometimes....I guess I really needed to get in touch with my feelings too and what was going on with my life and epilepsy....Well with the taking the pictures and things we talked about and just sharing our stories about our families and the difficulties and...I think that was it.

As she began to get in touch with her feelings, she gained insight into her interactions with family members and others and how that had affected her.

And how I depended on other people and how the results of things...the results of depending on other people, the results of non-support and...by a lot of people, several people and the support of others.

Learning from others. In addition to learning more about themselves, participants also learned from others. Although they might have each claimed a certain expertise about their own types of epilepsy, medications, and other treatments, they broadened their knowledge in these areas by hearing the stories of the others in the group. Learning from

others was in three areas: their life stories, their conditions and progress, and the caregiver role.

Their life stories. The participants were experts on their own life experiences dealing with epilepsy, but their knowledge and understanding increased as they added knowledge of other members' stories and how they had coped. Eagle "learned a lot by listening to the other stories of other people's personal experiences" since there are so many different types of epilepsy that affect people differently. She specifically talked about the impact of learning about the life experiences of others and how epilepsy affected them in comparison to how it affected her.

Learning other people's experiences with the various forms of epilepsy and how it impacted their lives and the precautions they had to take as opposed to the ones I had to take...and the percen...the limits they had and...the differences. There was a variety there because epilepsy does have a variety of expressions....And so ...and...and just...people that have been quiet before...just hearing their stories. It was very moving. It was very moving. So it was educational in a lot of ways.

Alice said simply, "It was good getting to know everyone, everyone's stories." She really gained from listening to the stories of others. It eventually helped her to see her own situation in another light.

Well like the feeling of anger I guess. I think it made me realize that...especially when someone would share about her immediate family being so supportive. That made me realize why possibly my family wasn't because they were afraid and it

helped me to see that it wasn't that they were just hateful and mean, it was maybe they had fear.

Their conditions and progress. Although participants were very knowledgeable about the types of seizures, medications, and procedures each had experienced, they learned much from hearing what the others had gone through. Cary recalled the hundreds of grand mal seizures he had witnessed and treated at home. Alice explained the misunderstanding she felt from her family because she did not have grand mal seizures. Because her seizures were not so obvious, some people in her family did not see that anything was wrong with her and could not understand or accept why she was not working. Her family members “thought I was making things up because these seizures did not look like the shaking and jerking. They were just staring out in space or not answering someone.” Alice found that “some people’s pictures made me understand how they were feeling about their seizures and their things that caused their seizures. Like the lights.”

Eagle found particular satisfaction in learning about other people’s experiences and specific conditions.

And I think anything you learn that way, especially since I’m trying to help people in that area, is really helpful. But even as a lay person, if you never planned to use that, it’s still helpful to understand people and what their experiences are.

The caregiver role. The unusual situation of having a caregiver as a member of the support group led to the sharing of many insights and perspectives that the other participants would not have known about otherwise. Cary was able to learn about the patient perspective from people other than his wife. The other members in turn were able to learn about the

caregiver perspective from someone other than his or her spouse and immediate family.

Members of the group had great respect and empathy for Cary. In discussing future uses of Photovoice, they wanted to make sure to include Cary as “a model to caretakers.” Yvonda explained the importance of their learning from him.

And to see how he was excited about doing those pictures for his wife and as you say, some were...some of ‘em hurt but yet the good that we found out of them, all of them together, because they...we all have caretakers, but do they talk about it?...[We] have a caretaker here that stands in for us...would say that he stands in for all of us.

Especially with the high rate of divorce among persons with disabilities, the group members wanted to be able to highlight Cary as a “model” and “example” of a caregiver who stayed in the situation and was committed. Yvonda summed it up as follows: “I think it was great because I just want to say he has just been through so much and been...he’s the greatest inspiration to me.”

Learning about photography. Brief instruction on taking photographs was part of the original orientation to the Photovoice project, mostly about issues regarding photographs of people and the need for consents of photographs taken of people. A few suggestions were made of how to include people, such as from the back or from a distance. Over time, participants learned more about photography by doing it and shared their recollections. Cary said, “My second group of pictures was better because I had learned something about...composition and just taking pictures” and concluded simply that it “made me a better photographer.”

Eagle, with her background in photography, gave a great deal of thought as to how to apply her knowledge of photography to helping Photovoice participants take better photographs without putting pressure on them. She provided a lengthy description of all the aspects that one could consider, such as, having the light behind you, framing the scene to have what is important take up the screen, not sticking your thumb in front (she laughed as she said this one), using symbols, focusing in closer for important items, the use of color, shape and line, and using a flash to fill in shadows. Yet she ended her long discussion of all these possible instructions, with an awareness of the need to provide useful information without intimidating people.

And then I would definitely say but always just remember, this is not gonna be something that's judged [laughing] for artistic merit. "This is your experience and as such...it's valid and however you experience it and then...you put your words with it to explain it and your...that's...." So you don't want to disempower people by making 'em feel like they've got to do...professional something or another.

Learning about and exemplifying the methodology. Participants learned about the Photovoice methodology by doing it. Cary did a lot of thinking about the value and purpose of the methodology and how it worked. First, he commented on the importance of participants rather than observers taking the photographs and the simplicity of the method.

...if you told an observer what you wanted, you might not get...get exactly what you wanted. I think the participants are the one to take the pictures and...the pictures don't have to be perfect technically, that's a minor point....So I'm a lousy

photographer. I didn't feel that that affected the...what I wanted to do. Which is nice. And you can use a \$5.00 camera. That's all it takes.

Next, he commented on what he learned about the power and impact of the technique in communicating issues to other people.

And...I learned...I learned...I formed an opinion about the Photovoice that it was a good techn...a really good technique and that it's a technique that...powerful technique. Both times when I was...over at UXE, the people...no one fell asleep, not even me. [laughing] But they...it's emotionally, it grabs you and...even the medical students who you would think would...be familiar with this...it affected them because they're...they're not that familiar with it. They don't see...they don't see that many seizures, I'm guessing. I can't say that for sure. Most people haven't seen that many seizures unless they are...say, have a spouse or a child or a parent with a seizure disorder and they see some seizures. But other than that, you don't usually see the seizures in public, sometimes you do. Usually a grand mal and everyone notices that. If it's a, say a complex partial...seizure, you might not notice it or think something's wrong with the person but you don't know what it is. You don't know it's a seizure unless it's so identified.

Eagle spoke so enthusiastically about Photovoice, it was almost like a little free verse refrain. "Oh Photovoice. Photovoice. Photovoice. The advocacy for people with disabilities, the advocacy." Through her participation in the project, combined with her passion for advocacy, she gained a good understanding of how the methodology worked and how it could be used to further educate people about epilepsy and other disabilities. "We need to get

the faces of epilepsy out there and the stories.” In response to my open-ended question at the end of interview three, asking if there was anything she wanted to add about her epilepsy story, Photovoice, taking photographs, or the overall experience, one of many topics she initiated, was that of the relationship between Photovoice and the grieving process described by Kubler-Ross in her book *On Death and Dying* (1969). Eagle connected the losses associated with disability that were expressed by participants during the Photovoice project with the process of grieving, stating initially that “Photovoice was part of the grieving process.” However, she also saw it as part of the acceptance process for people who were feeling hurt because “Photovoice gave us a chance to be heard.”

All the participants learned about the Photovoice methodology by their participation and experience of it. As discussed in the section *Understanding the Purpose and Value of the Research*, Yvonda went from feeling like it was “Greek” to her to really appreciating what it had done for the group and the opportunity it afforded them to educate others about epilepsy. Cary came to a deeper understanding of how the methodology worked and its value and impact. Eagle took what she learned about the methodology and began to strategize how it could be used in the future, as well as connecting the impact of Photovoice on the group to a theory of grieving and loss.

In addition to learning about the methodology, the participants also exemplified it by putting its principles into action. Participatory action research is designed on the premise that the research is being done with co-researchers rather than on subjects. As a PAR method, this premise also applies to Photovoice. In the Photovoice project there was no explicit explanation of PAR, but it was implicit in the fact that the participants developed their own

themes to photograph and were part of developing and giving the final presentation. During the course of this study, I observed growth of participants into even more of a participatory role. This was especially apparent during the final group interview when Eagle started giving themes and describing how she had seen the group go from isolation to group and stigma to dignity. However, the process started much earlier than that because Cary was making up and photographing his own themes in addition to the three that the group had chosen. He revealed this in our third interview.

And I had, I guess themes. What people with seizures might not be able to do that they could do before. Things that were dangerous for people with seizures that weren't dangerous to the rest of us, stigma things...like the sign that I made [of the] North Carolina Eugenics Board.

He also took photographs of two different mental institutions to communicate past and present views of seizures disorders, and the following two ideas: "1. [they] have a stigma; 2. epilepsy confused with mental illness and which further stigmatizes it and I wanted to show that."

The participants' emergence into a greater participatory role was most apparent in the final group interview where much of the conversation took off in directions initiated by the participants as they went beyond the scope of the original Photovoice project and my study to discuss broader issues of eugenics, disability rights, civil rights, and future societal dangers to persons with disabilities. It seemed that because of the personal issues that they had worked through as a result of the Photovoice experience, they had developed stronger inner resources

and become more able to think beyond themselves and reach out to help others and advance the cause of epilepsy awareness.

Facilitating learning. Being able to present the Photovoice research project to a group of medical students was the highlight of the project in the sense that having the opportunity to share results was the ultimate goal of having done the work. Cary “was impressed at how...how the medical students were so...interested and emotionally affected by our stories. That impressed me very much.” Yvonda was so excited about that opportunity to share.

We helped the students as much as you helped us allowing us the opportunity. But it also helped us to know that we helped them. They are medical students and they didn't know these things so it was a very rewarding experience and I guess that's in anything. *You've got to go through the rough edges to get to the smooth part.*

She also spoke of the impact of the experience on the medical students as reflected in several “fan letters” she received afterwards.

Yeah. Yes. It would be much different than me just saying it because now these students that are sitting around us, they see it because that's what they told us. I never was able to find any of my fan letters because I did get a couple. I call 'em fan letters. But...what they said was they had never...they had read it in books but they had never...people look at epilepsy as...you're just a dumb person...you're crazy...you're moody. But they saw us as intelligent people. They saw us as people that were living a normal life because what they said to us personally...*I mean they said to us that they had read it in the book but they had never seen it.*

As participants discussed the presentation to the medical students, it was evident that they felt encouraged by the experience and empowered to do more. Eagle spoke of how important it was to her that they were “making a difference” while Cary particularly expressed a feeling of being “useful” which he did not normally have in his daily life.

Eagle explained her perspective regarding the importance of the presentation to the medical students.

It made me feel like the effort was definitely worth it because it changed some medical professionals...people who are going into the profession and training. It gave them additional awareness...and it could potentially help other people so that really helped.

Participants recounted multiple instances of personal growth and learning. Growth in the emotional, social, artistic, spiritual, and intellectual areas of their lives followed the initial challenging experiences of entering into the research process, particularly the resurfacing of painful memories and emotions. Learning about oneself combined with learning about others to enable participants to reach out and affect the learning experiences of others. The next section proceeds to discuss changes that occurred concurrent with the study as participants moved toward their eventual goal of effecting social change through Photovoice.

Finding 3: Influence and Change

It allowed me to do photography again even by that simplicity, which I couldn't do anymore.

– Eagle

The ultimate purpose of a Photovoice research project is to effect social change through the impact of the presentation of results to community leaders and others (Wang &

Burris, 1997). The Photovoice research project with the epilepsy support group was followed by a presentation to medical students and became a highlight of the experience for members of the group. Even before the presentation, however, they were taking steps along the way to do something about the very problems the research project was addressing. In addition, once the project was over, they continued to be involved in activities to effect changes in the ways other people perceive persons with epilepsy.

The three themes of the original Photovoice project were Stigma and Discrimination, Accessibility and Barriers, and Family and Support. During the project, members of the group were taking photographs that depicted these three themes and working through the themes one at a time. Ironically, group members did not have to wait for years to see progress in these three areas. It was happening at that very time. As they talked about problems of marginalization, the very act of talking and sharing with each other and the researchers was helping to bring them out of the margins. In addition, their personal work in these three areas did not stop with the presentation to the medical students. They each continue in their own way to work on the issues that have become important to them.

Fighting stigma. After dealing with the researcher who Yvonda thought was creating stigma, the participants made headway in reducing the stigma of epilepsy by presenting the project to a group of medical students. Even before this, however, they were doing something about stigma by sharing their stories with each other. Each individual became more aware of the problems the others had faced and were facing. This awareness helped to broaden their perspectives beyond themselves and lessen the isolation each of them felt. They were particularly moved by the photograph Alice had taken of her photo ID (Figure 15) that she

had to use instead of a driver's license. For her, it symbolized the stigma that people with epilepsy face, because when others would see the card, they would wonder what was wrong with the person who could not get a driver's license.



Figure 15. The photo ID.

In describing what he thought were the two best photographs, Cary recalled,

One was of a car, one was of an ID card and...the ID card was a brilliant thing 'cause it's about being like disenfranchised. People see this and they say "what's wrong with you?"

Cary seemed to be on his own little campaign to reduce stigma and discrimination, whether or not he realized it. He revealed in the interviews that he had made up his own themes to take photographs of, such as what people with seizures might no longer be able to do, things that were dangerous to people with seizures but not to others, and tests and treatments that people go through. It seemed that the project really energized him and gave him a focus beyond the caregiver role. He continues to be very concerned about the eugenics issue, having taken several photographs depicting the North Carolina Eugenics Board, and is well-informed on practices in other states such as Indiana, in addition to North Carolina.

At the end of the group interview, Eagle presented her observations about the themes she had heard the group discuss. “And the second one was stigma and then I hear dignity.” She expressed the movement of members of the group from one place in time to another, from feeling like victims of stigma to feeling like people of worth because their voices had been heard and would continue to be heard.

Removing barriers. As participants shared their respective stories, other members of the group became more aware of issues that had not affected them personally, better equipping them in turn to help others facing issues with accessibility and barriers. For example, because Eagle had photosensitivity epilepsy, she was restricted from being in places with fluorescent lighting or other types of lighting that flickered. Even with her specially made Irlen lenses that help with light sensitivity, it was difficult for Eagle to go most places, whether for shopping, eating out, or even going to her doctor’s office. In fact, one of her photographs from the Photovoice project showed the fluorescent lights and other reflections at her eye doctor’s office (Figure 16). So she had to face possibly having seizures

induced by the environment of the medical office she was going to in order to get help with her environmentally induced seizures.



Figure 16. The eye doctor's office.

Becoming aware of her problems made other members of the group think about lighting issues when they planned to rotate their support group meeting to other locations. Even though many people wear dark glasses, Eagle often felt conspicuous about wearing hers

because they still looked different from regular sunglasses. After one of the sessions in the Photovoice project, the participants took a stand for solidarity with Eagle by taking a group photograph with everyone wearing dark glasses and standing in front of the van that gave rides to persons with disabilities.

Getting support. Lack of family support was a particular problem for Alice and a unique problem for Cary who was a caregiver. As the project progressed, the sharing of photographs and stories led to deepening of relationships and increasing understanding among the members, which in turn led to increased support among the members.

In the absence of much family support, Alice had found support in her faith, as previously discussed in the *Spiritual* section under *Areas of Growth*. Like Eagle, she also found support from her pet dog.

I think I took some [photographs] of the dog. I don't think that that was...that was very encouraging...I mean not encouraging but it was nice to take that because they have unconditional love and they're right there always when you need to talk to somebody or do whatever. And that was encouraging. And then I think the...I think taking the pictures of the car and...was a little hope...helped me have a little hope. Through her participation in the Photovoice project, she began to gain new support from the people in the group.

As a full-time caregiver, Cary was quite isolated from outside social contacts. He found solace in his creative pastimes of sculpture and calligraphy, but had little social interaction with others. During the Photovoice project he had the opportunity to share his unique story as a caregiver with the others, which helped each side to learn more about the

other point of view. The appreciation of the others for him as a caregiver, and his appreciation of them for providing an outlet for sharing, was mutually beneficial and provided a base of support that he had not had previously.

At the conclusion of the group interview, Eagle explained the first theme she had heard the group discuss. “I was listening, [and] in the first one we talked about isolation and then we talked about going to group. So it moved us...even though isolation – those are two opposites.” She also talked about the value of the support group in working together to effect change.

I think when I started in a support group it started really helping to start doing [something]. If everybody can do one little thing...it gives you a little bit of power because you're starting to change something. You're starting to do something. You're not just a victim but you're doing something to fight back...I don't know if fight back is a good word but you're being proactive.

The process of solidifying the group as a cohesive support group meant that a new source of support was being created for all the members regardless of other support that they already had or had not had.

The participants may not have realized it at the time, but they were working together to make headway in their own spheres of influence to reduce stigma and discrimination, improve accessibility, remove barriers, and provide themselves and others with better sources of support. The next section continues the Photovoice story with a discussion of meaning making as participants “put it all together.”

What They Took Away from the Table

I felt like we had people at the table. – Eagle

This section presents the final finding specifically related to the second research question: How do members of a support group make meaning of their participation in a Photovoice project? This finding explores the more immediate outcomes along with the longer term impacts of the Photovoice experience, as participants described how they made sense of what had happened to them during and following the project. This section represents the process of looking back and putting it all together in retrospect, along with looking forward to what could be in the future.

Finding 4: Meaning and Purpose

It was a moment of value and treasure for me because I was able to share and do the lemon and the lemonade thing. – Eagle

The participants each came to the Photovoice project at whatever stage they were in dealing with life with epilepsy. They then went through the process of entering, adapting to, and eventually embracing the Photovoice research experience as a valuable life event. What they took away from the table was not only the memories, but the lasting impact of the experience. The process of finding meaning and purpose has three aspects: restorying, reflection, and retelling.

Restorying. The process of looking back at the Photovoice research experience involved a reconsideration of the stories and photographs taken at that time along with the new photographs taken for this study. In both the individual interviews and the group interview, participants demonstrated that they were thinking differently about the past and

reworking their stories. They became aware of changes in themselves as well as in others. In some instances, the interpretation and meaning of particular photographs or the situations they represented changed. Photovoice was a catalyst to influence them to see the past in a different light. As Yvonda reflected back on her experience of “regressing” and “reliving” painful memories and how her interpretation of them changed, she said, “And that’s what I’m doing now. I’m thinking about it in a different way.”

Changes in self and self-perception. Alice reflected on the impact the project had on her. As she came out of denial and became more aware of her feelings, she increased in self-awareness. She said, “I think my attitude was...became better because I had had a bad attitude some of the times because of situations in my life.” This in turn led to a greater compassion for other people. “Having had this experience makes me more aware of people, their needs.” Cary came away from the project feeling that he had a story to tell and that other people were interested in the story. This was particularly important to how he felt about himself because of the narrow life he lived as a caregiver. He noted, “Yes. I’m retired, I’m not working. I’m on disability and so...sometimes I feel ‘Oh, I’m not doing anything’ when actually I am....[So] this was important to me, this project.” The Photovoice experience made him feel that he was helping others.

...but what it did was, I felt that I was being helpful and I felt that I had something to say to people with seizures and people that are caretakers and people that are none of the above. I felt that...that my pictures told a story....I felt that I was helpful and even...with the...with the medical students, who of course know much more than I do but...*but I felt that...that my pictures were helpful; they told a story.*

Yvonda was very aware of the changes within herself as a result of her Photovoice experience. She felt that in becoming aware of her sensitivities, she gained strength for dealing with similar situations in the future.

The fact that I did regress a little bit then, I think as far as...I think it showed...it helped me to recapture some of the sensitivity I had in a positive way and that if I should be in a situation like that again that I probably...even if I would be reluctant at the time to do it, I would try to think of all the...think of some good that it would do and that's been the whole thing about epilepsy anyway. It's not...*epilepsy is not who I am, it's a disorder that I have* and I certainly think that that will play a part in that. Having been sensitive about that, it helped me to be positive. "Yvonda, this epilepsy is still not who you are, it's a disorder that you have."

Her personal gain in strength also made her feel that what she learned about people from working in the group setting made her better able to recognize and accept differences, as well as handle criticism better.

I think I would be much stronger because I think what I realize is that even in a group setting, and I've learned that over the last four years so I say even in a group setting with people that have epilepsy....I would have to evaluate me as it turning out to be a positive thing for me because I think I had suppressed some of the feelings and when I was first able to talk about 'em, I think some of it I think because of the criticism. But even now I think I could take some of the criticisms because I would know how to brush them off even better...I wouldn't let it affect me like I don't think I would let it affect me like it did.

She summarized all these changes as a gain in emotional health, explaining the back and forth process that she went through with the resurgence of past memories. “And so doing the Photovoice, *I went back to where I was but it helped me to come back to where I am and to proceed on...and I think it brought me from yonder to here.*”

Eagle was the one participant who specifically was not aware of changes in self or self-perception because she felt that she had already worked through many of the personal issues before participating in the project. “No. I’ve got...I had already done a lot of pretty extensive stuff before that so I think that probably was not the case.” The main impact on her was in learning about others because “it broadens you as a person.”

Changes observed in others. Participants made a variety of observations about the changes they saw in others as a result of the Photovoice project. In general, they each felt that they and the others benefited from the study and had a positive experience. Their comments reflected both observations about individuals and the group as a whole. Cary felt it was good for the group in general.

It seemed to be...[a] positive attitude and even some almost excitement about some of the pictures they had taken. I think the whole project...It made them more involved in...in the group because we had a project. I just...that’s...I can’t say I asked them and they said that but that was my impression.

Yvonda felt that overall members of the group were “delighted” and “enjoyed it.” Once they got over some initial “reluctancies” and the fact that it caused some of them to “regress,” it became an experience that was good for the group as a whole because of the way that they were all able to share.

I think it was good for the group. *It was good for the group.* And as you know, being an epilep...a patient of epilepsy, you never feel comfortable about talking about it, period, even if your doctor...now I felt comfortable with my doctor because he was a [com]passionate person. But to talk about it in front of others...first we come together as a group and then to be able to share some of our experiences with each other and we really do appreciate you bringing it.

In addition, they all emerged having had a very significant experience because of being able to share not only with one another but with the medical students. As Yvonda noted,

And but overall, they were really happy about doing that because what they thought...it was something they had never been able to do before. I think they all felt that and I want you to know that. *It was an opportunity that we had never been able to have our say before.*

Yvonda continued with some individual observations, noting that for Cary “it was a way out” and a way for him to “give back in a positive way.” She recalled the enjoyment others had in talking about their photographs, Eagle’s discussion about her little dog having made a big impression. The most marked change she saw was in Alice.

...and I can’t go any further than to say that to see the progress Alice made. I haven’t heard Alice talk like this in such a long time. I haven’t seen her talk in a long...and I’ve been knowing Alice for a long time. But I’ve never...I don’t think I’ve ever heard Alice talk like this. And to see what photograph...Photovoice has done for her....

Eagle agreed, saying that although Alice was “quiet normally in group meetings, she...she was able to vocalize some things and it was very, I think, it seemed to be empowering for her....*It gave her, her life back.*” Eagle also commented on the emotional impact of photographs, particularly on Yvonda. She saw Yvonda “become more emotional as far as the sadness just reflecting over the losses....I think maybe it telescoped it all into one thing for her.”

Alice in turn had very specific observations about the changes she observed in each of the others. Alice said, “I think Yvonda and...and Cary, it was very good to hear their...and I feel like they benefited a lot from this because they realized, I think, they had support and they’re thankful for that, more I mean.” In general, she thought the project helped them get in touch with their feelings, with the most impact being on Yvonda. For Eagle, she thought that it lessened her isolation.

It possibly helped her see that she was not alone in having photogenic seizures or photo...whatever it’s called...Photosensitive, being photosensitive....And that people finally understood after a while and it was very difficult for her dealing with all that...that...with going to classes and doing different things.

For Cary, she observed that “maybe it helped him be more...more compassionate....Because I think he also saw...how things were affecting all of us....And helped him maybe understand his wife a little bit better.”

Most of the observations of changes in others were expressed by participants about other participants, but Eagle also had a view on changes in the medical students.

It made me feel like the *effort was definitely worth it because it changed some medical professionals...people who are going into the profession and training. It gave them additional awareness...and it could potentially help other people so that really helped.*

Changes in the interpretation and meaning of photographs. Participants interpreted some of their photographs one way at one time and another way at another time. During the first interview, Cary had separated out a few photographs that he said did not really apply to the project. Then we had the following conversation:

Researcher: Okay. Now this is your other set but these are not related to the Photovoice thing?

Cary: I don't...I don't think so.

Researcher: They're beautiful.

Cary: Yeah. Those...those are...they have statues. I just go through them for...those are in front of [the hospital] and I don't know that they have anything to do with...unless there's a seizure.

Researcher: Oh, I like that one.

Cary: It's upside down [laugh].... You could...these are in various poses. You could ...together...say that they represent a seizure in different stages. [Pause]. I guess. But they're...they're interesting. This is ...this is something that amused me that has nothing to do with a project like this.

Cary did not say it explicitly, but I had the impression that he had initially taken the sculpture photographs because of his interest in sculpture as an avocation. He makes larger than life wire sculptures of fantastic animals that populate his back deck.

By the time of the group interview less than four months later, he had a totally different interpretation of the sculpture photographs. I had asked participants to share four or five photographs from their rolls of film to explain their Photovoice research experiences. Rather than being photographs that he was not even sure if they applied to Photovoice, the three “epilepsy” sculptures in Figure 17 were among his top five.

This is a sculpture. There’s a series of them and I see it as a child doing gymnastics, tumbling. And it represents what my wife, very athletic, could do before her disability and it represents what she can no longer do at all and what she misses and what has been taken away from her. It also represents hope because just in the last couple of weeks, she has...has gotten much better and I didn’t know if she ever would. So that represents the hope.



Figure 17. Epilepsy sculptures.

Not only did the meaning of some of the photographs change over time, but one participant used the same photograph to mean two different things at the same time. Yvonda took a photograph on the campus of UXE (Figure 18) to show both the reluctance she had in participating in the project as well as the triumph she feels now at having presented the completed project there.

I came through Valleyview to try to get some pictures of the university because I wanted to show the reluctance that I had either for the group, or for whatever...reluctancy I had and it was for the group mostly....We have come from that now and look where we are now. We're back at...we're at...I'm back at the university to show the progress that we have made.



Figure 18. Reluctancy and progress.

Both Yvonda and Alice took photographs of their kitchen stoves for the Photovoice project at which time they symbolized a precaution for avoiding a potential danger since one could have a seizure and fall forward and get burned. Yvonda discussed this at length under *Painful Memories, Difficult Emotions*. As Yvonda reflected back on those photographs, she changed her perspective from precautions of things she should not do to the blessing and triumph of being able to do it.

When I look at those pictures of the one that I took of the stove, where I'm not supposed to cook on, the...the front of the stove, that was really hard because my husband [who was visually impaired] was not able to cook and so I had to do it anyway. But then I look at it from another point of view now. He *blessed* you to do it

because you would not have...I mean you had to eat. You couldn't go out and eat all the time. So I've been able to cook from the front of the...from the front eyes and I did it a lot of times anyway. That was traumatizing to see that that's what happened but it was also triumph to know "Well I can cook anywhere I want to now."

Alice took several new photographs of her stove for this study (Figure 19), and also had a different story to tell compared to when it symbolized precautions and dangers. This time it represented her joy of being able to cook now that she is seizure free.

This is a picture representing being able to cook and not worry about being burnt from having a seizure or something. And I love baking and cooking and so that is why I have taken the picture of the stove. And there's a picture of the oven where I was getting ready to bake some brownies and the most fun is baking bread and I can bake also.



Figure 19. Safe stove and oven.

Yvonda did not take a second photograph of the university hospital where she had been hospitalized numerous times and had numerous outpatient appointments. However, in

recalling the photographs she had taken for the Photovoice project, she compared the initial meaning of the photograph to what it has come to symbolize now. This change in perspective was a result of working through the painful emotions that came out during the project.

When I took that picture of [the university hospital] oh, that was a horrible place that I went so many times, so many times, so many times. I got asked so many questions. “What did your mom have? What did your dad have?” Even asked, “How many....How much you been drinking? How many people in the family had seizures?” I mean all those questions came back, but I also looked at it now as that was where I got my help from.

Like Alice, Yvonda also used a new photograph taken for the study to illustrate both her past and present perspective on the same thing. This was a photograph of her medications that she shared at the group session (Figure 20). “But these are medications that I still take but I see ‘em as a different view now. Then it was a chore but now I see it as a healer.”



Figure 20. Medication as healer.

In each of these instances, the participants expressed a change over time in their perspective on a life situation, and in each case, it was a change from a negative view to a more positive and hopeful view.

Reflection. Participants reflected deeply and at length about the meaning and impact of the Photovoice research project as they looked back and processed various aspects of the experience. They expressed their thoughts and feelings on a variety of topics, from specific areas that were important to them as individuals to the impact of the study as a whole.

A phenomenon early on that made the whole project possible was that participants felt that the group was a safe place to share their experiences without having to be on guard. “I felt like we were in a safe place with the group,” said Eagle. Yvonda concurred saying,

I feel that too, that *we were in a safe environment*. We were safe among each other. And we felt confidence in each other, I don't know if I had said that to you. But I think that that was one of the safe things for me and I certainly thought [that] at that time.

Yvonda then relayed a striking contrast between what her life had been in the past and what it was now due to the impact of Photovoice.

Yeah, because I used to sit in my room by myself. I didn't want to be bothered with anyone. I never did take a lot of the medicine that they gave me because I never wanted to be doped up, but I felt like I was in prison and I think you unlocked the door, that *Photovoice unlocked the door*....so I think it was...I can't thank you enough for bringing it to us because it's something that we never...I've never been exposed to it period and I don't think either of them had either. But to be able to talk about your personal stuff in pictures...you see, that was the thing about it. *When you was talking about the photos, the photos told the story* and while I say for me it brought back memories and for them it did and where we are now even if we're just sitting in a group setting. But I still think it showed where we had been.

Eagle reflected on the effects of disability and how Photovoice benefited each of them, explaining that "Disability puts so many fragments and so many different harms but this...the project helped to put some of that back together that exist because of invisible and sometimes visible disability depending on what variation we have got." She also gave a long explanation about the concept of "The Other" because she felt it was so central to the disability experience that they have all had. She explained a story that is often used about

white geese and one black goose that was persecuted by the others, but later turned out to be a beautiful swan. For her, the support group as it went through the Photovoice experience was a place where you were not “The Other,” but a member of a community.

But it was...it was “The Other”....It wasn’t like us...and you get a lot of that with disabilities. And so when we’re together in that group, it’s not “The Other,” it’s...that’s...that’s community is what that is....And so I guess I just really like...that feeling that, “Okay I’m here. I don’t have to explain myself. I don’t have to...to ask for this or that. It’s just I can be here and the understanding’s here.”....And I felt they *gave me my dignity back that something out of my control had taken away. So I think the dignity and community and purpose* and you...the glass half full as opposed to half empty. It just gave more positives and those were...*those were all the things that came out of that project.* So if you asked for feelings, I think that’s a good thing.

Eagle further summarized the positive overall effect that she thought the project had in giving voice and reducing stigma.

But as far as...attitudes and things like that, I mean it was a *positive experience as far as being able to have a voice and to contribute positively to other people’s understanding of a variety of experiences...* [what] people with epilepsy of various types experience. And so I guess...that was positive and being able to help *destigmatize* some things or...or do away with some stereotypes or some myths.

Cary emphasized the importance of photographs as a part of the telling of the epilepsy story, since he “felt my pictures told a story that could not have been told more effectively without the pictures.” Eagle explained that from her perspective the photographs were crucial because they communicated even when someone such as herself, who had some cognitive challenges, could not come up with the right words to say what they wanted to say.

And the photographs really helped me because you got a visual and you could think about it at home and get creative and if the words aren’t there in the group, this gives them the reminder and...[laughing] kind of...comes out hopefully, and Janet sorts through it all. [laughing]

Yvonda also spoke of the story aspect of Photovoice, summarizing the value of the photographs and how the whole experience brought the group together.

I feel that the photos is just...it’s just a story...it’s a new story of our story and it did cause us to...it brought us...well I think we were close but it brought us closer together. It caused more communication.

Her greatest triumph, however, was the presentation to the medical students, as she explained,

We were all able to have our say....Being able to be invited to a university and being able to be a part of that classroom but yet being the...each one of us was the keynote for that classroom....And with this Photovoice, I thought that we had brought even more awareness.

According to Yvonda, overall it was “a very rewarding situation; it was for me and think it was for everyone else because they still talk about it.”

In addition to the story and photographic aspects, Eagle provided a very detailed summary of the potential impact of the Photovoice project from the perspective of giving voice.

I just think it's very positive that this group, it was a voice...it was heard. It was heard at...one of the better institutions in the United States by people who wanted to hear it...and responded pretty positively...and they were in an area where they could impact other people, so I think...it had all the elements in there that y'all wanted was *to bring people from no voice to voice* to experience being conveyed to reception to...carrying that to other people or into the medical field to give positive...interaction with patients in a more informed and compassionate treatment. She continued by expressing the advocacy aspect of the project, explaining that "Photovoice is like an...it's not an offense, but it's like taking it...taking it out there."

Yvonda, as the group leader, was continually referring to the impact on the group because it was so important for her to have seen that. She felt that the openness of communication prompted by Photovoice was a unique factor in creating group cohesion that would not have happened otherwise.

I don't think it would because the fact that we had formed a group and had become a team, I think that was one part of us coming out of the shell. *But being able to show and share our experiences, I think that was the second phase of it and it certainly...I think it was a great phase of it 'cause I don't know...as many epilepsy meetings I've been in, I've never known anybody to talk about it like that.* Even in the big meetings that I go to. We have...the books that we have printed, they have the patients on that

but...and they may have things like that but I've never heard 'em talk about it. Even when I talked to them about it in the meeting, I don't think [the foundation staff] knew what I was talking about.

Yvonda summarized her feelings about the project by explaining how it correlated with her original goals for the support group. "My main reason for wanting to start an epilepsy group was to educate people on epilepsy and bring awareness that there are people that live daily to be...they live daily wanting to be epilepsy free."

Eagle expressed a unique perspective on how the early discomfort of the Photovoice experience became something beautiful.

So I think if everybody could realize that, there...and their participation in Photovoice was that...I'm sure it wasn't comfortable for everybody to talk about everything, but it was a gift. *They took what the experience was and they allowed it to be made into a gift to other people.*

In looking back at the Photovoice project through reflection, participants expressed the significance of the experience to themselves as individuals, as members of a group, and as a means of sharing their epilepsy stories with others in a way that was uniquely understandable.

Retelling. The opportunity to tell the story and continue telling it was a great encouragement to support group members. They saw the opportunity to look forward and apply Photovoice to help other individuals, affect medical professionals and other groups, and have an even wider effect on society in general.

Because Yvonda had personally experienced that Photovoice “brought me from yonder to here,” she saw it as a tool to help other members of the support group have the same experience. In discussing Brian, who had come occasionally in the last year or so with his mother, she recalled how he not only did not seem ready to talk about his life with epilepsy, but that he was also not comfortable hearing other people’s stories at this point in his epilepsy journey. Yet she felt that Photovoice could be used as a tool to help him come out of his shell and have hope for the future.

Well...one day you may be there and you may be able to talk about it...It’s a daily battle with them, one more day being seizure free. And I think showing our pictures of things that happened to us during our time would certainly be a tool for them. She was not sure if he would physically be able to participate in a Photovoice project, but felt it would be so beneficial if he could be involved in a thing like that...I think once he does...if he were able to come out of a shell like that, then it would really help him....If he was able to see himself and see how it affects him but also as to how he may be one day...I think it would help him, even if he had some negativities. *Sometimes negativity is not always negative*. It can be positive. It can be a positive in the long run, I’m trying to say.

Eagle expressed her hopes for the future and the continuing impact of Photovoice on the medical community.

‘Cause we’ve seen some victories in spite of the battles we’ve had. And some things...are beyond human ability to change, but God knows the answers and I guess that’s...that’s a big improvement. But I would like the doctors and the medical

students and all that, through the Photovoice, to know more about it so they can really help...help us help other people that don't have the help that we've gotten.

Listening to another group member recount a painful experience during a hospitalization, Eagle interjected, "And until people hear our voices, they won't know this picture."

Cary summarized the project as something that was permanent, useful, and could have an enduring impact on other people.

This is a permanent thing that can be...used or viewed over and over again and it's...it's helpful and was like a group project. We help each other by talking, by exchanging information but...but this helped us because it made us think about certain things and it helped us because we felt we were contributing something that would be useful not just for the group but to any number of people. And so we felt...I think I could speak for the group, really just myself – I felt that I was...had done something useful. It was a good feeling.

Eagle also reflected on the issue of usefulness and how people with disabilities of any type often lose their sense of purpose. Then something like Photovoice could be a way to help them reclaim a sense of identity.

It gives you an iden...your identity that you had before you had the disability is like based on work or family or whatever and when a lot of that's taken. Then you're left without some of that....So it gives you that purpose. It gives you that...framework of...it's not a total purpose, but it gives you that affirmation....Being with a group, and just...I don't know. It's just like...it's a positive thing....That's the lens I was looking

at it through as well as myself. And when I feel like I'm making a difference, it makes me feel better. It just does, 'cause it's not in vain, it's not a waste of a life.

With her strong concern for disability issues, Eagle had a very broad view of the importance of conveying the epilepsy story to the broader society, with Photovoice being one of the tools to do it.

We need to get the faces of epilepsy out there and the stories. And then you need to get somebody to take it...to be the spokespeople, to be...to go on the talk shows or whatever and to say....“This is what we experience. This is a civil rights issue. We are being discriminated against and it's based on stereotypes. Let us debunk the myths for you today.”...And...the stories are what we have.

Cary expressed the confidence that he had gained from participating in the project. “We did that and we can do it again,” to which Eagle echoed, “Cause our voices are speaking.”

Yvonda, who frequently came up with pithy sayings, concisely expressed her view of the value of Photovoice. “I think that Photovoice is *a great ammunition...for healing* not only in epilepsy but in anything.”

Participants made meaning of their Photovoice experience by restorying, reflection, and retelling their stories, with the hope of continual retelling in the future. “What They Took Away from the Table” was that they had been at the table and had been given the opportunity to go out from there, living fuller lives with meaning and purpose. As Eagle described in one of her photographs (Figure 21),

I felt like we had people at the table. We were all around the table and there was life there....It wasn't just an isolation that that symbolized...all of us together and the light that we were allowed to shine.



Figure 21. We have been at the table.

These are survivor stories of people who have been deeply hurt by life events and circumstances and who are still persevering. They have grown and learned and changed, experiencing personal transformation and empowerment. They have continued to face life more openly and are pursuing the personal and group causes that are meaningful to them. They are heading full throttle into the future. Despite limitations and with limitations, they are still moving forward.

The one caveat I have on meaning making is that the Photovoice experience has a certain meaning at this particular time, but it is ongoing, a process. I am sure it is different now for the participants looking back than it was at the exact ending of the original Photovoice project. Thus, the interpretation of meaning may continue to evolve and change in the future as the story is retold and told again.

Summary and Conclusions

I developed a conceptual diagram to express the chronological story of the group members over time as they experienced the ups and downs of life starting with the intrusion of epilepsy into their lives, and continuing through the various effects of the Photovoice research experience (Figure 22). This diagram can serve as a cryptic summary of the participants' lives with epilepsy and the subsequent changes brought into their lives by Photovoice.

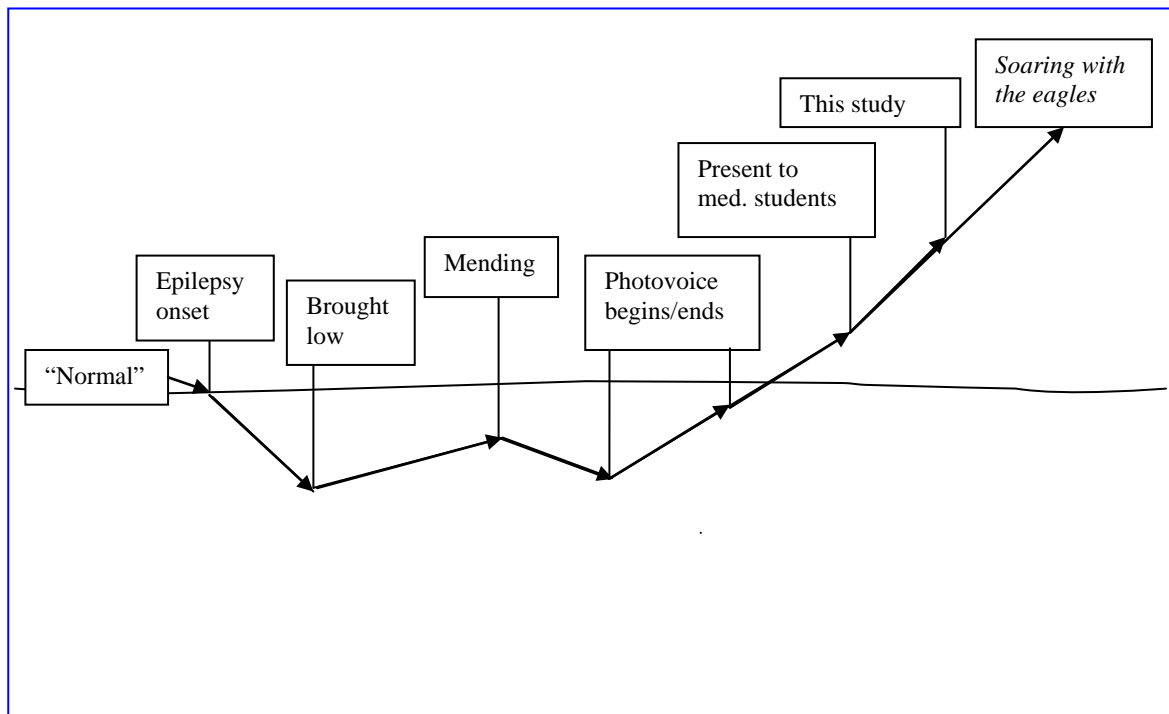


Figure 22. Conceptual timeline of the collective participant experience.

This concludes the findings of this study exploring the individual Photovoice research experiences of members of an epilepsy support group. Participant information and findings were presented under the three headings of *What They Brought to the Table*, *What They Found at the Table*, and *What They Took Away from the Table*. Descriptions of the support group context and the individual participants set the stage for the study in *What They Brought to the Table*. The first three major findings under the heading *What They Found at the Table* addressed the first research question: What are the experiences of individuals participating in a Photovoice research project aimed at social change? These three findings were:

1. Choices and challenges the participants faced as they decided to participate in and remain in the research study.
2. Growth and learning in a variety of areas.

3. Influence and change in the three areas they were documenting for the research.

The fourth finding under the heading *What They Took Away from the Table* addressed the second research question: How do members of a support group make meaning of their participation in a Photovoice project? This finding was:

4. Finding meaning and purpose in life through the Photovoice experience.

In the final chapter, I discuss findings in relationship to the literature, complete the meta-story, and offer study conclusions. I then present implications in several categories, make recommendations for further research, and provide a concluding summary.

CHAPTER FIVE: CONCLUSIONS, IMPLICATIONS, AND RECOMMENDATIONS

This research study developed out of a concern for the problem of marginalization that affects people with non-visible handicaps, particularly those with the highly stigmatized condition of epilepsy. The purpose of this study was to describe the individual experiences of epilepsy support group members who had participated in a Photovoice research project. The two research questions that guided this study were:

1. What are the experiences of individuals participating in a Photovoice research project aimed at social change?
2. How do members of a support group make meaning of their participation in a Photovoice project?

The structure of the chapter is as follows: First, I will summarize the study. Then, I will relate the study findings back to the major concepts, theories, and areas of literature in the earlier chapters, complete the meta-story, and draw conclusions. Next, I will discuss implications that apply to researchers, practitioners, and others. Lastly, I will make recommendations for further research and provide a final study summary.

Summary of Study

This retrospective qualitative study explored the individual research experiences of members of a vulnerable population who had participated in a Photovoice research project. Although Photovoice is a participatory action research (PAR) method whose purpose it is to effect social change, my research interest was in the individual experiences of the participants during this research process.

Study participants were members of an epilepsy support group. All four of the group members who had been in the original Photovoice research project agreed to participate in this study. Three of the participants were persons with epilepsy and the fourth was a caregiver for his wife who had epilepsy and was unable to attend support group meetings.

Visual narrative inquiry was the specific qualitative methodology that was used, enhancing the storytelling process with the addition of photographs. Data for the study came from a series of three interviews with each participant plus a final group interview. Photographs from the original Photovoice project along with additional photographs taken specifically to depict the Photovoice research experience provided a significant addition to the interview data.

I maintained a detailed research log along with extensive field notes written at the conclusion of each interview. The log and notes, along with transcripts, photographs, and documents and artifacts, served as data sources for the study. Data analysis focused on stories, both stories that accompanied the photographs and stories not associated with the photographs. I developed a free verse poem to provide the Gestalt of the overall story of participants' lives with epilepsy up to the point when they became involved with Photovoice. After reviewing the stories told by research participants about their Photovoice experiences, it seemed best to convey those stories in chronological order from the beginning to the end of the research experience. I grouped the stories into findings, relating the findings to the research questions. There were three findings for research question one and a fourth finding for research question two.

I used the metaphor of “being at the table” to conceptualize the overall research experience, with the three major headings of *What They Brought to the Table*, *What They Found at the Table*, and *What They Took Away from the Table*. Descriptions of the support group and the participants comprised the initial section *What They Brought to the Table*. The three findings under *What They Found at the Table* answered the first research question: What are the experiences of individuals participating in a Photovoice research project aimed at social change? These three findings were:

1. Choices and challenges the participants faced as they decided to participate in and remain in the research study. This finding dealt with the experiences, both negative and positive, that participants had as they made the decision to participate, and then entered and adjusted to the Photovoice research process.
2. Growth and learning in a variety of areas. This finding expressed a variety of areas of personal growth and dimensions of learning that participants experienced as a result of their Photovoice research participation.
3. Influence and change in the three areas they were documenting for the research. This finding demonstrated how participants were already influencing and effecting change in the very areas of stigma, barriers, and lack of support that they were documenting for the Photovoice project.

The fourth finding under *What They Took Away from the Table* answered the second research question: How do members of a support group make meaning of their participation in a Photovoice project? This fourth finding was:

4. Finding meaning and purpose in life through the Photovoice experience. This finding illustrated how participants made meaning and found purpose in their Photovoice research experience through restorying, reflection, and retelling their personal and Photovoice stories.

I further developed a conceptual diagram that summarized the chronology of the participants' lives with epilepsy and the ups and downs of their lives before, during, and subsequent to their Photovoice research experience.

Discussion

Interpretivism was the conceptual framework for the study. I chose this as the conceptual lens through which to view the study because I felt it would allow for multiple realities and various ways of meaning making that I expected to find from the participants' stories of their lives with epilepsy and their Photovoice experiences (Baskerville, 1999; Krauss, 2005; Merriam, 1998; Miles & Huberman, 1994; Prasad, 2005). Study data confirmed that interpretivism was indeed the appropriate conceptual lens since the participants told their stories from the perspective of their own life experiences and interpreted the meaning of their experiences according to the ways in which they saw the world. The value of interpretivism as a conceptual lens was further demonstrated when participants retold and revised their stories over time, especially the stories of their photographs. Some of these revised stories discussed in the previous chapter were about the epilepsy sculptures, the UXE campus, the stove, and the medications.

For the societal level, I reviewed the history, purpose, and working of participatory action research (PAR), a research methodology that views the participant as co-researcher

rather than subject (Kindon et al., 2007; Reason & Bradbury, 2008a). In PAR, the ideal goal is to involve participants at all levels of the research and to value their knowledge and perspectives since they know their own worlds best. Photovoice is a particular type of PAR that seeks to effect social change through the medium of documentary photography by bringing the stories of various marginalized groups to policymakers and others (Wang & Burris, 1997).

I did not have any particular expectations of how the participants would view the methodology itself, but was gratified to discover how participants responded to it. Cary thought deeply about the methodology and shared his opinions about how it worked and its value. During the Photovoice study, he took the initiative to develop his own themes for photographs in addition to those agreed upon by the group. In the final group interview for this study, Eagle took the lead in the discussion and described the themes that she saw being worked out in the lives of the participants. During that interview, there were several other instances when participants took the lead in the discussion and began to facilitate and moderate the conversation. The Photovoice experience was a very significant life experience for each of the participants and each of them emerged from the experience more hopeful, encouraged, and empowered to function effectively in their respective spheres of influence.

Although there was no particular teaching on PAR and how it works, the participants each experienced it and began to take on an increased role of co-researcher in this study. However, unlike the negatively empowered persons described in the study by Carlson et al. (2005), the support group experience brought all the participants along on the journey to

empowerment so that there was no ensuing conflict between the transformed and the untransformed.

With such a wealth of data on the individual Photovoice experience emerging through this study, it caused me to wonder what it would be like to concurrently capture individual experiences while the Photovoice project was ongoing. Although Riecken et al. (2005) were conducting a video project, the simultaneous reflective writing that occurred was notable and created an extra dimension to the study that linked individual experiences with the overall community goals of the project. A similar strategy for Photovoice participants could be a valuable addition, without negating the advantages of looking back at a situation in retrospect to determine its enduring effects.

Shifting focus from the societal to the individual view, I had expected to see self-care as described in Orem's self-care deficit theory (2001) as an important factor in the support group experience. Support groups for persons with chronic illness can also serve as self-care management groups (Clark et al., 2001; Sousa & Zauszniewski, 2005/2006; Sousa et al., 2005) and I thought there might be some similar effect on self-care from this study. However, this did not turn out to be the case, as I realized that self-care effects would be more applicable to a condition such as diabetes that is more amenable to changes in health behavior, which epilepsy is not. (While self-care did not arise as a major topic of discussion during the course of this study on the Photovoice research experience, I have heard participants discuss self-care issues, especially related to medication management, during regular support group meetings).

The concept of self-efficacy did, however, turn out to be applicable to this study. According to Bandura (1994), self-efficacy is the belief that one is capable of producing a certain level of performance that in turn may influence one's decision to attempt a particular action or activity. Participants in this study had all experienced years of isolation and discouragement as they battled the physical and emotional effects of a highly stigmatized non-visible and hard to treat condition. They were in varying stages of coming out of this long phase of separation from the world when the Photovoice project began. The personal experiences they had learning from one another, along with the group experience of being able to present the project to a group of medical students, acted together to give the participants an increased confidence in their ability do whatever they needed to do to move forward in their lives. Having overcome the challenges they faced with the resurfacing of painful memories and having successfully completed and presented the project made them feel that they were ready to conquer the world. As Cary so aptly put it, "We did that and we can do it again." I believe all of them experienced an increase in self-efficacy.

Because I expected to find examples of individual change as a result of the Photovoice research experience, I reviewed seven models of individual change in my literature review. These were the transtheoretical model, field theory, the Health Belief Model (HBM), transformative learning, self-renewal, stages of grief, and spiritual transformation. I had expected that within Prochaska's transtheoretical model, the stages of change component would best describe the changes that would be reported by participants (Petrocelli, 2002; Prochaska, 1979; Prochaska & Norcross, 1994). However, once again, this was not the case. None of the participants felt that they had experienced health behavior

change; nor had they observed it in each other. In thinking about this further, I realized that just as Orem's self-care deficit theory (2001) would be more applicable to a condition for which self-care can make a significant difference, the transtheoretical model also fits better with health problems for which health behavior change can make a significant difference. For example, if someone has diabetes, what they eat and how they exercise can affect blood sugar control. For someone with epilepsy, however, there is less difference that health behavior can make in the prevention or control of seizures. They can remember to take their medications and they can avoid known triggers, but there is often not much in the way of lifestyle modification that will make a difference in seizure activity. Thus, I can see why the transtheoretical model was not a good explanatory model for the changes that the participants experienced.

The one aspect of the transtheoretical model that was relevant to my study was consciousness raising, the first of ten steps in the processes of change component of the model (Prochaska & Velicer, 1997). Kleinknecht (n.d.) referenced both photos and self-help groups as experiential procedures that could lead to consciousness raising. This was definitely demonstrated by the responses of participants in this study. The photographs taken by participants and shared with the others in the group, as well as those shared with the medical students, did have the effect of increasing and heightening awareness of the various life problems that people with epilepsy encounter.

Although the transtheoretical model as a whole was not a good fit with the data, Hudson's (1999) self-renewal model was. In his model, he postulated four components of the change cycle: Phase 1: Go for it, Phase 2: The doldrums, Phase 3: Cocooning, and Phase 4:

Getting ready. For persons suffering with the onset of a sudden, unexpected, and debilitating illness, Hudson's model does a good job of describing how an individual could retreat from the world following the loss of a dream, go through a period of cocooning, and eventually re-emerge ready to face the world with new hope and new direction. The individuals in this study all experienced this process in one form or another, depending upon their illness progression and improvements over time. Even though not all of them have had marked physical improvement, they all experienced improved social, psychological, and spiritual health.

It was particularly notable to me that Alice took five different butterfly photographs in her garden to show the status of her life today now that she is seizure free, since the butterfly is the perfect illustration of what happens when the cocooning stage described by Hudson (1999) is over. Figure 23 is one of the butterfly photographs that Alice took. Without consciously knowing they were following Hudson's model of self-renewal, the study participants have indeed been writing their own "script" to make their "world work," as Hudson had suggested, and as such, are even moving beyond individual change to take more active roles in the society around them.



Figure 23. Butterfly.

Interpretivism may be applied not only to the varying views and perspectives of the participants, but also to the process of aligning their reported and observed changes to various individual change models. Although I see Hudson's (1999) model as the best explanatory model for the changes in the participants, other models discussed also have applicability.

The changes that the participants experienced were not reflective of the highly cognitive ten phase transformative learning process initially described by Mezirow (as cited in Taylor, 1998). However, the slower and more intuitive aspects of transformation described in Mezirow's later work (2000) could better describe the experiences of the Photovoice

research participants, especially the artistic impact of taking and interpreting photographs. However, the concept of knowing through images and the promotion of transformative learning through artistic means as described by Dirx (1997, 1998, 2000) may be even more applicable. In addition, during her third interview, Eagle specifically referenced Kubler-Ross's (1969) stages of grief and related the grieving process to the losses that persons with disabilities experience. When applying this model to chronic illness, personal transformation may be the eventual outcome as one progresses through the stages.

Having heard discussions of spiritual matters during the original Photovoice project and at some of the later support group meetings I have attended, I expected that spirituality would arise as a topic even though I had no specific interview questions about it. Although the participants frequently mentioned spiritual matters, especially the role of personal faith in sustaining them through the various life difficulties they encountered, significant spiritual change did not seem to be an occurrence. Rather, the participants already had their own spiritual walks within the Judeo-Christian tradition and acknowledged the presence and working of God in their lives. This would put them in the stage of spiritual integration described by Neal et al. (1999). I believe it was those frequent references to spiritual matters in the discussion that encouraged Cary, especially, to speak up more than usual when he made the reference to medications being "a gift of God." Mahoney and Pargament (2004) discussed the fact that outcomes of spiritual transformation could be either personal or empowering to social action. In the case of the Photovoice research participants, it seemed to be both personal and empowering to social action.

In my discussion of the individual perspective, I considered varying views of individual change within a group context, particularly support groups. Results of this study confirmed the occurrence and importance of individual change within the group context as suggested by Scott (1997). The participants acknowledged individual change within themselves and also observed it in others. While exploration of the possible effect of Photovoice on a support group was not one of my research questions, participants also reported the positive effects on group formation that they experienced through Photovoice. It seemed that there was a synergy between the mutually supportive nature of the group that provided a sense of community (Wuthnow, 1994) and the nature of the Photovoice experience that promoted deep sharing through the use of photographs. The participants felt that as they grew personally, they also strengthened their relationships and that in turn promoted the solidarity of the group through a new common experience.

Although the photography in Photovoice is viewed and used as documentary photography (Wang & Burris, 1994), I felt that photography was also an art form (Daval, 1982; Gassan, 1972) and that there was an artistic feature to the taking of photographs. This was definitely borne out by the data from this study. Each participant already had at least one form of artistic expression in his or her life and each of them had some concept of the creativity involved in the taking of photographs. Cary and Eagle, especially, had much to say about choosing the subject and composition of a photograph, while all of them demonstrated growing creativity in the types of photographs they took. In addition, as several of them admitted, the preference not to take photographs of people due to the need for consents was at least a partial motivator for this creativity.

Presentational knowing, one of four ways of knowing described by Heron and Reason, is derived from experiential knowing and uses various art forms, both nondiscursive and discursive, to express images deriving from the imaginal mind (Heron & Reason, n.d., 2008). Stories and photographs, such as those in this study, are just two examples of presentational knowing. The numerous stories told by participants, along with their photographs, provided a multitude of opportunities for presentational knowing. When participants talked about the photographs that they remembered and the stories that went along with them, it was evident that they had experienced presentational knowing. Several of Alice's photographs, such as the ID card and the single place setting at her kitchen table, were among those vividly remembered by others. Yet she was the quietest one of the group and when she did speak, her comments were brief. Her ability to take photographs that made a lasting impact reflected her own unarticulated artistic ability.

In the data analysis, artistic growth and learning about photography emerged as two sub-themes under the second finding of *Growth and Learning*. Restorying was the first major sub-theme under the fourth finding of *Meaning and Purpose*. And of course, the whole study was about stories, both with and without accompanying photographs. There were stories of life with epilepsy and both individual and group stories of the Photovoice research experience, all of which reflected presentational knowing. Considering storytelling as one form of presentational knowing, the participants exemplified narrative learning (Clark, 2001) by the increased self-awareness and personal growth that occurred through the telling and retelling their own stories and their learning from the stories of others.

The photographs were the main triggers for the stories told by participants, but the documents and artifacts they provided during the individual interviews also helped to illustrate some of the points they were making about Photovoice, as well as communicate more of who they were as people living with chronic illness. Clandinin and Connelly (2000) explained that such items trigger memories to help people tell and retell their stories, making these collections serve as an “archaeology of memory and meaning.”

In the *Areas of Growth* section, several of the areas I described, emotional, social, artistic, spiritual, and intellectual, map to several of Gardner’s (2004) types of intelligences. The similarities are as follows: emotional maps to intrapersonal, social maps to interpersonal, artistic maps to spatial, spiritual would map to his spiritual category (if he decides to add it), and intellectual maps to linguistic and possibly logical-mathematical.

A model which I have recently discovered is Ferrell’s (1996) Quality of Life Model. This model has been used extensively with cancer patients. However, it can easily be adapted to other health conditions and I see it as equally applicable to the condition of epilepsy. The four categories in this model are physical well-being and symptoms, psychological well-being, social well-being, and spiritual well-being. I have substituted the word “illness” for three references to “cancer” in Ferrell’s following description of the four domains:

Physical Well-Being is the control or relief of symptoms and the maintenance of function and independence.... Psychological Well-Being is the attempt to maintain a sense of control in the face of life-threatening illness characterized by emotional distress, altered life priorities, and fear of the unknown, as well as positive life changes....The Social Well-Being domain provides a way to view not only the *illness*

or its symptoms but also the person...it is the means by which we recognize people with [the] *illness*, their roles, and relationships....Spiritual Well-Being is the ability to maintain hope and derive meaning from the *illness* experience, which is characterized by uncertainty. Spiritual well-being involves issues of transcendence and is enhanced by one's religion and other sources of spiritual support. (pp. 911, 912, 913)

Three of the areas of growth from my study, emotional, social, and spiritual, fit very well with Ferrell's Quality of Life model (1996). Although my study included life with epilepsy in the participant profiles, this was not the focus of the study. However, all the physical challenges of living with epilepsy, including the need for avoidance of certain environments and hazards, would fit with the physical well-being aspect of this model.

In this section I have highlighted some of the significant connections between the literature and my research findings. A final connection is with the problem of marginalization that underlies the reason and purpose for the study. The experience of being marginalized, stigmatized, and being treated as the Other (Crisp, 2007; Jones et al., 1984; Kemmis, 2008; Lynam & Cowley, 2007; Vasas, 2005) were often expressed by the participants as they relayed various hurtful life experiences and recollections. Eagle brought up the concept of "The Other" in her discussion of the safe and positive experience she had in the support group, just the opposite of what persons with disabilities often go through. In the group interview, they also discussed ongoing situations of stigmatization and marginalization in society that persons with epilepsy and other disabilities continue to face.

I found a myriad of confirmations, contrasts, and connections between the literature I reviewed for this study and the study findings. In some instances the findings helped to better

illustrate or confirm the literature. In other instances, the findings did not line up with some of the models I had expected them to agree with. Thus, I saw the progressively revealing nature of qualitative research interact with the literature in an enlightening way.

Conclusions

In the original conceptualization of this study, I had planned to compose a metanarrative out of the separate narratives provided by the individual participants. As the study evolved and the data emerged, I began to change my ideas about a single metanarrative and ended up with three separate expressions. The first was the poem “My Life with Epilepsy – The Unfinished Story” provided in Chapter 4 as a composite story of the participants’ lives with epilepsy. The conclusion of that poem follows as a way of expressing the final positive outcome of the Photovoice research experience. (See Appendix D for the entire poem).

My Life with Epilepsy – Conclusion

And I did get better. Some things changed. At least I think they did. Or maybe I just got stronger, stronger inside and out. Learned new work arounds. Whatever it was, I got out more, related to more people, shared my story without shame, reached out to others.

And driving helped!

Today I am an advocate. Today I am an artist.

Today I am a clown. Today I am a lawyer.

And I will tell anyone my story.

The second expression was the chronological diagram of the participants' collective experience (Figure 22), also presented in the previous chapter, that illustrated the intersection and impacts of Photovoice on the timeline of their lives and visually reflects the downs and ups of the participants' lives with epilepsy as they relate to Photovoice.

The final expression is a single photograph chosen by the group to express their composite experience. During the group interview, the participants agreed upon one photograph to represent their Photovoice research experience and we subsequently discussed it using the SHOWeD technique. The photograph, taken by Eagle and shown in Figure 24, was composed of a Bible, a roll of scotch tape, and a plant.



Figure 24. Bible, tape, and plant.

The group's description of the photograph follows and is a composite of comments from the participants as they chimed in their ideas and interpretations.

Yeah the Bible and the flower.... Well I see the Bible as a source of...resource of faith....The plant, that's growth. You would put soil to that and it grows and I think

this is what Photovoice has done to us, has been soil to our...to our group...The Scotch tape is...taping us together....It's taped all the pieces that were sort of lost...together in a way that's a positive statement. Because you know, disability puts so many fragments and so many different harms but this...the project helped to put some of that back together that exist because of invisible and sometimes visible disability depending on what variation we have got...and the Bible says not to "cast your pearls before swine." And a lot of times, that's what, you know like *with the ID cards and things like that, we've cast our pearls – we've given our things and our dignity and then people have not understood and have tried to [put us down]. But in the faith context, that was, you know, those pieces were kind of brought back together for me too with the group.*

Thus, the participants felt that their faith provided continuing sustenance while Photovoice helped put their fractured lives back together and engendered personal growth that was continuing.

In trying to further distill the findings and the meta-stories to a more concise summary of what I found in this study, I present the following conclusions:

1. There was an individual effect of Photovoice research participation.
2. The Photovoice project had the potential to derail the continued participation of the participants due to factors that could be dealt with in future research.
3. Photography was not only documentary but artistically based and promoted creativity in the composition, taking, and interpretation of photographs.

4. Presentational knowing through photography and storytelling helped to overcome some of the limitations imposed by the chronic conditions of the participants while enhancing their ability not only to communicate their individual stories, but also to understand the stories of others.
5. Participants incorporated the story of their Photovoice research experience into their personal life stories and considered it an important factor in their subsequent improvements whether physical, social, psychological, or spiritual.
6. Rather than looking to policymakers and others, participants became their own agents of transformation in addressing the problems that they faced, particularly stigma, barriers, and lack of support.
7. The Photovoice experience helped participants to clarify and expand their sense of meaning and purpose in the suffering associated with chronic illness and was a factor helping them to feel empowered for helping others in similar situations of marginalization.
8. Although the group effect was not included in the research questions for the study, participants expressed the learning and positive associations they gained from the interpersonal relationships in the group that were enhanced by the Photovoice experience.
9. The individual effect was profound, significant, long-lasting and persistent, and led to personal growth, learning, and transformation.

Implications

This study provided an in-depth examination of the experiences of four members of an epilepsy support group who had participated in a Photovoice research project. As a qualitative study, it makes no claims as to generalizability to persons with other health conditions, other support groups, or other individuals who have participated or will participate in Photovoice research. However, the breadth and type of experiences reported by these participants makes it likely that other Photovoice research participants have experienced some type of individual effects due to their research participation.

In thinking about implications for practice, I considered how I might use Photovoice in my professional practice as a nurse and an educator as a result of what I have learned from this study. For example, I could see using Photovoice with other support groups that I work with. I also considered how persons in other fields of study might apply these findings. For example, I could see relevance to persons conducting online learning and persons working with special education populations. For the purposes of discussion, implications are divided into five categories: implications for persons using the Photovoice research methodology, implications for persons with disabilities, implications for health care professionals, implications for educators and administrators designing learning experiences, and implications for persons working with special populations. Note that these categories are not mutually exclusive as implications in one category may be applicable to another. Health care professionals may also be educators; educators may also be researchers, etc.

Implications for Persons Using the Photovoice Research Methodology

For persons using the Photovoice research methodology, it would be important to take additional care describing risks and benefits in the study proposal and especially the consent form. For future studies with persons with disabilities and others dealing with the effects of long-term chronic illness, researchers should make sure that the consent form provides an accurate reflection of the possible psychological effects of remembering past hurtful events, as well as the potential benefits of positive personal change. It would also be important to be fully aware of the health conditions and other limitations of the persons who are being invited to participate in Photovoice research. Encouraging all researchers to be respectful of possible participant limitations that may become evident during the research process may not only improve participant experiences, but should be part of the overall effort to model true participatory action research principles.

Photovoice researchers could consider giving additional instruction on taking photographs beyond what is typically done, enough to enhance the participants' understanding of more artistic options, but not so much as to be intimidating or limiting. For any future studies looking at individual experiences of Photovoice research participation, it could be beneficial to include spouses, significant others, and/or family members and friends who can verify or confirm self-perceived changes reported by study participants. This could serve as an additional triangulation strategy to demonstrate trustworthiness of the qualitative data. I also recommend that individuals participating in Photovoice research engage in reflective journaling or other methods of self-report, especially photographs, in order to provide a concurrent view of their experiences as the research progresses. This would not be

to negate the retrospective view of individual experiences, but to enhance the data gathered, as one might expect that reflections during the research may differ from reflections looking back at the research at some future time.

Implications for Persons with Disabilities

Persons with disabilities should educate themselves about the features of participatory action research projects such as Photovoice in order to become informed about potential impacts that such research could have for them personally, as well as for any causes associated with their particular disabilities. Persons with disabilities need to become well-informed about any research opportunities presented and make sure to ask questions about any benefits or risks that are unclear. They should take advantage of invitations to become co-researchers in projects of interest and be proactive in offering comments and suggestions as to how to improve the research process.

Implications for Health Care Professionals

Health care professionals such as nurses, social workers, and others leading support groups, should consider tapping into the potential benefits of a Photovoice project to create, enhance, or deepen relationships among members and accelerate group formation. Photovoice could also be used with support groups to help them create community awareness about their specific conditions, while also assessing their individual experiences during the research process. At the same time, it would be important to realize that there may be some potential participants who would not be ready to look inward in such an intense way or to hear the sometimes painful stories of others. Photovoice could also be used as a clinical tool

in health care settings to assist students in a variety of health professions to learn more about client reactions and interpretations of the illness experience.

Implications for Educators and Administrators Designing Learning Experiences

Educators and administrators should realize the potential usefulness of a Photovoice project for both traditional classroom and online classes whose content includes issues related to marginalization and/or other social issues. Taking photographs and subsequently discussing them would work well in both classroom and online venues, with the difference being that online students could be taking their photographs in vastly different communities from the other students. This could in turn affect the choice of topic. For online students, use of technologies such as Elluminate to allow verbal storytelling would maintain the feature of presentational knowing that could be eclipsed by only permitting written descriptions of photographs.

Implications for Persons Working with Special Populations

Persons working with special populations should recognize the potential benefits of using Photovoice with persons whose modes of learning and expression could be facilitated by photography and storytelling. People who may be better able to communicate inner thoughts and feelings by a photograph than by describing those thoughts could find an empowering outlet for expression through Photovoice. In discussing the transcripts, Eagle specifically mentioned that she thought Photovoice would be great for people with memory problems because the photographs can help with encoding, as well as serving as a memory trigger.

A final general implication applicable to all these groups is that Photovoice has the potential to affect participants in many dimensions of life in mostly positive ways and that its artistic aspects can be especially powerful in both reaching and teaching people about themselves and others. Presentational knowing through the arts of photography and storytelling is worth acknowledging as a potential addition to the theoretical bases for and benefits of Photovoice.

After reviewing the transcripts, Cary wrote an email describing his view of the ongoing value of Photovoice.

I really like the Photovoice idea, its simplicity in execution and its brevity for time limited presentations, no need for fancy equipment and big grant bucks, plus ease in training picture-takers. The picture-takers all seemed to know what to do, what was important to them and the potential audiences. I have a feeling Photovoice is effective for a wide variety of audiences.

Let's make it happen.

Recommendations for Further Research

I can envision a number of research studies that could be generated from this study. Since my research was a qualitative study with one particular support group of people representing the specific non-visible handicap of epilepsy, it would be interesting to discover if similar individual reports would surface from studies with other handicaps, both visible and non-visible, and particularly if similar results would occur with a less stigmatized condition such as diabetes. The visual narrative inquiry method I used could be applied to exploration of the individual experiences of such persons with disabilities who are former

participants of other Photovoice research projects. It would be interesting to compare the individual experiences of Photovoice research participants who were already members of a support group with persons who had just met each other as a result of joining a Photovoice research project. I would also like to see a comparison of the individual learning and group formation processes of support groups with and without caregiver members to assess possible differences. Designing a Photovoice research project using Felton's Quality of Life model (1996) as a theoretical framework could be done to assess the effect of individual experiences of persons with either a disability or a chronic illness on quality of life. Because of the many participant references to the group effect, I would like to include that as a research question in future studies with support groups composed of persons with a disability or chronic condition. Most importantly, I would like to see the incorporation of a concurrent method of documenting individual experiences into a new Photovoice research project in order assess individual effects at the end of the project along with the social change impact.

The Continuing Story

A key photograph that symbolized Eagle's epilepsy story was hurdles. Figure 25 shows a series of hurdles, one after the other in close proximity.



Figure 25. Hurdles.

It was not just the hurdle of epilepsy to overcome, but all the other ones that have come along for her: the loss of relationship, multiple other medical conditions, the challenges of

succeeding in academia with a disability, and the ongoing daily challenges of living and working in a world that is seizure-inducing and toxic to her. The other study participants also identified with this photograph as they could each apply the concept of hurdles to their respective personal health stories. In the world of sports, there is a final hurdle before the race is over. For Eagle and the others in the group, the hurdles never end, as life continues to bring new challenges. One may hope, however, that there is occasionally a little extra space between the hurdles as some treatments provide new help, while other changes in perspective or inner strength may help the participants to more easily surmount the next hurdles that come along.

Summary

The participatory action research strategy of Photovoice aims to produce social change by putting cameras in the hands of various marginalized groups to document, explain, and interpret community issues (Wang & Burris, 1997). As Photovoice becomes used for an increasing diversity of purposes and for more individual and interpersonal purposes than it was originally conceived (LeClerc et al., 2002; Lopez et al., 2005), it seemed important to consider the possible effects on individuals of Photovoice research participation. It also seemed reasonable to consider other features of Photovoice that might expand the original conceptual underpinnings of empowerment education, feminist theory, and documentary photography (Wang & Burris, 1994). One of my suppositions was that there was value in exploring the aesthetic aspects and potential effects of the photographs in Photovoice as both art and a form of presentational knowing.

The research focused on the individual experiences of support group members from a vulnerable population who had participated in Photovoice research. The conceptual framework was interpretivism. The major areas of literature considered were (a) participatory action research, Photovoice, and the societal perspective, (b) self-care, the transtheoretical model, and the individual perspective; and (c) photography as art, art as healer, and the potentially transforming effects of photography and storytelling as forms of presentational knowing.

Visual narrative inquiry was the qualitative methodology that was used. This methodology combined narrative inquiry with visual images such that the recounting of participants' Photovoice research experiences could be linked with photographs from the prior Photovoice research project, as well as additional photographs they had taken to illustrate their research experiences. A careful and credible research process was designed to elicit data that portrayed the respective research experiences and meaning making processes of the participants.

The three findings of

1. Choices and challenges the participants faced as they decided to participate in and remain in the research study,
 2. Growth and learning in a variety of areas, and
 3. Influence and change in the three areas they were documenting for the research,
- answered research question one, which was: What are the experiences of individuals participating in a Photovoice research project aimed at social change? The fourth finding of
4. Finding meaning and purpose in life through the Photovoice experience,

answered research question two which was: How do members of a support group make meaning of their participation in a Photovoice project?

In this final chapter I have summarized the study and related the findings back to the conceptual framework of interpretivism and the three literature areas, noting aspects of the study results that either supported or did not match well with the literature. I concluded this process by relating the findings back to the problem of marginalization that underlies the purpose of the study.

In accordance with my plan to create a meta-story or metanarrative of the Photovoice research experience, I presented three different expressions: a poem, a conceptual diagram, and a summary photograph chosen by the study participants. These three expressions, along with the conclusions given, assert that there was an individual effect of research participation in the Photovoice methodology designed for social change, that the individual changes were significant, profound and enduring, that the artistic aspects of photography were an important part of the meaning making process, and that the participants became agents of their own transformation as they learned to assume the co-researcher role.

Implications for researchers, persons with disabilities, health care professionals, educators and administrators, and persons working with special populations, reflect the range of things learned from this study that can improve the research and learning experiences of future Photovoice participants as well as enhance the design of future Photovoice research projects. Recommendations for further research suggest a variety of studies that could be done to continue to explore the individual experiences of Photovoice research participants, particularly persons with disabilities and chronic illness in support group settings.

In choosing the title for this research, “Giving Light to Voice,” I received some questions as to how light and voice could be related. Yet in the course of this study, it all came together with the importance of light to the making of photographs, the challenges that lights can bring to many persons with epilepsy, and the insights on light provided by Eagle, for whom light is especially precious due to her visual limitations. As we were discussing how much she loved light during our second interview, I mentioned the proposed title for this research, and she immediately recounted a story in which she had approached a politician before one of his speeches to put in a plea for him to remember people with disabilities. Then after his speech, she went up to him again. There she was in her dark glasses, having been stuck away in a dark corner as he spoke. He looked at her and said, “It’s like we need to bring the *voice* out of the shadows and the *light* to people who are going through these various things.” She was so excited that her brief comment to him and the visual image she later presented caused him to make that connection. So it is with the photographs, recordings of light, according to Gassan (1972), and the stories, voices of people who have been marginalized, that come together in Photovoice to make a difference in people’s lives both individually and collectively.

The photograph of light (Figure 26) taken by Eagle seems almost too bright, but it symbolizes how much light is often needed to bring a neglected issue into public view, in this case, the plight of persons from a vulnerable population with the highly stigmatized condition of epilepsy. In contrast to the hurdles, this light provides great hope.



Figure 26. Full light.

For the participants of this study, who became true co-researchers, Photovoice has given them voice. They have come out of the margins onto the page in a story that will continue to be written. As Yvonda said, “It’s a new story of our story.” So in the spirit of participatory research, I will let Yvonne, the leader of the group, and an even stronger epilepsy advocate following her research experience, have the last word on Photovoice and the last photograph (Figure 27), which significantly, shows her cane, a symbol of disability, her car, which she can now drive, and her license plate, which invites people to ask about her story.

I...I guess I can't find the words to say right now but I would say that it is positive. It was positive and I was glad to be a part of it and I'll probably find the word. Remember I have epilepsy.



Figure 27. Always the advocate.

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APPENDICES

APPENDIX A

Photovoice Research Process Outline and Narrative

These are the steps of a sample Photovoice research project, once the topic has been chosen and the potential research participants have been contacted.

1. Informational meeting. Explain project. Give out consents. Give instruction on taking photographs. Discuss themes. Give out first camera and remind of theme.
2. Participants turn in cameras at central location or are picked up by researcher. Two week turn around. Get prints developed.
3. Meeting one to discuss photographs, using SHOWeD technique. Discuss top three or four photographs. Group decides on one or two photographs to discuss in-depth using SHOWeD technique. Hand out second camera and remind of second theme.

<p>SHOWeD</p> <p>What do you See here? What is really Happening? How does this relate to Our lives? Why does this problem or strength exist? What can we Do about it?</p>
--

4. Participants turn in cameras at central location or are picked up by researcher. Two week turn around. Get prints developed.
5. Meeting two to discuss photographs, using SHOWeD technique. Hand out third camera and remind of third theme.
6. Participants turn in cameras at central location or are picked up by researcher. Two week turn around. Get prints developed.
7. Meeting three to discuss photographs, using SHOWeD technique.
8. Meeting to discuss themes, reflect back.
9. Develop presentation.
10. Presentation to community group, policy leaders etc.

The initial meeting to describe the study and obtain informed consent was at the public library, but by the time we began to meet to discuss the photographs, we were meeting at a local restaurant with a private dining room, since scheduling at the library had become too difficult. The core group members, Yvonda, Alice, Cary, and Eagle, had all decided to participate in the project.

Following the basic Photovoice process, we first met to discuss possible themes for the photographs. The three themes chosen and agreed upon by the participants were Stigma and Discrimination, Accessibility and Barriers, and Family and Support. We then proceeded through three rounds of taking photographs with disposable cameras on the chosen theme, providing the developed photographs back to the participants in duplicate, meeting to discuss the photographs, and then repeating the same process for the other two themes. In a final meeting we as researchers reflected back additional themes we had gleaned from the taped meetings and verified these findings with the group before going on to develop the presentation later given to the medical students.

APPENDIX B

North Carolina State University INFORMED CONSENT FORM for RESEARCH

Title of Study: Giving Light to Voice: Individual Stories of Photovoice Research Participation

Principal Investigator: Janet Morton

Faculty Sponsor (if applicable): Dr. Colleen Aalsburg Wiessner

We are asking you to participate in a research study. The purpose of this study is to describe the personal experiences of epilepsy support group members who have participated in a Photovoice research project.

INFORMATION

If you agree to participate in this study, you will be asked to 1. Attend a group meeting where the study will be explained in detail and consent forms will be signed. 2. Review the photographs you took for the Photovoice project and decide if there are any you would like to talk about to describe your personal experience of participating in the project. 3. Take a new roll of photographs with a disposable camera that will assist you in describing your Photovoice research experience and its impact on you. 4. Participate in three individual tape-recorded interviews of up to 90 minutes each, scheduled at least a week apart. 5. Participate in a tape-recorded group discussion lasting up to 90 minutes with the other support group members from the prior Photovoice project at the conclusion of all the interviews. Total time commitment will be six to eight hours.

RISKS

Recalling and talking about your Photovoice research experience may bring up memories or feelings related to epilepsy and its effects that you find discomforting. You will have the option during the interviews of ceasing to talk about any subject that you find particularly distressing. If you feel that you need a mental health referral as a result of these memories or feelings, it will be provided. There is also a remote possibility of injury or emotional distress associated with taking photographs about your Photovoice experience. The importance of gaining consent for taking identifiable photographs of people will be reviewed before you are given the camera. You will also be encouraged to exercise caution in taking photographs in places where you might fall or sustain some type of injury. In addition, if there are particular types of environments you know could cause you to have a seizure you are urged to take your usual precautions.

BENEFITS

Possible benefits from the research may be a greater self-awareness and understanding of the effects of your participation in the Photovoice research project. You may also gain new understanding or insights about or from the other members of the support group as a result of the final group discussion. Knowledge gained from this research has the potential to help other researchers conducting Photovoice research to understand the possible individual experiences of research participants as they develop future studies.

CONFIDENTIALITY

The information in the study records will be kept strictly confidential. Data will be stored securely in the home office files and computer of the researcher. No one else has access to this office. No reference will be made in oral or written reports which could link you to the study unless you specifically request that your real name be used.

COMPENSATION

There is no compensation associated with participating in the study. A complete set of photographs taken will be given to each participant at the end of the study.

EMERGENCY MEDICAL TREATMENT

It is not expected that participants will need any emergency medical treatment. However, if any is needed, participants will be expected to access whatever hospital or physician they would normally use, with any ensuing treatment to be covered by their personal health insurance. The researcher requests that each participant provide emergency contact information to her at the time of study enrollment so that she can be prepared in case any participant experiences a medical emergency during the interview process.

CONTACT

If you have questions at any time about the study or the procedures, you may contact the researcher, Janet Morton, at (xxx) xxx-xxxx (day), (xxx) xxx-xxxx (evening). If you feel you have not been treated according to the descriptions in this form, or your rights as a participant in research have been violated during the course of this project, you may contact Dr. David Kaber, Chair of the NCSU IRB for the Use of Human Subjects in Research Committee, Box 7514, NCSU Campus (919/515-3086) or Mr. Matthew Ronning, Assistant Vice Chancellor, Research Administration, Box 7514, NCSU Campus (919/513-2148)

PARTICIPATION

Your participation in this study is voluntary; you may decline to participate without penalty. If you decide to participate, you may withdraw from the study at any time without penalty and without loss of benefits to which you are otherwise entitled. If you withdraw from the study before data collection is completed your data will be returned to you or destroyed at your request.

CONSENT

“I have read and understand the above information. I have received a copy of this form. I agree to participate in this study with the understanding that I may withdraw at any time.”

Subject's signature _____ Date _____

Investigator's signature _____ Date _____

APPENDIX C

Interview Guide

Interview questions are based on the following proposed interview plan:

Interview 1: Focused life history

Interview 2: Details of Photovoice research experience

Interview 3: Sense or understanding of the Photovoice research experience

Group Session: Reflections, Commonalities, and Conclusions

A general outline of questions follows:

Interview 1: *Focused life history*

Today I'd like to get an overall view of your life, especially as it relates to epilepsy. We hadn't specifically asked for photographs about this, but if there are any that you think are helpful for illustrating your life, feel free to share them now or as we discuss other questions today.

(Background information: education, family, work, leisure, chronic conditions)

1. Tell me a little bit about yourself. What are the first things you would like someone to know about you when they meet you?
2. I'd like to know something about your life with epilepsy. Tell me how this all came about.
3. How does epilepsy affect your daily life?
4. What are some of the things you have learned about dealing with a chronic illness or are still learning?
5. When you knew you were going to be interviewed today, were there some things you expected us to talk about that we haven't discussed? Tell me about it.

6. SUMMARIZE: The purpose of our discussion was to get an idea of the story of your life with epilepsy. We've talked about...So is there anything else about your epilepsy story that you would like to add? (Was background information obtained?)

Interview 2: Details of Photovoice research experience

Today I'd like to talk specifically about your Photovoice research experience. First, I'm wondering if you have anything you have thought about since our first meeting that you would like to add....Are there any photographs or other artifacts that you would like to share about your Photovoice experience? Feel free to share them now or along with any of the other questions we discuss today.

(Background information: prior experience with research and with photography)

1. To begin with, I'm interested in how you decided to participate in the Photovoice research project.
2. Tell me about your experience as a participant in the Photovoice research project.
3. I'd like to find out about any outcomes or results you saw or experienced from this project.
4. What was it like to take and talk about photographs of your life with epilepsy?
5. When you knew you were going to be interviewed, were there some things you expected us to talk about that we haven't discussed? Tell me about it.
6. SUMMARIZE: The purpose of our discussion was to talk about your individual experience as a participant in a Photovoice research project. We've talked about...So is there

anything else about Photovoice and sharing your epilepsy story through photographs that you would like to add? (Was background information obtained?)

Interview 3: Sense or understanding of the Photovoice experience

We're continuing to talk about your Photovoice research experience, so I'd first like to review some of the things you talked about last time and see if there is anything you would like to add....Are there any additional photographs or other artifacts that you would like to share about your Photovoice experience? Feel free to share them now or along with any of the other questions we discuss today.

1. What about health effects, changes in attitude or behavior that you experienced yourself?

Have you experienced any specific changes in health behavior as a result of participating in the Photovoice research project?

2. What about health effects, changes in attitude or behavior that you observed in other participants in the project? Have you observed any changes in health behavior in other members of the group as a result of participating in the Photovoice research project?

3. I'm really interested in knowing how Photovoice as an art form to communicate about epilepsy impacted you personally.

4. Are there any other effects on yourself that you noticed as a result of your Photovoice research participation?

5. When you knew you were going to be interviewed today, were there some things you expected us to talk about that we haven't discussed? Tell me about it.

6. SUMMARIZE: The purpose of our discussion was to talk about your understanding of the experience of being a participant in a Photovoice research project. We've talked about...Since this is our last individual interview, is there anything else about your epilepsy story, Photovoice, taking photographs or the overall experience that you would like to add?

Group Session: *Reflections, Commonalities, and Conclusions*

Now that I have talked with each of you individually, this is our opportunity for a group discussion about your Photovoice research experience and its impacts. Are there any particular photographs or other artifacts that you would like to share with the group about your Photovoice experience? Feel free to share them now or along with any of the other questions we discuss today.

1. First of all, I'd like to know about any ideas or insights you may have had during the course of our three interviews that you would like to share with the group.
2. What are some of the effects of Photovoice research participation that you noticed on yourselves?
3. Are there any effects of Photovoice research participation that you noticed in others that you would like to share?
4. What about the experience of taking and seeing photographs others had taken? How did the photographs and stories told about them affect you?
5. SUMMARIZE: The purpose of this last discussion was share reflections and note commonalities and differences in your respective Photovoice research experiences. We've

talked about...So is there anything else you would like to add or any conclusions you would like to make as a group?

APPENDIX D

My Life with Epilepsy

I had a life and it was a good life. It wasn't a great life or a perfect life, but it was *my* life. I was married and had a career and satisfying relationships with friends and family.

And then one day it all changed.

I had a seizure, and then another, and another and it wouldn't stop. It didn't matter where I was. I couldn't stop it and the doctors couldn't stop it. My life was out of control. It was confusing and disorienting. I was injured, body, mind and spirit.

Why this? Why me?

It wasn't just one isolated seizure from a known source. Like a child with a febrile seizure. Stop the fever and stop the seizure. It was epilepsy and it jumped into my life and disrupted everything.

The seizures left me foggy-brained. The medications left me foggy-brained.

I couldn't do for myself. I couldn't go where I wanted to go when I wanted to go. I couldn't work. I couldn't drive. *Sometimes I didn't even know who I was.*

And worst of all, it was invisible. If I broke a leg, people would give me sympathy.

But between seizures, no one could see the "it."

So maybe I didn't really have a problem. Maybe I just didn't want to work or take care of the house. Maybe there wasn't that much wrong with me.

Get over it, they said.

But worse than the worst, it was scary and threatening. Specters from ancient history. Myths and misconceptions. Did I have supernatural powers? Or was I doomed by some great unknown sin?

Don't tell the neighbors. Don't tell the family. Don't tell anyone! Keep the secret. So much stigma and so much shame.

The truth is, I wouldn't have gone anywhere even if I could have gone.

Some left me alone. Some abandoned me. And even when I was with others, I was still alone, because no one really knew what it was like.

It's not as though epilepsy is a popular disease...like high blood pressure or toe fungus.

I lost my moorings. Adrift in an unfriendly sea. Or marooned on a lonely island. Or stuck in a long earthquake where the shaking ground never stops.

And no one understood.

Well I could have given up. I thought of it. But I didn't.

I kept living one way or another. Try this, try that. Maybe a little better. Maybe a little worse. Days became weeks; then months and years. If I hold on long enough, maybe something will work for me. A new medicine. A surgery. Something.

Perhaps one of the good things about a good but not perfect life was that I had endured some difficulties in the past. Maybe I could get through this. Maybe what worked for someone else would work for me. Or maybe I'd be the one to find something new

that worked just for me.

They say there are no atheists in foxholes. I'm glad I already wasn't one before I fell into *this* hole. My faith sustained me, kept me going on the darkest days. Just the smallest glimmer of hope could lift me up. A verse of scripture, a little prop to my sagging spirit.

Some little bright moment or event in a day.

Then, after a while, out of all the things I couldn't do, there were things I could do. I could make others laugh; I could make a beautiful object; I could reach out to someone who had just started the struggle; I could be a voice to those with less of a voice than even I had.

Timid steps at first in new directions, then more boldly pursuing new dreams and ideas. I can't do this, but I can do this. It seemed my body crumbled daily but my spirit soared.

Or if it didn't soar, I could always hope it would.

And I did get better. Some things changed. At least I think they did. Or maybe I just got stronger, stronger inside and out. Learned new work arounds. Whatever it was, I got out more, related to more people, shared my story without shame, reached out to others.

And driving helped!

Today I am an advocate. Today I am an artist.

Today I am a clown. Today I am a lawyer.

And I will tell anyone my story.



The light shines in the darkness, and the darkness has not overcome it.

(John 1:5 Revised Standard Version)