

Midlife Development and Disability Onset

in a Family Context:

A Qualitative Integration

by

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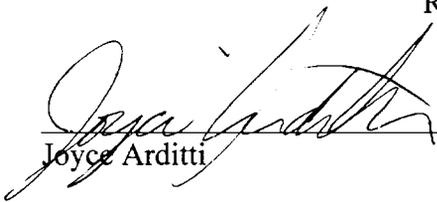
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FAMILY AND CHILD DEVELOPMENT

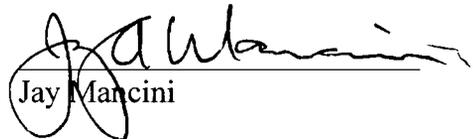
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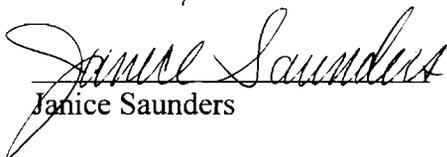
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MIDLIFE DEVELOPMENT AND DISABILITY ONSET IN A FAMILY CONTEXT:  
A QUALITATIVE INTEGRATION

by

Nancy Poe Wingfield

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(ABSTRACT)

Much research on disability has focused on individuals with congenital anomalies and birth defects, and has emphasized the medical aspects of various impairments. Investigations have centered on the treatment and management of problematic physical symptoms with little attention given to the meaning of disabilities for people's family and social relationships. The literature fails to reflect a recognition that most disabling conditions occur later in life as a result of injury or illness and are inadequately defined or described in singularly negative terms. This study was undertaken to examine how adult-onset disability is experienced in various social contexts, and to consider how individuals who become disabled in adulthood and their family members develop an understanding of what disability means, beyond consideration of medical care and physical treatment.

Qualitative data were collected from a purposive sample of 9 intimate couples in which one of the partners had been diagnosed with multiple sclerosis. In-depth conjoint interviews were conducted with each couple, followed by private interviews with the 18 individual partners, rendering different perspectives on disability as a personal and familial experience.

The results indicate that disability onset in middle adulthood is an important, but not all-encompassing, experience that shapes the individual lives of

those affected and their loved ones, as well as their shared life as a couple.

Contrary to much research that frames disability in terms of stress or deficit models which assume negative and problematic experience, the results of this investigation indicated that disability is perceived as having some positive aspects on personal and family development. The data indicated that disability is a process that takes place over time and through which people's perceptions and experiences are altered, as opposed to a being a permanent identity or status that occurs as a result of a discrete event.

## Dedication

This work is dedicated to Mom,  
for providing roots and wings;

And to Dad,  
for teaching about whatsoever things.

(William D. Poe, MD  
November 2, 1918 - April 18, 1994)

## Acknowledgments

Successful completion of this undertaking reflects not only my singular effort, but the efforts, contributions, and support of many people without whom this project would have been far more difficult and far less gratifying.

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I wish to acknowledge Katherine Garvin, Executive Director of the National

Multiple Sclerosis Society, Blue Ridge Chapter, for her interest and endorsement of this study, and for her invaluable assistance in participant recruitment.

To the individuals and couples who comprised my “sample,” thank you for opening up your homes and lives to me, and for being willing to share your experiences with the hope that others will be helped.

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## Preface

This project was originally undertaken as a personal quest to inform my own experience. As a person entering midlife, whose marriage partner had been diagnosed with an unexpected disabling disease at the age of 34, and whose social work career had centered on practice in family contexts, I perceived the experiences of aging, disability, and family as inextricably connected and believed there was potential for them to be mutually informing. From my perspective, these three phenomena share a number of commonalities. All involve developmental processes. Each occurs in the context of, and in interaction with, the larger culture. None happens in a predetermined, prescribed way for every person. The three events are uniquely constructed by the players at micro, meso, and macro levels.

It was interesting, then, when I commenced my research to find that an integrated literature did not exist. Further, the body of research on midlife aging was criticized from within as being fraught with problems of conceptualization and operationalization. Much information centered on the identification and demarcation of a midlife developmental stage based on specific social and psychological indicators. These efforts have proven problematic due to wide variability in experience of midlife on the basis of culture, gender, socioeconomic status, historical period, and other confounds that obscure a clarion view of how one proceeds into midlife and what it is about; that is, how adults come to locate themselves at this place in the life course and what it means for them.

Similarly, the published research on disability was roundly criticized by sociologists as being framed in exclusively medicalized impairment terms, with little

attention given to the social aspects of disability. Most studies were noted as being negatively skewed and for failing to include direct accounts from people with disabilities. In terms of my particular interest, I found very few studies in social science publications that dealt with adult-onset disability. Rather, much research was available on disabled children, particularly those with Down's syndrome and spina bifida, and those accessing special education services. Notable exceptions were studies on Alzheimer's disease, osteoporosis, cancer, and cardiac illness, but these generally focused on people of advanced years. Other than references to veterans with post traumatic stress disorder, a social psychological examination of midlife disability was virtually absent in the literature.

Finally, the family science literature did address concerns of midlifers in the contexts of parenting, marriage, divorce, remarriage, and caregiving of elderly parents. This approach reflects a delineation of activities and roles associated with midlife rather than the meanings it has for middle-aged people. Although explicit attention to adult-onset disability in the family context was rare, the family literature did contain deliberations about, and examples of, research that included the experiences of people formerly neglected in studies of human behavior such as those with disabilities. Acknowledgment of how family science has emerged with norms established by the dominant--ablebodied--culture to the exclusion of disabled persons' lives was present, particularly among feminist scholars. In family science literature, support for research and methods that would render alternative discourse regarding disability was conferred.

And so, from this disparate foundation, I drew from the fields of family studies,

adult development, and disability, to undertake a qualitative study exploring midlife couples in which one partner encountered unexpected disabling illness. Included is an examination of the personal, familial, and social experiences of people with adult-onset disability and their able-bodied partners; particular emphasis is placed on the meanings given to these experiences and their impact on the development of the partners as individuals and the couple as a family unit.

The research project is presented in three articles, reflecting different aspects of the study and its results. The first, entitled “Adult-Onset Disability: The Meaning of Multiple Sclerosis as a Personal, Family, and Social Experience,” reports on the experiences of people with adult-onset disability as represented by those with multiple sclerosis, and their intimate partners. It focuses on the developmental process by which individuals and couples come to terms with the **meanings** of disability in their personal, family, and social lives.

The second, entitled “Midlife Development and Adult Onset Disability: Responding with Realistic Resilience to Normative and Nonnormative Life Events,” challenges the popular assumption that the events of midlife aging and disability onset are essentially negative in their consequences. Approaching these two events, one normative and the other nonnormative, with a view for process and outcome, I sought to discover how people “become” middle aged or disabled, and what occurs in their families as a result.

The third article, entitled “The Experience of Listening for Experience: Hearing and Giving Voice in a Qualitative Study,” is a reflective essay focusing on this research

project, myself as a researcher, and the practice of constructing story into science. This article presents an evaluation of my efforts and an acknowledgment of the participants whose expressions of experience were so generous and unique. This portion of the research report reflects my observations about the process of knowing and being known in a research context, and how to honor the individual while making scientific inquiry. This self-evaluation was sparked by Hewitt (1994), who stated,

I think it offers the best hope of a humane science--one that avoids distorting our diverse human natures into particular and narrow caricatures, but also one that respects and emphasizes the value of theoretically guided empirical inquiry as one of the best hopes of humankind for creating a better world. (p. 111)

This project was based upon the personal accounts of individuals and families whose lives are directly touched by middle-agedness and disability. By converging family, aging, and disability studies into a life span orientation, informed by symbolic interactionism and human ecology, I sought a contextualized view of the dynamics and meanings of midlife transitions and diagnosis of impairment. What I found were interesting developmental processes in the way that people come to terms with their own experiences, incorporate them into their personal, family, and social lives, and go on about the business of living.

# **Adult-Onset Disability: The Meaning of Multiple Sclerosis**

**as a**

## **Personal, Family, and Social Experience**

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### **Abstract**

*In recognition of the fact that people with disabilities account for a large segment of the population while being conspicuously under represented in social science literature, this study was undertaken to focus attention on adult-onset disability. Diverging from medicalized impairment models of disability, this project involves the exploration of the personal, family, and social experiences of people with adult-onset disability as represented by people diagnosed with multiple sclerosis (MS).*

*Utilizing qualitative methods informed by symbolic interactionism, human ecology, and a life span perspective, I conducted indepth conjoint and individual interviews with 18 people, comprising 9 intimate dyads in which one partner had been diagnosed with MS after the couple's relationship had been established. The interviews focused on the experiences of contracting the disease and how the diagnosis of disability has been incorporated into the participants' lives. All informants reported that beyond dealing with the unpredictable onset, physical effects, and course of the disease, it was necessary to come to terms with the **meaning** of disability for both the person with MS*

*and his or her intimate partner, their family, and those in their social milieus. All accounts describe a developmental process in which the meaning of MS and disability grows from a reactive-recipient perspective (“why did this terrible thing happen to me/us/you?”) toward the adoption of a proactive-participant approach to MS in which the disease is viewed as a “fact of life” that must be considered but is not central to one’s self concept or life experience.*

The number of family scholars interested in disability phenomena has increased significantly over the last 40 years, yet the field is still perceived in medical terms and not as an issue central to the concerns of social scientists (Meyerson, 1988). Wang (1992) concurs, arguing for medical disability to be reframed as a socially embedded experience and studied accordingly. She noted that the biomedical approach within Western science and clinical medicine most commonly views disability as the diagnosis of physical deficits. One of the limitations of this model is its view that impairment is inherent in the person and independent of social barriers.

In fact, such a shift in disability inquiry from individual-impairment to social constructionist models is underway. Recent developments in health care policy (Percy, 1989), advances in medical technology (Meyerson, 1988), enactment of legislative provisions (Percy, 1992) and growing political activism (Shapiro, 1993) are converging to reshape the social landscape for disabled and nondisabled citizens alike. The continuation of these trends will require the attention of scholars as efforts are made to explore, understand, and address the complexities and ramifications of disability issues.

The need for an expanded research agenda was voiced by Appleby (1993) who stated an obligation exists to for scholars to undertake vigorous and honest examinations of disability that question ablebodied assumptions and privileges. Fine and Asch (1988) also acknowledge the need for further research while cautioning against a major limitation of the usual protocols for the study of disability: failure to focus on the lived experiences of people with disabilities, and failure to directly include people with disabilities. Another limitation is that most of the disability literature in family science deals with people who have developmental disabilities--those that onset during pre-, peri-, or post-natal periods-- to the neglect of people who become disabled later in life. The virtual exclusion of adult-onset disability fails to reflect the distribution and incidence of disability in the population. Indeed, fewer than 15% of disabled Americans were born with their disabilities (Shapiro, 1993), meaning that an overwhelming 85% of disability occurs later in life and must be incorporated into one's sense of self after the formative years of childhood. It was my intention to redress these limitations in designing and conducting the present study. This research was based on the personal experiences of people who encountered unexpected disability in middle adulthood and their intimate partners; their accounts served as the centerpiece of the study.

A final observation that frames this examination is in order. Most people with disabilities live their lives embedded in nondisabled social worlds (Rolland, 1994; Scotch, 1988; Shapiro, 1993), the most significant of which is the family system. Ryff and Seltzer (1995) discussed the importance of a developing a dual perspective that brings together the realms of family relations and individual development. In their

conceptualization, as in the one adopted for this study, “family life is antecedent to individual development, and individual development is antecedent to change in family life in a reciprocal pattern over time” (p. 95-96). Consideration is also given to the interaction of these families with the forces and institutions of the larger society.

## Literature Review

### Disability Studies

Historically, the study of disability has been firmly situated in a medicalized, individualized, isolationist perspective and has centered on issues which are important to medical professionals (Chappell, 1992). Referred to as the individual impairment model (Sheer & Groce, 1988), this approach focuses on measuring performance levels in activities of daily living, mobility, and functional capacity. Many researchers are now calling for the discipline to be reframed to include sociocultural and economic considerations of disability (Atkin, 1991; Biklen, 1988), as well as its psychosocial aspects within the purview of social relationships and family life (Hammell, 1992; Hill & Zimmerman, 1995; Rolland, 1994).

Indeed, remarkable advances in medical, surgical, and rehabilitative technologies have dramatically increased the survival rates of persons following major trauma and illness (Hammell, 1992; Meyerson, 1988). However, survival does not indicate full recovery. Rather, the outcome of many medical advances has been a growing number of ill and injured people who survive their infirmities to face challenges of life-long disability (Hammell, 1992). Many of these people, especially those whose disabling conditions occur during adulthood, remember life as ablebodied citizens and many retain

expectations of full economic and social participation. They have not incorporated a self-image of dependency and they expect to live as normal adults (Scotch, 1988).

Defining disability. To appreciate the magnitude of disability phenomena and the complexity of how it is experienced, it is helpful to consider how disability is defined and how definitions shape the understanding of human impairment. Meyerson (1988) notes that, while there is a “salient biological component” (p. 179) to the perception, experience, and definition of disability, biology alone is not sufficient in explicating the phenomenon. Instead, as Hahn and Longmore (1983) point out, the definition of disability is literally determined by public policy and is a status legitimated by the implementation of laws and regulations. Two statutory definitions of disability have emerged over the past two decades in the wake of political action by, and on behalf of, disabled persons. The first, considered a categorical one, was utilized in Public Law 94-142, Section 121a.5. It defined a disabled person as one who is evaluated as possessing a disabling condition, indicating that disability is located within the individual on whom an evaluation is conducted. The second definition, considered a functional one, was initially utilized in the Rehabilitation Act of 1973, Section 504, and was adopted more recently in the development of the Americans With Disabilities Act. It defined a handicapped individual as:

any person who has a physical or mental impairment that substantially limits one or more major life activities, has a record of such an impairment, or *is regarded as* having such an impairment. [emphasis added]

This definition, in its final clause, views disability in the context of individuals with

impairments attempting to live social lives, working with, interacting with, and *being regarded* by others. This trend toward the social construction of disability is further advanced by Schneider (1988) who reiterates an important point: “Categories such as disability are not ‘givens’ in nature, but rather socially constructed categories that emerge from the interpretive activities of people acting together in social situations” (p. 65).

Embedded in these definitions and in the various policies through which they become law are important distinctions between the concepts of impairment, disability, and handicap. These distinctions speak to the interaction of individual and societal factors in the understanding of disability. According to Sheer and Groce (1988), *impairment* is the loss of some physical or cognitive capacity due to illness, injury, or genetic condition. *Disability*, a related yet distinct concept, refers to the impact of impairment on one’s ability to carry out the functions of daily living. *Handicap*, on the other hand, refers to those social conditions that interact with an impairment or disability in such a way as to limit, segregate, or deny social involvement and participation of the person with the impairment.

Minority group model. Given the handicapping processes of limitation, segregation, and denied involvement, along with the staggering number of people with disabilities, Fine and Asch (1988) suggested that disabled people constitute the largest minority group in the United States. Using federal health survey data, the Institute of Medicine concluded in 1991 that 35 million Americans--one of every seven--have a disability that interferes with daily activities such as work or keeping a household (Shapiro, 1993). Disability ranks as the nation’s largest public health problem, affecting

not only individuals with disabling conditions but also their immediate families, and society at large through lost wages and the enormous impact on the health care and insurance industries (Pope & Tarlov, 1991). Continuing the minority group conceptualization of the disabled population, Shapiro (1993) makes the observation that disability is the one minority that anyone can join at any time, as a result of a sudden accident or unexpected illness. However, unlike other minority groups, most disabled people do not have meaningful connections and affiliation with other people who share their devalued status. Instead, their lives are usually embedded in the world of the able-bodied, creating isolation and dependence on family members.

#### Expanded Research Agenda

It has become apparent that the focus of disability research must be broadened from a strict biological approach that examines physical functioning to one that also includes consideration of health care systems, cultural dynamics of discrimination and stigmatization, and political and legislative machinations related to civil rights, education, and transportation (Scotch, 1988; Shapiro, 1993; Wang, 1992). In response, I undertook the current research which rests upon assumptions found in the theories of human ecology and symbolic interactionism: that disability is best understood when viewed as an experience of person-in-society, embedded in and filtered through family contexts via communication (Bubolz & Sontag, 1994). Accordingly, the research questions guiding this study were designed to penetrate the adult disability experience at three levels. At each level of inquiry, the focus was on the various meanings and interpretations brought to and rendered from one's disability experiences and how these are mutually negotiated,

influenced, and synthesized between, across, and among self, family, and society. The three levels and related research questions are:

1. Individual. What meaning is given to and derived from the experience of being diagnosed and living with a disabling disease (or being the intimate partner of someone so diagnosed)?

2. Family. How is adult-onset disability in one partner incorporated into the dyadic relationship and experienced by the couple as a family system?

3. Social. How is adult-onset disability negotiated beyond the family in broader social arenas and, conversely, how are the societal responses to the disability perceived by individuals who enter this status and their intimate partners?

The formulation of these questions and the overall design of the study were informed by symbolic interactionism within an ecological perspective. These theories, when used in tandem, allow a holistic, contextualized view of human phenomena, and of how interpretations and meaning are constructed within and across various levels of social experience. Stated simply, this study recognizes that people and “families interact with multiple environments” (Bubolz & Sontag, 1993, p. 426) and considers both in the approach and understanding of adult-onset disability. Data were gathered through open-ended, semi-structured interviews. These in-depth accounts revealed that the meaning of diagnosis and disability is not static; rather, various meanings evolve over time and across contexts. The experience is neither singularly defining nor inherently negative, supporting the observation of Meyerson (1988), who questioned the assumption that disability has only negative consequences by considering the possibility that some families are resilient

in the face of crisis, and thereafter not only function well but thrive.

## Methods

Despite increasing interest in disability phenomena, many investigations are flawed from inception by prejudicial assumptions, theoretical bias, or by methodological error (Meyerson, 1988). In an attempt to overcome these flaws, this study was established with a goal to elicit and learn rather than “to impose...definitions of reality on those researched” and “to correct both the invisibility and distortion of experience” (Lather, 1991, p. 71). I sought to bring visibility and clarity to the lives of people with disabilities and their companions by including their voices as the centerpiece of the study. My intention in adopting this approach was to provide a corrective for “a virtual absence of studies that report, in people’s own words, the routine experience of living with chronic illness and disability” (Shneider, 1988, p. 63).

Consideration of methodological rigor in qualitative investigations generally relates to issues and questions of validity, reliability, and generalizability. Arguments have been made that these concepts are anchored in positivist philosophies of science and do not translate to post-positivist and postmodern philosophies and qualitative designs. Even so, scientific enterprise requires attention to the selection and defense of method. I chose a qualitative design because my interest was in discovering the **meanings** that midlife development and disability onset had for people, rather than in explaining or predicting experiences (Snyder, 1992). By using multiple sources of data (couples, well partners, ill partners, myself), collecting data to the point of theoretical saturation, and confirming my initial findings in subsequent interviews with the participants (Gilgun,

Daly, & Handel, 1992), I maximized the precision of my analysis and the rigor of the method.

### Target Population

To this point I have referred to my target population as midlife couples in which one of the partners has encountered unexpected disability. Quite obviously, this population is huge and extraordinarily diverse. Men and women of all races, educational and socioeconomic levels, medical backgrounds and treatment options with histories of cancer, heart disease, diabetes, traumatic injury, any number of chronic and chronic-progressive illnesses, stroke, and a host of other conditions make up the population of interest. For the purposes of this study, I chose to restrict the target population on the basis of diagnosis. This examination focuses on adults diagnosed with multiple sclerosis (MS) and their intimate partners.

Limiting the population on the basis of diagnosis helps establish manageable parameters while still allowing heterogeneity in the focus of the study. The diagnosis, experience, and course of multiple sclerosis is widely variable and unpredictable. More women than men get the disease, but the prognosis for men tends to be less favorable. People of all races can be affected, though Caucasians, especially those from northern European extraction, comprise the largest ethnic group of MS people.<sup>1</sup> MS does not have class, education, or lifestyle correlates. The etiology is unknown, and currently there is no cure. Treatments are available, but costs are very high and effectiveness rates are

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<sup>1</sup> “MS person” is the term of preference for people with this diagnosis, outside of medical contexts where “patient” is considered appropriate.

relatively low across the entire population of people with the diagnosis. Once believed to be a rare disease, MS is now considered the most common neurological disease of young and middle-aged adults, affecting a third of a million Americans and an estimated 1.1 million people worldwide (National MS Society, 1996).

### Participants

Informants were 18 individuals comprising 9 intimate dyads in which one partner has a diagnosis of MS. Participants ranged in age from 31 to 57 , were predominately working- and middle-class, and had been together as married or cohabiting couples for an average of 21 years total, and 13 before being diagnosed with MS (see Table 1).

Participation was solicited on a volunteer basis from support groups and through a letter sent by the executive director of a local chapter of the National Multiple Sclerosis Society to chapter members (see Appendix A). Interested volunteers completed and returned a form (see Appendix B) with their names and telephone numbers. I used the returned forms to contact potential participants by phone. I gave a brief synopsis of the study, conducted an initial screening (see Appendix C), and then scheduled initial conjoint interviews at times and locations convenient to each couple. When we met for the initial interview, I reviewed the informed consent document that had been approved by the Institutional Review Board at Virginia Polytechnic Institute and State University (see Appendix D). At the conclusion of the conjoint interviews, follow-up individual interviews were scheduled with each partner of the dyad.

### Data Collection and Analysis

Data were collected through indepth, semi-structured interviews. I interviewed

Table 1: Participants

Couple	Years as Couple	MS Partner	Age	Well Partner	Age	Years with Diagnosis	Disease Course +
1	35	Lynnette	53	Dexter	54	7.5	relapsing-remitting
2	13	Jay	55	Deb	41	5	primary progressive
3	21	Beatrice	46	Rich	47	18	secondary progressive
4	12	Rod	40	Maggie	36	5.5	secondary progressive
5	35	Julie	54	Bob	57	10	secondary progressive
6	7	Rebekah	31	Sol	34	7	relapsing-remitting
7	20	June	48	Hank	50	5	primary progressive
8	22	Mike	49	Robin	48	8*	secondary progressive
9	25	Rachel	44	George	50	6	relapsing-remitting

+ See Appendix E for classifications of disease course

\*diagnosis was made 2 years ago, but couple reports that symptoms have been present for 8 years

each informant twice; once in the context of a conjoint interview with his or her intimate partner and once individually. Conjoint interviews ranged from 1.5 to 3 hours in length; individual interviews ranged from .5 to 2 hours in length, for a total of more than 40 hours of interview time.

In all cases, the conjoint interviews were held first, utilizing a general question guide (see Appendix F). I customized the order and wording of each question to maximize the informants' participation in telling their own stories in their own words. The content of the individual interviews emerged from the responses and themes elicited in the conjoint interviews. More specifically, participants were asked to reflect upon and clarify their reports of family experiences from an individual perspective.

The interviews were recorded on audiotape, transcribed verbatim, and analyzed according to the constant comparison method. This form of analysis involves the researcher in a process of focusing on key themes that emerge from the data, categorizing them, and subsequently collecting many incidents for each category (Snyder, 1992). Constant comparison involves working back and forth between the various sources of data to establish a balance between generalizing from data and remaining aware of the distinctiveness of individual experiences (Murphy, 1992). Constant comparison enables a comprehensive examination of how each individual's experience is both similar to and different from every other individual's experiences (Snyder, 1992). The constant comparative method of data analysis allows "each new family's data [to] illuminate the previous family's data and helps to refine the theoretical concepts" (Murphy, 1992, p. 155).

My method of performing a constant comparison of the data included making observational field notes in a research journal immediately after the conjoint interviews, usually in my car after driving a short distance from the participants' homes. These notes included my initial impressions of what the respondents' had said, of interactions between the partners during the interview, and questions that I wanted to ask the individual partners. Within 2 days after each conjoint interview, I listened to the audiotape twice: once to check and augment my field notes, and once to formulate the questions I would ask of each partner in the follow-up, private interviews. As I progressed through the conjoint sessions with all couples, the questions drawn from the shared interviews were asked of all of the successive individuals, the result being a cumulative compilation of questions, clarifications, and reported experience with and between all 18 individual respondents and the 9 dyads. After each individual session, I made field notes regarding impressions, observations, and questions, which, as in the case with the conjoint interviews, were checked and augmented by listening to the audiotaped recording.

Selection of themes and development of coding categories was made with attention to two principles: one was theoretical, the other methodological. Theoretically, I was guided by symbolic interactionism, human ecology, and a life span perspective. Thus, in my selection of themes and categories, my attention was drawn to participants' references to meaning, interactive processes, contextual differences in experience, and reports of change, age, and personal history.

Methodologically, I was committed to keeping the people in the center of the data

analysis, and honoring the tenet of qualitative research of listening and giving voice. As I attempted to honor this principle in my analysis of the data, I focused on the words and passages which the respondents' repeated, emphasized, or punctuated with emotion through gestures, facial expressions, or change of tonal quality in their voices.

Conversely, I noted those instances in which participants changed the subject or avoided a question, believing that silence can be as revealing as voice.

Verbatim transcriptions of the conjoint and individual interviews were made, and reviewed for accuracy against the audiotaped interviews, and re-read in entirety on one occasion. The literature on qualitative analysis and collaboration with colleagues engaged in qualitative research suggested that multiple readings of transcripts is the established protocol for data immersion and analysis. However, I found that the transcripts did not adequately capture the voices of the respondents in this study. As a result, my analysis involved multiple "listenings" of the tapes rather than multiple "readings" of the transcripts. Additionally, partial readings of the transcripts occurred after themes were identified to select excerpts for inclusion in the report.

### Findings

The interviews yielded approximately 40 hours of audiotaped interviews and 1,000 pages of transcribed data; contextual accounts rich in description and insight regarding experiences of becoming disabled. Most notable was the consistent report that the meaning of disability changes over time rather than becoming constitutionalized as a discrete event or a static condition. All respondents described an evolution of how they perceive and negotiate MS in their lives. It was interesting that personal experiences and

meanings were consistent for both the MS and well participants, suggesting that disability onset in one partner is indeed an experience shared by the other. A related finding was that just as meanings change over time for the informants, so they also change according to the context being considered or occupied at a particular moment. Thus, the reports on family and social processes were different than what the partners go through as individuals.

Using Bronfenbrenner's (1979) description of nested contexts, the present study includes consideration of how disability is negotiated at micro, meso, and macro levels of human experience and interaction, and the links between these levels. On the micro level, the experience of disability onset was reported as a process in which there were shifts in perception across four domains. These shifts reveal how the *meaning* of the disease evolved over time in terms of its saliency in life decisions. As the meanings of MS are constructed by individuals, they are incorporated into, and negotiated with the meso and macro contexts of people's lives. At the meso level, defined in this study as the respondents' family systems represented by adult intimate partners, three salient themes emerged regarding how disability onset is perceived and what it means to the family. At the macro level, defined as the respondents' social sphere, the accounts suggest that a recursive tension exists between private and public spheres related to perception of, and response to, adult-onset disability. The findings at each level are presented below.

#### Meaning in the Micro Context: Individual Perceptions

As noted above, the data revealed a developmental process by which perceptions in the meaning of disability onset change across four domains of experience (see Table

2). When viewed together, the shifts were found to characterize a general shift in how MS is perceived by the individuals with the disease and by their intimate partners: movement from a reactive-recipient perspective that asks, “why did this terrible thing happen to me/you/us?” toward a proactive-participant approach to MS in which the disease is viewed as a fact of life that must be considered but is not singularly defining of one’s self-concept or life experience.

Table 2: Categories of Perception in the Meaning of Multiple Sclerosis

Domain	Reactive-Recipient Perspective	Proactive-Participant Perspective
Response to Diagnosis	FEAR	RELIEF
Reality of Diagnosis	DEVASTATION	FRUSTRATION
Reference of Diagnosis	CENTRAL	PERIPHERAL
Regard of Symptomology	WHAT IS CLAIMED	WHAT REMAINS

Fear to relief. Due to the difficulty in diagnosing multiple sclerosis, partners deal with a period of time ranging from a few months to more than a year during which their health status is uncertain. Both partners ponder possible explanations for the symptoms that are being experienced. One symptomatic woman, Rachel, reported that,

**RACHEL:** It’s scary. Things cross your mind like, could that be a brain tumor or a stroke? And I worried. I thought, “I’m only 38 years old and I’m dying.”

**MIKE:** I was tested for everything imaginable. They thought Lou Gehrig’s.

They thought Lyme Disease. I was tested for chronic fatigue. Um, rheumatoid arthritis. Just name it. I mean just about everything. Epstein-Barr. Infectious disease. I felt like a time bomb of worry. Something was wrong, we knew it. And you try to hope, but it's hard when you don't know.

Lynnette, a woman with a nursing background, recalled her initial suspicions.

**LYNNETTE:** I knew something was wrong. Very wrong. Because I work in health care, I knew about the symptoms and I thought, "Oh god! This could be ALS." It was horrible. I just started to cry and begged the doctor to tell me that I didn't have ALS. That's a death sentence. We could handle anything else. Just tell me it's not ALS.

The well wife of a husband with primary-progressive MS remembers,

**DEB:** The doctor had told us that he had probably had several strokes because there was just all these spots on his brain. It was several strokes or some type of infection. And the doctor scheduled a spinal tap. That was the worst for me, and I remember looking at the doctor and asking, "Is this fatal?" Because they couldn't figure it out. And I knew a spinal tap was serious. And an infection or strokes can be fatal.

Another spouse relayed his wife's experience with doctors:

**SOL:** Her doctor didn't know. We wondered about Lupus. Or Vasculitis. We wondered about everything. It's very mysterious you know, and the mystery spooked us.

When MS was finally diagnosed, usually through a combination of lumbar puncture and magnetic resonance imaging, the accounts revealed that initial response was fear. This was the reaction of the disabled and well partners alike. A woman whose father had suffered for years with very debilitating MS, said,

**BEATRICE:** I was floored. When I was going through the diagnosis, even though it was horrible, I could hang on to a shred of hope. But this made it real.

Another woman recalled her initial reaction:

**JULIE:** I was almost petrified. I thought, “Oh no, oh no, oh no.”

A husband whose wife was diagnosed acknowledged that his response was very emotional:

**DEXTER:** I knew something was wrong with her. We’d been to every doctor in the city trying to get answers. And when we finally got an answer, I was quite frightened, really. Very scared. Very scared. I was very frightened.

And a wife had a similar reaction:

**MAGGIE:** At that moment, I became so afraid. What’ll happen to him? I envisioned terrible things for him. And I was afraid for me, too. Can I handle this? I was overcome with worry about what this would mean for our lives together. It was scary that life could change so drastically in just a split second.

Following diagnosis, MS people and their loved ones received information about

input, filtered through earlier worries about terminal illnesses, allowed the respondents to balance “what is” against “what might have been,” resulting in fear giving way to relief. All of the participants made similar reports of gathering information, coming to a realization that life goes on, and preparing to manage the illness:

**RACHEL:** Then there comes a point you find out and you’re relieved that it does have a name and it’s not going to kill you, and all that. I read everything I could get my hands on. I talked to other people that had it. I went to support groups. I called the MS Society. I wanted to know what I was in for. Some of it was quite upsetting, but mostly reassuring. I was going to live. What else really mattered?

**LYNNETTE:** When I came to my senses, well, I was relieved. Y’see, up to that point I was thinking I was going to die. So I was truly relieved.

**JULIE:** We got to a point of relief. And gratitude. We were just very grateful that it’s not something else like cancer. If it’s not a matter of life and death, it’s not worth worrying about. I really believe that. So, I was fine. We were fine.

**DEB:** We were really relieved to find a name for this illness. This illness is called MS. People live with MS, they don’t die from it.

**MIKE:** When I finally found out, and it sunk in, which took a little while, of course. But when it did, I realized it's not the end of the world. I can think of many things worse than MS. And when I was thinking like that, I could deal with it. I asked myself, "Am I gonna have MS or is it gonna have me?" I decided early that it's not gonna have me.

**ROD:** After I got over being scared to death, I began to feel sorry for myself. But then I saw people with lots worse problems. I got to know other people who had MS and saw that they were still working, still having fun. Still living a normal life, pretty much. And that was very comforting to me. It was a relief. Just because I had MS didn't mean that life had to stop. Seeing people who had MS for years and years, and seeing that they were doing okay, was a big relief.

**MAGGIE:** I was like, okay, this sucks. I was very upset, but at the same time, at least we had something to work with. He wasn't going to die. That was a relief. I wanted to find out what we were dealing with. I located medical libraries and went on a mission of information. I freaked out about some of it. But mostly it helped to put it in perspective. I called the local support group. The woman was so helpful, and we went to a few meetings. Some people were more disabled than my husband and that bothered me. I wondered, "Am I looking at our future?" But then there were others who

seemed fine and they gave me hope. I guess all this desensitized me to MS. It took the mystery and fear out of it. I mean, it still sucks, but I'm not very upset anymore. Well sometimes I am, but most of the time, we're cool with it.

**ROBIN:** I had a weird experience with a co-worker. When I told her what we'd been going through and that he finally got diagnosed with MS, she said, "Thank God it's just MS!" I was so offended by that. I thought, "How insensitive!" After all, this was a horrible thing for us. But she went on to tell me about several people she knew that had it and they were doing fine. She described a woman who was very old and had MS for many years. She said that she still gets out everyday, takes care of her pets and her yard. And then I started thinking, "Yeah, it's just MS. It's just MS. It's just MS." When she said it, it was so insensitive at first. But then I started believing it. I became relieved that, you know, it's just MS.

This shift from uncertainty to fear to relief suggested a developmental process through which individuals move from being reactive to proactive in their perception of and response to diagnosis.

Devastation to frustration. The data revealed a developmental shift in how individuals, both those being diagnosed with MS and their intimate partners, realize the actuality of MS in their lives. Initially, the disease is interpreted as a devastating reality.

**RACHEL:** I can remember back, thinking, "How am I gonna deal with

this?" I just prayed to God, "Help me. Help me." There wasn't a thing I could do for myself. It shook me to my core.

**LYNNETTE:** I suffered with horrible images of wheelchairs, crutches, full nursing care. I was devastated.

One of the men who was diagnosed 5 years ago revealed that,

**ROD:** I'm not a person who usually gets down about things. I'm pretty laid back. We were building our dream house at the time. I went out to the land where we were building, sat on a rock and cried my eyes out. I was a mess. Should we build the house or not? What if I can't work, we won't be able to afford it. I love sports. I didn't think I'd ever be able to play sports again. It was a bleak moment. I was devastated.

One of the well husbands described his devastation and concerns about caregiving:

**DEXTER:** We pretty much knew she had it. I mean, her medical background helped her figure that out. But to deal with it was something else. Knowing for sure, well, that was pretty devastating. How are we gonna cope? Things went through my mind about taking care of her. I felt like the rug had been completely pulled out from under us.

Eventually, though, this experience of devastation was reframed by respondents.

Global assessments were replaced by situational definitions; that is, general devastation was reduced to specific incidents of frustration. One woman with MS offered the following illustration:

**RACHEL:** And the frustration! Like to walk downstairs to do laundry. You have to think, “Do I have everything I need before I go down, ‘cause I can’t be going up and down them steps after something I forgot.” That’s kind of annoying, because I used to run up and down the steps seven or eight times a day thinking it was great exercise.

Another reported a similar story:

**LYNNETTE:** The worst is wanting to do physical things, like yard work. I love working in the garden. But if I go out and spend the afternoon, I know that I’m going to have to recover for 3 days. That’s frustrating.

**MIKE:** The biggest disappointment is the lack of energy. I’m a runner and I keep on running. But a lot of times I come home from work and think, “I’d like to go running but I just literally don’t have the energy.” There are things I like to do, but by the end of the day, I can barely move. So I end up sitting around. It’s very disappointing. Having to budget energy.

The well partners gave their accounts of the frustration that MS brings:

**DEB:** There’s nothing devastating about this. It affects everything in life, but it doesn’t stop hardly anything. Like buttoning a shirt is hard, but that doesn’t mean you have to go around naked. Velcro works magic. Opening a jar can be a problem. This frustration doesn’t mean you have to starve. Order pizza. You can’t get all out of whack. You know, there’s more than one way to skin a cat. It’s amazing how creative you can get when you’re

frustrated enough.

**RICH:** MS isn't devastating. I mean it is, but it's not. You can still do things, just not in the same way. Which can be frustrating, of course. Instead of backpacking, we car camp. It's not quite the same, but it's still enjoyable. Except when a family pulls in with a big RV and turns on the portable radio or tv. Now that's frustrating!

**MAGGIE:** Sometimes, when he's feeling bad, he just doesn't feel like doing anything. It's the fatigue. And that bothers me, because he's always been such an active, physically active person. And it bums him out. It's kind of isolating too, because he worked out with his friends. And now he doesn't do that as much when the MS is bad. So it's sad, but it's not devastating.

This change in the meaning of MS reflects a change not only in how individuals experience the disease, but how they relate to it.

Center to periphery. The data revealed that, closely associated with this change from devastation to frustration in the realization of MS by people affected by the disease, a shift occurs in how they refer to its location in their lives. Upon receiving a diagnosis of MS, both ill and well partners reported that they became preoccupied with it. Energy, attention, and concern all focus on the disease. The totality of experience suddenly revolves around an MS entity which usurps the center of one's life. One woman discussed

how MS served as her reference point immediately following her diagnosis:

**RACHEL:** I did the whole nine yards. I went to support group meetings. And I just read everything. And of course he and I had talked about it a lot. I'm sure he got so sick of hearing it, 'cause the first few months I was totally absorbed with it. Like I said, reading, talking to people with it, support groups, everything.

Likewise, well partners reported the centrality of diagnosis:

**BOB:** When she first got it, we discussed it a lot. She'd bring these books home to read about it. Seems like we didn't talk about anything else that first month or so.

**MAGGIE:** When he first got the diagnosis, I couldn't think of anything else. MS, morning, noon, and night. Last thought before I fell asleep, first thought when I woke up. Every time I looked at him I saw MS. That was the worst. MS obliterated my view of who he was. I knew that wasn't good. I knew I had to do something. Some girlfriends invited me over for dinner and one of them said, "This is fun night out. MS isn't invited." We spent the night just having a normal time, without thinking about MS. That was a real turning point for me.

This "turning point" was consistently reported. The accounts revealed that as life continues with all the attendant demands of homemaking, work, family responsibilities, and so forth, a shift occurs. MS becomes incorporated as one factor among many in one's experience. As a reference point for life and identity, MS is moved from the center

to the periphery. The following comment sums up the experience for the well partners:

**DEB:** I've accepted the fact that he has MS and it's not a daily thing I think of. I never get up in the morning thinking, "Jay has MS." I get up and think, "I want some coffee" and I go on with life.

For the partners with MS, the theme is similar:

**ROD:** I just really don't focus on it. I've thought about it more during this interview than I have in the last couple months put together.

**LYNNETTE:** Okay, so I'm an MS patient. But I'm also a wife. A mother. An employee. A sister. A neighbor. A friend. I'm opinionated. And can be stubborn. I'm funny and I have excellent taste in clothes. I'm a lot of things that have nothing to do with MS.

**BEATRICE:** I don't get that philosophical about it. Shit happens and I mean, while MS is a part of me, it's not all of me. What I am is more than MS.

What is claimed to what remains. When receiving a diagnosis of MS, the respondents regarded their symptoms or those of their partners in terms of abilities claimed by the disease. Objective experiences of numbness, lost vision, paralysis, incoordination, and other symptoms are translated into subjective evaluations of inability to perform particular activities.

One man with MS remembers that he regarded his symptoms as all encompassing:

**MIKE:** Right off the bat I thought wheelchairs. I thought lost mobility. I

thought dependence.

Another woman was concerned about her career:

**JULIE:** I wondered, “Suppose I have to quit work?” I couldn’t stand and I couldn’t write legibly. In my mind, that meant unemployment. That was bad news.

Another man who was used to a very active lifestyle remembered a particularly low point during a severe exacerbation of symptoms:

**ROD:** One time when I was having real bad symptoms I couldn’t button my shirt. I couldn’t peel a banana. I couldn’t write. I couldn’t drive because I couldn’t work the clutch. And I felt like a complete invalid.

One husband remembered his perspective of his wife’s symptoms:

**SOL:** All I could think of is what we wouldn’t be able to do. Such-and-such was impossible. So-and-so was out of the question. We’d have to give up everything. The diagnosis sort of turned into a long list of “don’ts” and “can’ts.” That was a bad time. I mean, really, she could still do a lot of things, but we couldn’t see that. Or at least I couldn’t. All we could see was what was no longer available to us. It was a real bad time where we felt like we were at the mercy of this dreaded, horrible thief that was robbing all the fun out of our lives.

The accounts revealed that this functional incapacity perspective gets modified to one in which individuals no longer concentrate on what they lost and instead, attend to the abilities that remain. A woman who has had MS for 18 years sums up this shift:

**BEATRICE:** Okay. So I can't hike up a mountain like I used to. But I can ride up there on horseback.

A man who was recently diagnosed but has been symptomatic for many years also reports that,

**MIKE:** I'm worthless at the end of the day. But in the morning, I can do almost anything. So it's not like I've lost it, I just have to rearrange it. If you wanna come over to my house at 5:30 in the morning, you'd take a look at me and never know anything was wrong. But 5:30 in the afternoon? Forget it.

Another talked about shifting activities to accommodate his diminished agility:

**ROD:** I used to play a lot of volleyball. Two evenings a week and every weekend. I was pretty good. I tried to play after I got MS and I was stumbling around like a drunk. My hand-eye coordination was completely shot. And my gait, well that was just ridiculous. So I took up biking. And I enjoy that just as much.

A woman reported her perspective on how her partner focuses on remaining abilities rather than grieving over lost capacity:

**MAGGIE:** He seems to make the most of what he can do. And doesn't take it for granted. He often says that many healthy people his age can't do half of what he's able to do, even though he has MS. It's true. I guess knowing that you can lose it any moment makes you appreciate and use what you have.

One well partner of a very active couple reported the following incident related to his partner's use-it-or-lose-it philosophy:

**DEXTER:** We had a run-in with the doctor about different activities. The doctor we had at the time was real cautious and didn't think she should do a lot of the things she was doing. He was afraid she'd get too hot. Or too tired. And she just blasted him one day. She said, "Look. I'm not going to quit doing everything just because there are some things I can't do anymore. I can't just stop living. I'm not just going to give up. I'm not the quitting type, so either help me or get out of my way." Well, he didn't really get out of her way, it's more like she pushed him out of the way. We don't use that doctor anymore. He wouldn't get with her program.

#### Meaning at the Meso Level: Family Perceptions

The data from conjoint interviews focused on how the experience of disability onset in one member is incorporated into and negotiated within family life. Embedded within the various accounts were recurrent themes of enriched intimacy, renewed individualism, and reorganization.

Enriched intimacy. MS was perceived by the families as a catalyst for emotional expression and connectedness. The dyads reported that their relationships intensified by having to face MS and deal with its encumbrant uncertainty. Dealing with the disease required partners to communicate more openly and on a deeper level with each other than many of them had experienced before. Aside from the accounts of initial diagnosis, the relationship accounts evoked the strongest responses from the participants. To reflect the

saliency of these stories to the meaning of MS in the respondents' family relationships, several accounts are included at some length below.

**REBEKAH:** MS changed me. I used to be this happy, passive wife who never complained or argued about anything. Well, now I'm different and I don't play those games anymore. So it's been hard, because he's wondering, "What's your problem?" But we don't sweep anything under the rug anymore. We deal with everything. And although it's not always real pleasant, it's more honest than anything we had before. We sure aren't afraid of fighting anymore. In fact, we've gotten real good at it. We aren't afraid of anything. God, after what we've weathered together, what's there to be afraid of?

**BOB:** It seemed to bring us a little closer, because I help her. I have to be more sensitive, and she has to ask for help. We're more tuned in to each other now.

**ROBIN:** We've got a unique relationship and the MS has only made it better. It's enhanced the friendship. I guess anytime you go through something serious together that can happen.

**GEORGE:** Anybody living with somebody with MS is going through it, too right along with them.

**RICH:** We've always been very connected. God, you can't stay together and be happy for 20 years if you're not. But MS makes you talk about the ugly stuff. If you can't talk about the ugly stuff, then you're not really talking. We've talked about what if she gets to the point where I have to feed her and bathe her. I mean, that's just reality. You can't pretend that possibility doesn't exist. Because it does. And you can try to deny it, but you're only fooling yourself. So we talk about it. The only rule in life is that you have to play the cards you're dealt. We were dealt these. So we're playing them. We don't hide from this. We don't hide from each other. We talk about it and then move on.

**MAGGIE:** When we got married we said all the traditional vows. Y'know, "in sickness and in health, for better or for worse" and all that. And you know, we didn't have a clue. But now we know. Our commitment to each other has been tested with this. And it proved deeper and stronger than we could've ever imagined. I think MS brought out the real me and the real him. And we found that the real us was pretty damn special.

In addition to experiencing a qualitative change in their own relationships, most respondents evaluated themselves as more intimately connected than other couples within their nondisabled peer group.

**JULIE:** I look around at people I know. Friends of ours. And they just seem to float through life without thinking about anything. Without a worry in

the world. They seem so superficial.

**REBEKAH:** We are different from other couples. We've got lots of people, just in our circle of acquaintances, who are splitting up over stupid things. It makes me wonder how they would handle something serious. And they feel sorry for us? I feel sorry for them! I think MS has made us be more honest about things. I think we have a lot invested. I mean, everybody has a lot invested in their marriage to a point, but we have a whole lot because of the MS, you know. A whole lot of emotion.

**MAGGIE:** I don't want to give MS credit for our relationship. I mean, it was good before MS. But it did make a difference that I see when I look at other couples who are our age, kind of at the same station in life. I don't want to be judgmental, but sometimes they seem to be so trivial. You know, petty, about each other. I know lots of couples who can't even talk over problems with each other. That seems so sad. I don't think MS brought us good communication skills. It's not that. It's more like MS just stripped us down to our basic values and we discovered that our relationship was one of those things. You know, it was valuable to us, like a treasure. We came away from MS knowing that we were more important to each other than anything in the world. You know, once that's established for real, everything else seems inconsequential. We still fight

over money. We still fuss about cleaning the house. There are still gripes and annoyances. But the character of our marriage is different from our friends. There's a totally different perspective.

Renewed individualism. Interestingly, the same dynamics that promoted intimacy are also attributed as bringing a sense of renewed individualism to the members of the dyad. Because of the uncertainty related to MS symptomology, outings, plans, and other family endeavors are generally considered tentative, depending on how the MS partner feels on any given day. The dyads described an informal agreement that requires and encourages each partner to make and pursue his or her own plans, independent of the other. For the well partner, it often took the form of undertaking personal projects when the MS partner was experiencing an exacerbation.

**RICH:** When she feels like crap, I work on the house. And there's millions of things to do. I've got different hobbies and things. Like fish tanks and bird houses.

**DEXTER:** I've become an avid reader and an amateur historian. I have friends that I play tennis with. I'm never at a loss if she's out of commission.

One woman, whose partner has significant impairments and limitations was adamant about this issue.

**DEB:** Am I supposed to sit around and feel sorry for myself because he's having an attack? I can't get caught up in that or I'd go crazy. So no, I say,

“See you later, I’m going out.” And he always says, “Have a good time.”

We can’t wallow around in MS all the time. There are things we like to do together, but everybody needs a break from each other now and then.

We’re not joined at the hip just ’cause we’ve been married forever.

For partners with MS, it often involved doing activities with associates outside the family when feeling particularly well.

**BEATRICE:** Sometimes, when I’m doing well I tell him that I want to go run around with my friends. I’ll wake up early and leave a note, “Gone to the mall, meeting Kathy for lunch. I’ll be home later” and he’s all for that. Because he knows I miss all that when I’m out of it.

And her partner said,

**RICH:** I love that, ’cause I know she’s having a great time, and besides, it means I can sleep late.

Rod, who has had MS for five years made a similar report:

**ROD:** When I’m having a good day, I want to get the most out of it. Doing as much as possible. If she wants to come, that’s great, but mostly she says “Nah. Go on. I’ll see you later.” It’s nice, because sometimes I feel like I have to depend on her so much that being able to do my own thing is nice for me, and it gives her a break too.

Perceived within the context of the family system as an unpredictable force to be reckoned with, disability onset served as a stimulus for family members to identify and develop their own interests, independent of the disease, and thereby, independent of each

other.

Reorganization. Adult-onset disability on one partner within an intimate dyad is experienced by the couple as a family system and must be incorporated into their shared life if the partnership is to survive. This process of incorporation was most clearly described by the respondents in terms of the need to reorganize. Targets for reorganization ranged from life in general, to homes, schedules, career plans, and finances, specifically. One couple in which the wife has MS reported their experience with reorganization:

**REBEKAH:** We used to be spontaneous. Get in the car and go. Running around acting like an idiot. But now, we plan. Financially.

**SOL:** We plan and plan and plan... It's just things are more figured out and structured. And it just doesn't feel like we're having as much fun as we used to. You know, everything's scheduled.

Another well spouse said, in the conjoint interview,

**DEB:** We still go on vacation, we just have to make sure we're on the ground floor. So you have to plan a lot more, but it doesn't stop us.

Three of the couples changed residences in response to the diagnosis to ensure an accessible and safe dwelling.

**REBEKAH AND SOL: (She):**We moved because of it. We needed to be closer in. I had fallen down the steps. I wanted everything on one floor. A handicapped couple lived here before us. We bought it from them, and it

has wide halls and doors. It's one floor. No thick carpet.

**(He):** Our old house was our dream house. We designed it. But we had to move. It made sense to move. I've gotten used to it.

Another dyad described their move to their current home.

**MIKE AND ROBIN:** No carpet. No steps. Low light switches. All that.

Everything is low maintenance. Streamlined.

And the third couple explained their health related move:

**RACHEL AND GEORGE:** We'd thought about moving before. We lived in an old place. We'd put a lot of work into it. But we kinda wanted to move into a newer place. But we didn't want to feel like we were moving because of the MS. We didn't want to feel like it was calling the shots. But then we found this place, and it's been great. I hate to think of dealing with that old place.

General organization was reported as an absolute necessity. In the conjoint interviews, partners reported the need for overall structure:

**ROBIN:** Order is very important. Because he has some cognitive involvement with the lesions, he has trouble remembering some things. We had to come up with systems for remembering things. And gadgets. Everything has to be in its place. If it's not, everything falls apart and we go bonkers.

**REBEKAH:** I have a strict routine. I do everything in the same way

everyday. That way, I know I'll get done what I want to get done. It also gives me a sense of control about life. Up in the morning. Walk the dog. Do the laundry. You know. You can set your clock by my routine.

In one of the individual interviews with a woman who has MS, the following explanation for order was offered:

**JULIE:** It's vitally important for me to feel useful. To do that, I organize what I'm going to do and how. I hate the thought of going through a day without accomplishing something useful. Being organized helps me do that. Having a routine helps us cooperate with each other.

The respondents also perceived the disability-onset as a "wake-up call" to get family priorities in order. All of the accounts were given in the conjoint interviews.

**BEATRICE AND RICH:** We have been real diligent savers, and we've been real prudent about a lot of things because of the MS. But, it's not what MS has taught us about life and love, but rather what life and love have taught us about MS. That it's important to have fun and, I guess, not putting off. Don't wait until you're 65 to take a really neat vacation or something. Because there are no guarantees. Not just for us, but for everyone.

**JULIE AND BOB:** You never know what life's got in store for you. Never take things for granted, because anything could happen.

**GEORGE AND RACHEL:** You know, it would be easy for us to worry about

MS and how things are going to be ten years from now. But you can't go through life worrying. I mean I could go out here on this curvy road and get killed by a car and what good would it have done me to worry about the MS?

**DEXTER AND LYNNETTE:** We decide what we want to do and do them. I mean, we realize we better do them now rather than saying, "We'll do that someday." Because the reality is that she may not feel like doing them someday. We've stopped putting things off 'til later. I mean, we don't know what later might bring.

**REBEKAH:** I tell the people who I love that I love them. I appreciate the simple things. Like, I'm thankful when I wake up in the morning and I can get out of bed. I'm real thankful that I can hold a glass. I'm thankful that I can write my name. When we signed the papers for this house, I could not sign my name.

**MIKE:** I don't want to say that this disease is a neat thing, but there's one thing that's neat about it. You learn to enjoy life. It makes you realize what's important.

**MAGGIE:** We pay attention to things like insurance and retirement

accounts. We watched for the open enrollment for disability insurance at his work. We put away the maximum amount for our annuities. We try to take good care of ourselves physically. Even though we're only in our 30s, we think about retirement facilities. But, it's weird. We plan more carefully for the future, but we live more fully for today. That seems contradictory but it's true. He goes for high thrill activities. Crazy stuff like skydiving. Scuba diving. But it's important to squeeze all the life you can out of each day. There may come a time when he can't do those things and then what? You want to be sitting around someday saying, "I wish I'd done it while I had the chance"? No way. Do it now.

#### Meaning at the Macro Level: Social Perceptions

Respondents' accounts revealed, in both the conjoint and individual interviews, that negotiating their experience of disability in a macro context is more complex than in individual and family spheres. The data showed that among issues existing in regard to participation in social life, the most notable included feeling forced to identify oneself or one's partner as disabled in deficit terms in order to access accommodations. Other macro issues revolved around lack of understanding and need for public awareness. It is noteworthy that, in their individual interviews, the well partners did not provide significant accounts of experience and meaning at the macro level. A notable exception was one woman whose partner is unable to drive and whom she accompanies on a continual basis out in public.

Being identified as disabled. The accounts revealed a consistent theme among all

respondents regarding the relative invisibility of MS as a disabling condition. Although participants were grateful that they could retain a degree of normalcy and privacy about the diagnosis, the hidden nature of MS also presented interesting dilemmas in negotiating social spheres.

**BEATRICE:** I got into trouble trying to use my special handicapped motorist sign. The cop like followed me up the street saying I was abusing the permit. And I felt like I had to go into a long explanation about the fact that I can walk half a block, but not a whole block. He didn't believe me. It really got ridiculous.

**RACHEL:** I've got it. I don't deny it. The doctor doesn't deny it. But I think there are still some people, like in our Sunday School class, who are so skeptical. It's like, "But you look okay and you're working. What, how much could be wrong with you?" But they don't realize the limitations. I feel like I've gotta be bedridden before they'll believe that I've got a problem here. So when I don't feel up to volunteering or socializing, I'm concerned they think I'm being snobbish. But it's not that at all. I just really can't go and do.

**MIKE:** If you were to just look at me, you'd never know anything was wrong. But that doesn't mean that I don't need certain things. So to get what I need, I feel like I should look pitiful. But I don't want to look

pitiful. I don't want anyone feeling sorry for me, but at the same time, I want and need a little extra time. Or to use a dictaphone instead of writing when my hand's numb. But to get that, I have to fit their notion of disabled.

And another told of an incident at work:

**ROD:** One time when I was having a real problem with walking, you know, I could barely lift my legs. Anyway, I still went to work everyday. And everyone said, "What are you doing here? You should be home." Why should I be home? I have a job and I can do it. I'm just having trouble walking. But it made them uncomfortable. After that, they wanted to get some doctor's citation for my personnel file. I fought that. I felt it was discriminatory. I hadn't missed any days. My work was good. I felt like they wanted to label me. I didn't want the label. The label was the problem, not my gait, and not my work. Just the label and a feeling that they thought since I was disabled I was totally incapacitated.

Lack of understanding. Closely related to the perceived pressure to identify with a stereotypical view of disability was a consistent report from all respondents that there is a general lack of understanding in the public arena about symptoms and concern about how the symptoms are construed or misconstrued by people beyond the family circle.

**DEB:** They were thinking the worst, but the truth is that his speech was affected by MS. Unless we announce his diagnosis, people think he's a drunk.

Another account revealed a similar lack of understanding:

**REBEKAH:** The neighbor said, “Well you don’t look sick to me.” What does she expect? For me to keel over? Would that make her more sympathetic? Not that I want her sympathy, but I don’t want her judgement either about why I’m not working full time.

One well wife expressed her perception of societal response to her husband’s disability:

**MAGGIE:** I wish people understood that there is a range of disability. I mean, in all fairness, I was this way, too, before he got MS. But it seems like people are understanding if you use a wheelchair. It’s visible, and they can say, “Okay, that person can’t walk.” Or if they see you using sign language, they say, “Okay, that person can’t hear.” But what about invisible disabilities? There’s disbelief. There’s doubt. They don’t understand that you can look fine and still have something terribly wrong.

Public awareness. To overcome the lack of public understanding, respondents conveyed a desire for increased societal awareness and education about MS. They believe advertisements and public service announcements would help challenge erroneous conceptualizations of the disease and its effects.

**JAY:** People don’t know what MS is. Most of the people I talk to ask, “Is that what Jerry Lewis does telethons for?” No, I’m not one of Jerry’s kids.

**JUNE:** Multiple sclerosis is anonymous. It’s low profile. People are aware of AIDS. People are aware of Muscular Dystrophy, thanks to Jerry Lewis.

That's what they usually associate with MS. People are aware of cancer and heart disease. But MS? Isn't that the name of that women's magazine? Isn't that Bill Gates' computer company? I mean please! How can so many people have it and so few people know about it? I hope that will change with Richard Pryor. And Annette Funicello. I think the more people who talk about it the better it will be. So I try to do my part in talking about it.

### Discussion

The assumptions of symbolic interactionism and human ecology suggest that reality is continuously constructed by, rather than imposed upon, human beings, and that behavior must be viewed in social context to be fully appreciated and understood. These assumptions served as theoretical moorings in analyzing the accounts of people with multiple sclerosis and their intimate partners. The accounts support the conceptualization of disability as a dynamic construct, the meanings of which change over time and across social contexts. The interviews also provided an insider's view of disability onset, shifting the focus away from expert clinical perspectives typically offered in studies of disability.

The descriptions of being diagnosed and living with a disabling disease (or being the intimate partner of someone so diagnosed) revealed a developmental process by which individuals come to terms with diagnosis. The reports showed that people initially react to the diagnosis and receive it as an intruder over which they have no control. Later, they come to view it as one factor among many in a full and complex life. Consistent with a life span orientation, it should be noted that this developmental process should not be

considered unidirectional. That is, just as a person can move from the reactive-recipient perspective of diagnosis to the proactive-participant orientation, so can he or she develop backward in the event of an exacerbation or other intervening circumstance. Likewise, individuals may develop at different rates across the various domains.

The research question about how disability in one partner is incorporated into the dyadic relationship and experienced by the couple as a family unit was answered in conjoint accounts of diagnosis as a shared experience. The families reported that disability in one member set processes in motion that changed the character and quality of their relationships. These changes were largely positive among these participants, challenging traditional stress models of caregiving and disability. However, it should be noted that the participants were all in longterm established relationships and were together as couples for many years prior to MS onset. The long family histories may temper the meaning of the diagnosis in a way that may not hold true for newer relationships.

Finally, the participants spoke about the meaning of disability within their social spheres. In this context, reports indicated a greater level of frustration and negative experience. No direct interpretations of stigma were reported as one might expect from the established literature on disability. In fact, the accounts suggested that rather than trying to conceal the disability in accordance with theories of stigma, the respondents felt life would be simpler if their disability were more visible. Lack of understanding and awareness were noted as key issues at the societal level.

A final observation is in order regarding the interaction of micro, meso, and macro

experiences in people's construction of meaning about disability onset. This was noted most clearly in the accounts of how participants' perceptions of their situation changed after getting information from doctors, support groups, and other sources. This is consistent with the theory of symbolic interactionism which purports that meaning evolves for individuals in and through involvement with others.

### Implications

I caution the reader to consider the following points when evaluating the reported findings. Such a deliberation is necessary before considering the clinical and research implications of this study. First, all the participants were volunteers who learned of the study through supportive networks such as self-help groups and a chapter office of the National Multiple Sclerosis Society. It is possible that people who lack these resources would offer contrasting accounts. Second, as noted above, all participants were in longterm, positive, intimate relationships which may explain the positive "skew" of the accounts. Third, all of the couples had adequate economic resources to cover living and medical costs allowing a degree of employment flexibility that many families do not have. Finally, none of the participants appeared, or reported, to be experiencing psychological depression often associated with multiple sclerosis. Two of the participants indicated they did take a prescribed antidepressant which had greatly improved their outlook, relationships, and general quality of life. While heeding these caveats, significant applications of the findings are still suggested, as well as areas for further research.

The delineation of developmental shifts in the meaning of disability may provide a valuable framework for therapeutic interventions. The formulation of disability

experiences into this reactive-proactive developmental model, replacing earlier grief and stress models which emphasize moving through difficulty toward closure, holds promise for understanding how people with disabilities and their loved ones move from disempowered to empowered positions relative to their diagnosis. This knowledge may help inform and establish new conventions for effective intervention for therapists, counselors, and other supportive personnel. Likewise, the findings regarding the impact of family and social factors on individuals experiencing MS could sensitize and inform more holistic and family-inclusive treatment for the medical aspects of MS.

Further research is needed to discover if these findings would generalize to other adult-onset illnesses and disabling injuries, or if they are peculiar to multiple sclerosis. Longitudinal investigation is needed to discern the existence of other developmental shifts in the meaning and experience of disability along the disease course and across the life span. Examination of adult-onset disability in various family constellations is essential. I limited my investigation to intact intimate dyads, excluding children, extended family members, and the family experience of single people, whether they were never coupled or from dissolved partnerships. Finally, examination of midlife adults with unexpected disability onset who are suffering, depressed, and unable to find meaning in their disrupted lives should not be abandoned. Although the current study uncovered resilient adaptations to adult-onset disability that counter research with a problem-centered orientation, a one-sided investigation, in either direction, renders an incomplete and inaccurate knowledge of disability experiences.

This study underscores the importance and utility of moving beyond adherence to

a strict biomedical view of disability reported by clinical experts to include first hand accounts in understanding the personal, familial, and social experiences of disabled persons and their loved ones. This approach marks a significant departure from traditional inquiry. Such investigations will become increasingly important to understand, address, and accommodate the lives, expectations, and needs of the growing number of people with disabilities in our society.

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**Midlife Development and Adult-Onset Disability:  
Responding with Realistic Resilience  
to Normative and Nonnormative Life Events**

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**Abstract**

*This study was undertaken to reframe the events of midlife aging and disability onset from pervasive deficit models into a resilience model. I sought to challenge the popular assumption that these two events, one normative and one nonnormative, are necessarily and essentially negative in their consequences.*

*Utilizing qualitative methods informed by symbolic interactionism and a life span perspective, I conducted indepth interviews with ablebodied and disabled midlife adults about how their experiences with aging and disability have been incorporated into their family relationships. Findings indicate that while respondents acknowledge the challenges associated with these two events and are realistic about the associated problems, the prevailing and ultimate response is one of resilience and forward focus.*

Research on midlife development is taking root in the 1990s, though there is still a dearth of knowledge on this phase of the human lifespan when compared to that of childhood, adolescence, or old age. More often than not, studies of midlife focus on

chronological age and traditional family events and continue to be framed and guided by stage models. Despite growing numbers of middle aged people brought about by the maturation of baby-boomers and increasing life expectancy, the development of a definitive knowledge base regarding midlife experience has eluded gerontologists and family scholars.

Becoming middle aged and spending many years in this developmental period is a normative event experienced by most people; even so, the dynamics of midlife remain obscure, tentative, and understudied. Brooks-Gunn and Kirsh (1984) suggest that “the variability of midlife markers and the lack of cohesion among them makes it difficult, if not impossible, to discuss transitions” into and through midlife (p. 17). Also cultural and historical shifts in the definitions and markers which signify the onset and the end of middle age complicate attempts at summary characterizations of the period in the life course (Huyck, 1989). So, in the absence of a solid body of cumulative research, and despite a melange of reports to the contrary, myths prevail regarding midlife as an experience of lost youth and crisis marked by vain attempts to stay young while fighting off old age.

Another demographic trend indicating an area of growing interest to family and other social scientists is the increasing number of people with disabilities. Disability is ranked as the nation’s largest public health problem, affecting not only individuals with disabling conditions and their immediate families, but also society at large through lost wages, policy decisions, and involvement with the health care and insurance industries (Pope & Tarlov, 1991). Using federal health survey data, the Institute of Medicine

concluded in 1991 that 35 million Americans--one in every seven--have a disability that interferes with daily activities such as work or keeping a household (Shapiro, 1993). It should be noted that, contrary to popular belief, congenital and birth defects account for only 15% of disabling conditions, leaving 85% of disability with later-life onset resulting from accidents, injuries, and disease (Shapiro, 1993).

While adult-onset disability at midlife is a nonnormative event, its rate of incidence suggests that systematic investigation of the phenomenon is warranted. Like midlife, the dynamics of disability remain obscure, tentative, and understudied. Another similarity between the two fields is that people believe that both aging and disability have primarily negative consequences (Meyerson, 1988). Western societies commonly view aging and disability as diagnoses of deficiency (Wang, 1992) and connect these events with people becoming burdens on their families and society (Dwyer, 1995).

The concerns of disabled and aging people are comparable in many areas (Shapiro, 1993), supporting the congruence of adult development and disability studies, and suggesting their ability to be mutually informing. Butler (1989) reported on the deterministic and defining power attributed to chronological age in affecting public perception of the aging process as well as older people's image of themselves. I suggest that receiving a diagnosis of disability also tends to have this deterministic and defining power in shaping perception; the result of which is a perception of decline. As people age into and through midlife or as they become disabled, they are compared, in deficit terms, to what they were before: young and vibrant or able-bodied and self-reliant, respectively. Guided by a life span perspective, I investigated the possibility of an alternative to deficit

conceptualizations of aging and disability.

One of the tenets of life span theory is that human behavior is best understood by examining the interaction of ontological, historical, and nonnormative events. Further, all these factors are viewed as being mediated through the individual. Despite the complexity asserted in this perspective, simplistic, linear explanations continue to be pervasive in shaping popular attitudes regarding the issues of aging and disability onset. Taking a life span orientation, this study represents an attempt to overcome simplistic explanations and to inform popular viewpoints.

To this end, it was my intention to address the apparent incongruity that exists between the literature and social consciousness. On the one hand, studies indicate that neither midlife aging nor disability onset is globally negative in its consequences; while on the other, contemporary characterizations of these two events center on notions or reactions of crisis, disparagement, decline, pity, protectiveness, and fear. To address this disparity between “what is” and “what we seem to believe” as it relates to middle agedness and disability onset, this research converges the fields of aging, disability, and family studies. It considers individuals within their family systems by including conjoint interviews with intimate dyads as well as individual interviews with each partner. I organized my research around the personal accounts of midlife couples, each comprised of one ablebodied and one disabled partner. My inquiry was made at two levels: process and outcome.

On a process level, I attempted to understand the complex, multidimensional dynamics of these events by asking participants to describe their experiences with midlife

aging and, when applicable, disability onset. Then, on an outcome level, I sought to discover the results of those complex dynamics by asking, “What changes have these events brought about for your family?”, “Do you see life differently because of these events?”, and “What lessons have you learned from these experiences?”

## Literature Review

### Midlife Development

Much research, especially that grounded in psychoanalytic and life script theories, advances “early formation” conceptions of personality development (Wrightson, 1988). These models, with an emphasis on biopsychological dynamics, suggest that childhood is active, progressive, and chocked full of preparatory experiences and challenges that serve to govern the future behavior, adjustment, and world view of an individual at maturity. Adulthood, on the other hand, is conceived of as relatively static; that part of life in which people simply live out the dispositions acquired in childhood. This thinking has been vigorously challenged on many fronts by scholars, philosophers, and practitioners who agree with Leonard Pearlin’s (1980) assessment of “adulthood as a period in which newness is more commonplace than stability. Adulthood is not a quiescent stretch interspersed with occasional change; it is a time in which change is continuous, interspersed with occasional quiescent interludes” (p. 174).

Fiske and Chiriboga (1990) concurred with Pearlin’s assessment and observed that the study of adult lives is inherently more complex than other stages of human development because adults have a longer experiential history. They insisted that meaningful examinations in gerontology require a multidisciplinary orientation

embracing not only psychology but social psychology, sociology, anthropology, and social history as well.

### Life Span Perspective

Life span psychology represents just such a multidisciplinary perspective, viewing development as a life-long process that involves the interaction of factors at biological, psychological, and sociocultural levels (Featherman & Lerner, 1985). Further, the joint impact of these factors are then mediated by the individual (Baltes, Reese, & Lipsett, 1980). Because the potential for variability in events along these three axes is vast, and because the interaction of biochronological, cohort, and idiosyncratic forces is filtered through, rather than imposed upon, the individual, “there is an explicit rejection of the notion of any universal kinds of experiences, particularly during the middle years” (Huyck, 1989, p. 24).

Instead, the life span perspective provides a more open orientation that considers human phenomena that entail change processes, by viewing them in the context of diverse antecedent and subsequent events (Baltes, Reese, & Lipsett, 1980). Although this open, nondeterministic, and multidisciplinary approach to the study of midlife is optimal for capturing developmental processes, it is not without drawbacks. One of the most significant difficulties arises when attempting a coherent conceptualization of middle age as a location in the life course.

The period denoted as midlife has shifted further along the life course with the protraction of young adulthood, improvement in health care and status, increased life expectancy, discontinuity of family life cycle staging related to divorce, blended families

and other reconstitutions of family structure, childbearing and rearing practices, and changes associated with career paths and work-life events (Brooks-Gunn & Kirsh, 1984). These factors, and others associated with midlife processes and transitions, vary according to an individual's gender, class, culture, previous experience, family constellation, socioeconomic status, educational attainment, and other ontogenetic, history-graded, and nonnormative experiences. Many events associated with midlife correlate only in a probabilistic sense; some are not experienced by all individuals, or may be experienced at different times, or in a different sequence. The variability of midlife markers and their lack of cohesion makes it difficult, if not impossible, to discuss transitions (Brooks-Gunn & Kirsh, 1984).

Even so, Chiriboga (1989), in support of early contributions made by Neugarten, Moore, and Lowe (1965) and Neugarten and Moore (1968) who were among the first to frame midlife as movement to and through culturally constrained, age-normed life events, proposed that "many so-called life events do occur more often at some stages of life than others...Despite the fact that life events generally are not restricted to one specific age,...they are helpful in charting the trajectory of the life course of specific individuals" (p. 47).

These two positions--one focusing on discontinuity and variability and the other on predictable, somewhat normative life events--give witness to the problematic study of adult development as a whole and midlife adulthood in particular. In response to the difficulty attendant to disentangling the morass of life events and psychological processes associated with midlife, Haan (1981) stated that satisfactory conceptualizations must be

relatively abstract and must rise above concrete details of ever-changing situations because it is impossible to control or otherwise “systematize the complex, intimate details or the sociohistorical contexts of persons’ lives” (p. 118). Thus, the following conceptualization is offered.

### Love and Work Conceptualization

Rather than attempting a theoretical synthesis or delineation, efforts should focus on identifying the central issues that dominate the study of the adult phase of life. Two of the most important life phenomena that play themselves out during these years are, according to Smelser (1980), love and work. The task of identifying these central issues was substantiated by Hale (1980) who observed that it was originally undertaken by Freud who reflected on work and love not as a systematic social philosopher but as a physician. “Freud’s clinical practice was overwhelmingly devoted to young adults between twenty and forty for whom the problems of work and love were poignantly acute” (p. 30).

The love and work paradigm allows for all of the various issues, matters, and tasks attendant to maturity to be, in their essence, subsumed under a simple yet comprehensive framework for the study adult development. Smelser argued that the selection of love and work as the central matters in adulthood is validated by looking to the major social institutions constructed to establish, regulate, and maintain practices related to the expression of love and work: “the occupational-bureaucratic complex, provid[es] the locus of most...work activities. ...and the family [is] the preferred...arena for the cultivation and expression of love and related affects” (p. 4). The love and work

conceptualization of adulthood has been used in several studies regarding life in the middle years (Hale, 1980; Merriam & Clark, 1993; Veroff, Reuman, & Feld, 1984).

There are infinite derivatives of the love and work constructs (e.g., courtship, mate selection, parenting, employment, career development, shifts in interpersonal and family relationships, etc.). These specific operationalizations are helpful and useful in specific empirical investigations. But using the abstract concepts of love and work as the central, unifying themes of adult life and growth helps to frame a more meaningful examination of the process of midlife development.

### Disability Onset

Similarly, by approaching adult-onset disability from an implications for love and work perspective, one is compelled to acknowledge not only the individual biomedical status of a person at midlife, but the environmental and cultural elements of one's status as well. Traditionally, the focus of inquiry into disability has been on degree of impairment and rehabilitation. Such an approach establishes comparisons of disabled people to able-bodied standards, inevitably rendering deficit models of disabled adulthood. Associated with this impairment and rehabilitation focus to the study of disability is the fact that it has been firmly situated in a medicalized, individualized, isolationist perspective, concentrating on issues which are important to medical professionals (Chappell, 1992). However, a contemporary theme among disabled persons and among researchers exploring their experiences is to define disability in sociological terms (Atkin, 1991; Biklen, 1988). Meyerson (1988) noted that, although there is a "salient biological component" (p. 179) to the perception, experience, and definition of disability, biology

alone is not sufficient in explicating the phenomenon.

Hahn (1988) offered three major models for understanding and defining disability: (a) the historical medical model that focuses on functional impairments, (b) the economic models with their focus on vocational limitations, and (c) the socio-political models which “regard disability as the product of interactions between individual and environment” (p. 40). Schneider (1988) reiterates this point: “Categories such as disability...are not ‘givens’ in nature, but rather socially constructed categories that emerge from the interpretive activities of people acting together in social situations” (p. 65).

This vantage point is congruent with the multidisciplinary orientation of the life span perspective, and holds promise for making real inroads in grasping the effects of disability on the growth and adjustment of disabled adults and their families. Proposed here was a move to examine how disability is related to, and what meaning it has for, disabled people and their families, in experiencing love and work. A comparison to nondisabled people was not sought. Instead, questions related to love and work were explored from the perspective of, and for the experience of, disabled people and their loved ones.

### Issues in the Present Research

The phenomena under investigation, transition into and through midlife and disability onset, constitute an unusual pair. One is a normative, the other a nonnormative life event. Neither has a categorical definition, yet both are frequently understood in simplistic, definitive terms. Persistent and negative myths, stereotypes, and assumptions

are attached to both experiences despite research findings to the contrary. Neither is supported by a cumulative, comprehensive knowledge base. Finally, both are examples of how social science has failed to inform social consciousness; that is, fallacious deficit models of both midlife adult development and disabled adulthood continue to occupy mainstream thought.

In this context I undertook the current exploration of midlife development and adult-onset disability. Originally, the study was designed to examine adult-onset disability and its impact on individual and family development (see previous article for a report of those findings). During the course of that investigation, a surprising development occurred. Participants' accounts did not simply describe disability and midlife aging in impact model terms, but more interestingly as dual processes shaping life experience. I pursued this direction in the course of the interviews, recognizing the accounts as illustrative of emphasis in life span theory on examining the interaction of normative and nonnormative events in explicating human phenomena. I was further guided by symbolic interactionism that stresses the need to explore how an individual's interpretations of experience are influenced by social involvement with others, especially family members, (Travis, 1995). I was particularly interested in discovering if people identify any positive aspects in their family relationships relative to their to experiences with midlife aging and disability onset. If so, the findings would constitute a challenge to the deficit models of stress, crisis, decline, and burden that pervade social thought about these two processes.

Data were gathered through open-ended, semi-structured interviews. These indepth accounts revealed that midlife development and adult-onset disability do bring

unique challenges and attendant problems with which families must contend. The interviews also revealed that these experiences present opportunities for personal growth, enhanced relationships, stock-taking about the meaning of life, and decisive action for purposeful living.

## Methods

### Participants

Informants were 18 midlife individuals, comprising 9 intimate dyads, ranging from 31 to 57 years of age with established relationships averaging 21 years in length. Each couple had one able-bodied partner and one with a disability, represented by an established diagnosis and disease course of multiple sclerosis (MS). (See Table 3).

Participation was solicited on a volunteer basis from MS support groups and through a letter of support sent by the executive director of a local chapter of the National Multiple Sclerosis Society to chapter members (see Appendix A). Interested volunteers completed and returned a form (see Appendix B) providing their names and telephone numbers. I used the returned forms to contact potential participants by phone. I gave a brief synopsis of the study, conducted an initial screening (see Appendix C), and then scheduled conjoint interviews at a time and location convenient to the informants. When we met for the interviews, I reviewed the informed consent document that had been approved by the Institutional Review Board at Virginia Polytechnic Institute and State University (see Appendix D). At the conclusion of the conjoint interviews, follow-up individual interviews were scheduled with each partner of the dyad.

Table 3: Participants

Couple	Years as Couple	MS Partner	Age	Well Partner	Age	Years with Diagnosis
1	35	Lynnette	53	Dexter	54	7.5
2	13	Jay	55	Deb	41	5
3	21	Beatrice	46	Rich	47	18
4	12	Rod	40	Maggie	36	5.5
5	35	Julie	54	Bob	57	10
6	7	Rebekah	31	Sol	34	7
7	20	June	48	Hank	50	5
8	22	Mike	49	Robin	48	8*
9	25	Rachel	44	George	50	6
	$\bar{x}=21.1$		$\bar{x}=46.6$		$\bar{x}=46.4$	$\bar{x} = 8$

\*diagnosis was made 2 years ago, but couple reports that symptoms have been present for 8 years

## Data Collection and Analysis

Data were collected through indepth semi-structured interviews utilizing a general question guide (see Appendix F). I interviewed each informant twice, first in a conjoint interview with his or her intimate partner, and once in an individual, private session. Interviews ranged from .5 to 3 hours in length, for a total of more than 40 hours of interview time.

The content of the interviews centered on the participants' personal experiences of midlife aging or adult-onset disability. I customized the order and phrasing of questions to maximize the informants' participation in telling their own stories in their own words. My goal was to facilitate a data-infused conversation in which perceptions and experiences were shared by participants, clarified by me, and brought into theoretical focus through the lenses of the life span perspective and symbolic interactionism.

The interviews were recorded on audiotape, transcribed verbatim, and analyzed according to the constant comparative method. This form of analysis involves the researcher in a process of focussing in on key themes that emerge from the data, categorizing these issues and subsequently collecting many incidents for each category (Snyder, 1992, p. 52). Constant comparison involves working back and forth between the various sources of data to establish a balance between generalizing from data and remaining aware of the distinctiveness of individual experiences (Murphy, 1992) . Constant comparison enables a comprehensive examination of how each individual's experience is both similar to and different from other individuals' experiences (Snyder, 1992). The constant comparative method of data analysis allows "each new family's data

[to] illuminate the previous family's data and helps to refine the theoretical concepts” (Murphy, 1992, p. 155).

My method of performing a constant comparison analysis of the data included writing field notes in a research journal immediately after the conjoint interviews. These notes included my initial impressions of what the respondents' had said and how they had said it; that is, observations of interactions between the partners during the interview, and questions that I wanted to ask the individual partners. Within 2 days after each conjoint interview, I listened to the audiotape twice: once to check and augment my field notes, and again to formulate the interview guide for the follow-up, private interviews. As I progressed through the conjoint sessions with all couples and drew questions from the shared interviews to ask the individual partners, I also asked the derived questions in the subsequent interviews with all of the respondents. The result of this continuous culling was a cumulative compilation of questions, clarifications, and reported experience with and between all 18 individual respondents and the 9 dyads. Consistent with my use of the research journal during the conjoint interviews, I made field notes after each individual session as well, regarding impressions, observations, and questions. As in the case of the conjoint interviews, I checked and augmented my field notes for the individual sessions by listening to the audiotaped recording.

Selection of themes and development of coding categories was made with attention to two principles: one was theoretical, the other methodological. Theoretically, I was guided by symbolic interactionism and a life span perspective. Thus, in my selection of themes and categories, my attention was drawn to participants' references to meaning,

interactive processes, and reports of change, age, and personal history.

Methodologically, I was committed to keeping the people in the center of the data analysis, and to honoring the tenet of qualitative research of listening and giving voice. As I attempted this in my analysis, I focused on the words and passages which the respondents' repeated, emphasized, or punctuated with emotion through gestures, facial expressions, or change of tonal quality in their voices. Conversely, I noted those instances in which participants changed the subject or avoided a question, believing that silence can be as revealing as voice.

Verbatim transcriptions of the conjoint and individual interviews were made, and reviewed for accuracy against the audiotaped interviews, and re-read in entirety on one occasion. In the process of analysis, I revisited some of the literature on qualitative analysis and collaborated with colleagues also engaged in qualitative research. I was concerned about neglecting the protocol of multiple readings of transcripts for data immersion and analysis. I was finding that the transcripts did not adequately capture the voices of the respondents in this study. As a result, my analysis involved multiple "listenings" of the tapes rather than multiple "readings" of the transcripts. Additional, partial readings of the transcripts occurred after themes were identified to select excerpts for inclusion in the report.

Consideration of methodological rigor in qualitative investigations generally relates to issues and questions of validity, reliability, and generalizability. Arguments have been made that these concepts are anchored in positivist philosophies of science and do not translate to post-positivist and postmodern philosophies and qualitative designs.

Even so, scientific enterprise requires attention to the selection and defense of method. I chose a qualitative design because my interest was in discovering the **meanings** that midlife development and disability onset had for people, rather than in explaining or predicting experiences (Snyder, 1992). By using multiple sources of data (couples, well partners, ill partners, and myself), collecting data to the point of theoretical saturation, and confirming my initial findings in subsequent interviews with the participants (Gilgun, Daly, & Handel, 1992), I maximized the precision of my analysis and the rigor of the method.

### Findings

The interviews yielded over 40 hours of audiotape and 1,000 pages of transcribed data; contextual accounts rich in description and insight regarding the experiences of midlife aging and adult-onset disability. Most notable was the consistent report that these events represent mileposts or bends in the road of interesting life journeys as opposed to critical shifts in direction or course. All respondents reported that while change was inherent in their process of aging into midlife or becoming diagnosed with disability, the change itself was not inherently positive or negative. Rather, participants emphasized that the outcome of aging and disabling processes depends on one's response to these events. All informants reported that they had learned important lessons about love and work from middle-agedness and diagnosis of disability that were unique to these experiences, and could not otherwise have been learned.

### Process

Without exception, respondents reported specific, detailed accounts of the process

of becoming diagnosed with multiple sclerosis. These accounts were primarily provided by the person with MS, but confirmed by the well partners who were active in elaborating on information and experiences omitted by the MS person. Usually stated in terms of “we,” these were shared narratives, constructed to be inclusive of both partners.

**JUNE:** My mother had died of a brain tumor, so we were scared that might be what was happening.

**HANK:** But you didn't have headaches, so that was a relief. We just needed to find out what was the matter 'cause...

**JUNE:** We didn't want to take a chance. The doctor actually thought it was a stroke because you know, on one whole side, the leg and hand...

**HANK:** Partial paralysis.

**JUNE:** Yeah, that's what he called it. But, well we told them, we just told them up front we didn't feel like we had to have a diagnosis...

**HANK:** Except to rule out the brain tumor possibility. We wanted to rule that out. That was fall. September? October? But the next May...

**JUNE:** Early May...

**HANK:** Yeah, what was the date?

**JUNE:** Oh, I'm not sure. I'll think of it in a second.

**HANK:** Yeah, but in early May, is when she started having numbness...

**JUNE:** When we stopped to think about it, we realized that I'd probably had symptoms for a couple of years before that.

The precision of this account was typical for all respondents, and is illustrative of the

salience that nonnormative events have in the description and explication of human experience. Even couples in which the MS partner had been diagnosed many years earlier provided detailed accounts of the experience which were embedded in the lives of both partners.

**BEATRICE:** It was almost 20 years ago. In 1978. I remember it was the day he was going to find out whether he had a job or not. I remember him saying he was gonna find out about his job. And by the time he got home, something was wrong with my eye. The next morning I had lost complete vision in this eye, my right eye.

**RICH:** She tearfully called an eye doctor and got an appointment right away.

**BEATRICE:** They diagnosed it as optic neuritis. I remember when I went to my general practitioner, that he had put initially, right there, that you know, the possibility of MS.

**RICH:** Then she comes in and says, "I've got MS."

Conversely, the reports of entering midlife, a normative event, were loosely constructed, and nonscripted, meaning that the couples did not provide shared accounts of this transition. In fact, several participants reported that they were confused by the question and had never thought about their transition into midlife.

**DEB:** I don't know what I expected it to be. I guess I expected never to be middle aged. I didn't think about being 40 with children and a business when I was 20 or 25...I don't think about it now. But I guess my life is

pretty normal. Yeah, I think it's supposed to be like this. Maybe I'm supposed to have a face lift, too. But I really don't know.

For those participants who had thought about the process of entering midlife, the transition was most often framed in terms of activities.

**REBEKAH:** We're probably midlife now...we've got two dogs and a kid and a mortgage, but I envisioned that I'd have a great career. Basically be a supermom with a great career. I still hope for that to happen before I'm old.

However, one respondent reported acute awareness of his midlife transition:

**DEXTER:** It's a life cycle thing...I've been with her for many years. And now she's doing her own thing...I'm watching her and me and am just starting to absorb into her lifestyle more. I mean, I'm just trying to absorb her qualities. Her creativity. Her femininity. All of that. Into my own lifestyle. I never would've even noticed these things before, or cared about them for myself.

His wife was surprised by his comments and teased him,

**LYNNETTE:** When did you become a '90s kind of guy?, corroborating the notion that transition into midlife is a more subtle, individual process, unlike the dramatic and explicitly shared process of disability onset.

Participants described the processes of becoming middle aged and disabled as curious and perplexing. Without being falsely sanguine about their unfolding experiences, the couples offered a characterization that is different from the frequently cited stress

models and role strain theories. For instance, respondents reported some of the less enjoyable aspects of aging:

**GEORGE:** Oh, the bones start to creak, and what you used to be able to do takes twice as long. You gotta have a sense of humor about these things. It's life, man!

**MAGGIE:** It's like all of a sudden you're realizing that life is just speeding by. When did time start going so fast? It must've been while I wasn't looking. And that can be a troubling realization, but it gets you off your butt to accomplish what you want to accomplish, for sure.

Similar observations were made about the process of disability onset:

**BEATRICE:** I guess there are things better than having MS, like not having it, of course. Given the choice, I wouldn't have said to God, "I'll take brown eyes, long legs, a sparkling personality, and why don't you throw in some MS while you're at it." I mean, I'm not stupid. But there's things worse, a lot worse, than MS, so I'll deal with what I've been given. I believe everything happens for a purpose, so I have to believe my having MS has a purpose, too.

As the accounts provided a view of midlife and disability onset as developmental processes, they also provided an inventory of outcomes associated these events.

### Outcomes

Outcomes were reported as the results of, or perceptual responses to, the

experiences of normative aging and nonnormative disability onset. An array of specific outcomes were reported which generally covered three areas: (a) noticed changes, (b) attitude differences, and, (c) lessons learned. The accounts were analyzed and organized in accordance with the love and work conceptualization of adult development discussed earlier. Indeed, most of the outcomes identified by the participants could be viewed as falling within these two realms, supporting the relevance of the framework to the study of adulthood. Case illustrations are provided below.

Noticed changes. Respondents reported that becoming middle aged or disabled brought definite changes to life. As they relate to work, the accounts related the following change outcomes:

**RICH:** We're more comfortable financially. And we're, our life is more settled.

**SOL:** I used to have more fun, with recreation things. But now my biggest fun's at work. Doing different projects, being involved with the people I work with, you know. My job is a big part of my life, more than when I was younger. Really, it's not a job anymore, it's more like a career, by that I mean I take greater interest in it. I'd like the opportunity for better growth and advancement.

For the partners with MS, employment outcomes were salient issues:

**JULIE:** It just got harder and harder, they were putting more and more on me at work, and I couldn't concentrate enough to get the work done. I

mean I did it, but it about killed me. I finally quit, and that was rough.

**LYNNETTE:** I switched from a physically demanding, more interesting position to a mentally demanding, boring position. I had to, I mean I couldn't do what I used to. But I miss the action. I miss the pace. But still, I mean, even though I miss it, I'm eternally grateful that this transfer was possible.

**MIKE:** So the biggest change has been needing and getting a routine. I used to work a very inconsistent schedule. I never knew how many straight weeks I'd get and I couldn't deal with never knowing when I had to work. So I offered to work more than my share of weekends if I could just get a consistent schedule. Now I've had the same routine for the past several years.

**RACHEL:** I went to part-time. It's perfect. I'm glad we could afford to do that.

Change outcomes related to love were reported in similar ways by both ablebodied and disabled midlifers who voiced the difficulty involved with trying to separate which effects are attributable to which process. This reflects the life span concept that it is an interaction of normative with nonnormative events, along with other factors, that shape human experience.

**ROBIN:** I don't know if its MS, or just being at this point in life. Maybe both. But we're better friends. We love each other, and you know, always have. But the friendship is deeper. We relate differently. It's not as much effort, it doesn't take as much, to make the relationship go. It's easier.

**REBEKAH:** We've gotten over a hurdle. We're past the seven year itch. We've been tested by MS. And we've come out all right. I've noticed that we've changed, we've gotten more, we've settled.

Attitude differences. Along with the tangible changes came attitudinal shifts in how the respondents regard the issues of work and love in facing disability onset and midlife. Some of the attitudes are conflicting as illustrated in the following two accounts:

**LYNNETTE:** Work has become my metaphor for health. I feel that as long as I can keep working, then I'm not really disabled. To me, MS doesn't mean disability, unemployment does. Work is much more important to me than it used to be. Some people have told me I should quit and collect disability. I find that suggestion appalling.

**GEORGE:** My attitude about work has changed. Going through her MS and getting older myself has made me look at things differently. Life shouldn't be about work. It should be about doing what's important. I feel like I've spent a lot of years living to work, rather than working to live. But now I know that life's too short and I'm not going to do that anymore.

A considerable portion of the interviews were spent on the respondents' descriptions and evaluations of their love relationships, including how their attitude and regard for one another have been altered as a result of aging and disability onset. The attitudinal outcomes of midlife and disability processes were numerous and varied. One woman who has MS reported in the conjoint interview that,

**JUNE:** I think it has made us think more about the, the, temporariness of this life, and made us realize our importance to each other.

And her husband later, in the individual interview, stated,

**HANK:** It's hard to feel out my thoughts and emotions. For our life as a couple. She handles adversity well. Better than me. Sometimes I feel like I'm just along for the ride. And it hurts me, for her to have to deal with so much. And I can see as we've grown up and older together, and faced the health problems, you know, just getting older and dealing with life, from my view, she's much stronger than I am. I don't think I could handle it basically as well. I may be the so-called "healthy" one, but she's the strong one.

Another well spouse gave this account of the outcome of aging on his attitudes about love:

**DEXTER:** My whole attitude and expectations about what love is supposed to be is so different than when we first got married. I was the man, you know, I was the king of the castle, I had to be in charge. Hey, at least I can admit it! I expected her to be the little woman, supper on the table, and all

that. Life has changed all that. We're much more relaxed now. Much more compatible. Being middle aged means there's not so much that you have to prove. To yourself or to the people close to you. It's nicer. It's totally changed the way I see her. I never knew it could be this way.

Another example came from a well spouse who reported his attitude in less buoyant terms:

**SOL:** Yeah, you could say there've definitely been some outcomes from the MS. It's really changed her from what she used to be, but I think I'm about the same. We argue more than, than we used to. We're in a rough period right now, but we'll work it out. We're seeing a counselor, therapist kind of person. We're committed. Not just to the marriage, but really to each other. This is gonna sound weird, but it's almost reassuring that we can admit things aren't the way they should be. I mean, we're not ignoring the problem hoping it'll disappear. It takes a lot of courage to be honest about difficulties in a relationship.

This final account was particularly interesting as it reframed negative experiences in the relationship into positive terms about the strength of the couple as a family unit.

Lessons learned. Finally, the accounts revealed that middle agedness and disability onset had provided lessons that the participants believed could not otherwise have been learned. Again, the responses focussed on the areas of work and love.

**JULIE:** I learned that I am meant to be a counselor. Getting MS got my attention. It forced me to slow down, physically, of course, but also mentally. Spiritually. It ushered in a whole new type of career for me. I had

to quit the job I held, but I am now a MS counselor, I do group work, I serve the chapter office. MS brought me into what I consider my life's work, my calling. I learned that I am very good at these things. I never would have known this.

One man with MS who had operated his own business but has since turned it over to his family reported that,

**JAY:** I learned that work is a privilege. I miss being involved. I really miss it.

An ablebodied man offered a different view,

**BOB:** I have learned that work is something, but it's not everything.

And a final note on lessons about work is offered by an ablebodied midlife woman:

**MAGGIE:** Lessons of being middle aged? That work is an important part of life. Not that you should be defined by what you do rather than who you are. That's not what I mean. But that work is how we connect to the world. To other people. It's not just a job. It's how I make my mark, my contribution. I'd be at a loss if I didn't have a job to do.

As the lessons pertain to love, the following reports were made and speak for themselves:

**JUNE:** I learned that I have a spouse who doesn't turn tail and run when a problem crops up. I learned that I can really count on him to stick by me through thick and thin.

**MIKE:** That we are strong. Our marriage is strong. That our love is strong.

**HANK:** I've learned about life from just living to be this old. And you put her MS on top of that, you learn even more. About what you're made of. About what's real. Like, we learned our faith is real and that God is real. How do you know that, really for certain, if you never have to deal with anything difficult? I've learned for sure what I believed all along, that love is not some mushy, sweet, feeling, but a strong, a tough, a solid thing, like an anchor that keeps you from going adrift or getting lost.

### Discussion

The purpose of this study as it emerged during the course of another investigation, was to explore the processes of normative and nonnormative life events, namely transitions from youthfulness into middle agedness and from healthful ablebodiedness into disabling illness. I sought to discover how these transitions are experienced within a family context and what happens to family members as a result of these life events. I particularly wanted to determine if evidence was sufficient to support an alternative to the prevailing discourse which frames aging and disability in largely negative terms. Data were gathered through open-ended, semi-structured interviews with midlife couples in which one partner has an established diagnosis of symptomatic MS.

These findings revealed that entrance into midlife or receiving a diagnosis of disability are not construed as life events, per se, rather as processes through which one changes in experience and outlook. The accounts answered the guiding question of whether these processes are necessarily and essentially negative in their consequences as suggested by some of the established models suggested in the stress, coping, and grief

literature. Along with a problem orientation, these models also view experiences such as disability onset, as events to be dealt with gotten past, rather than phenomena to be continually incorporated into one's life, identity, and outlook. Informants reported that midlife development and adult-onset disability do, in fact, bring unique challenges and attendant problems with which families must contend. But they also described these experiences as opportunities for personal growth, enhanced relationships, stock-taking about the meaning of life, and decisive action for purposeful living.

This finding indicates the presence of a dual perspective; one in which difficulty is acknowledged as both problematic and fruitful, suggesting the notion of resilience, which may provide an improved framework for the study of life transitions such as aging and disability onset. The findings of this study offer support for life span theory and a resilience model which recognize human phenomena as multidimensional, and view all change as developmental, whether it is progressive or retrogressive, generative or degenerative.

The concept of resilience is both allusive and elusive: Allusive in the sense that it conjures up many ideas and notions about strength, adaptability, hardiness, and psychological sinew; elusive in the sense that it defies definition and operationalization. Many of the conceptualizations of resilience (Anderson, 1994; Cicchetti & Garnezy, 1993; Rende & Plomin, 1993) refer to a quality of elasticity that enables persons to rebound from, or remain impervious to, difficulty. This definition is inadequate to address the experiences of the midlife and disabled people in the current study, who reported that they did not "bounce back" from their aging and disabling processes to a previous state,

or disregard their reality; rather, that these experiences were incorporated and brought different, and enhanced, ways of seeing and being in the world.

Outcomes of the processes of becoming middle aged or disabled were also identified by the participants. Organized around an implications for love and work paradigm drawn from the literature on midlife development, specific accounts of outcomes varied greatly between informants. Identified outcomes ranged from reported changes in mundane activities such as housekeeping to the development of philosophical insights about the nature of love. The characterizations of the outcomes were distributed along a positive-negative continuum, across three areas (noticed changes, attitude differences, and lessons) with a preponderance of positive responses. This finding provides further evidence and support for developing a resilience model to replace deficit models in framing midlife and disability research.

#### Implications

I caution the reader to consider the following points when evaluating the reported findings. Such a deliberation is necessary before considering the practice and research implications of this study. First, all the participants were volunteers who learned of the study through supportive networks such as self-help groups and a chapter office of the National Multiple Sclerosis Society. It is possible that people who lack or do not avail themselves to these resources would offer contrasting accounts. Second, as noted above, all participants were in longterm, communicative, intimate relationships which may explain the positive “skew” that would not be found among people whose family situations and relationships are more conflictual. All of the couples had adequate

economic resources; none was financially constrained or unable to meet basic living and medical expenses. This may explain the participants' ability to cast experiences in a different light than would be possible for less affluent families. Finally, it should be noted that none of the respondents reported acute or chronic psychological distress related to midlife transitions or diagnosis of disability, with the exception of two MS persons who were receiving and responding well to treatment for depression. It is possible that a resilience model was found appropriate and stress models lacking because the sample was comprised of unusually high functioning, optimistic, and resilient people.

While heeding these caveats, significant applications of the findings are still suggested as well as areas for further research. The formulation of becoming middle aged or disabled as a multidimensional process that takes place within and through interpersonal family relationships, may provide human service personnel with a perspective and a tool for empowering people to view these events as life developments in which they can and should be actively involved, rather than as negative inevitabilities over which one has little control. The study underscores the importance of going beyond the realm of individual experience to consider family context to fully understand dynamics of experience.

The findings relative to resilient responses could be used to inform and focus treatment conventions of therapists and other practitioners who work with disabled clients, midlife adults, and their loved ones on adjustment issues. Likewise, the findings provide data that have the potential to sensitize and correct popular misconceptions about the nature of normative aging, nonnormative disability onset, and the consequences of

these processes.

Further research is needed to discover if these findings would generalize to other adult-onset illnesses and disabling injuries, or if they are peculiar to multiple sclerosis. Similarly, replication of the study in different family contexts is essential to substantiate the findings reported herein. I limited my investigation to intact intimate dyads, excluding children, extended family members, and the family experience of single midlifers. Whether the process and outcomes discovered in this study are idiosyncratic to this family constellation or global in their application is a question for future research.

This study underscores the importance of methodological flexibility while engaging in qualitative research. The accounts provided by the participants that informed this report emerged spontaneously during the course of the interviews, adding an unexpected layer of discovery to my original investigation about adult-onset disability. Just as my agenda was to challenge strict adherence to deficit models of aging and disability studies, the participants' unfolding stories challenged my strict adherence to a predetermined line of inquiry. I became acutely aware of my responsibility to hear their experiences accurately, and to respect the scientific value of "particular truth, sourced in the specific experience of a knower" (Krieger, 1991).

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**The Experience of Listening for Experience:  
Hearing and Giving Voice in a Qualitative Study**

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During my doctoral studies, I have had the privilege of exploring ideas and questions through stimulating interaction with my professors and classmates. Reading, writing, conversation, and debate has centered on the philosophies of science, ways of knowing, construction of knowledge, and the application of findings to improve the world for all its inhabitants. I would be hard pressed to select a specific concept as standing out among the rest to which I have been introduced. Even so, the idea of being inclusive and the importance of “giving voice” in research as a corrective for the exclusive science that has dominated the construction of knowledge would certainly be among the particularly valuable lessons of my academic career. Instilled with an enthusiasm for exploring people’s lived experience, and a respectful desire to give voice to people with disabilities and their loved ones, I undertook a qualitative study for my dissertation, in which I conducted multiple indepth, semi-structured interviews. My goal was to have the participants tell their own stories in their own words, and, through the research report, bring visibility and clarity to their lives.

This goal was consistent with efforts described by Appleby (1993) who warned against collusion with ablebodiedism and exhorted scholars to seek research practices

“which integrate the experiences of disabled [people] from the outset” (p. 268). I wished to contribute to the reformulation of established yet flawed (Meyerson, 1988) ways of thinking, knowing, and studying about people with disabilities and their private and social lives. Indeed, Fine and Asch (1988) found that much research about disabled people is framed by scholars outside the disability experience, making “the person with the disability the object, not the subject, of study and distances the research from the disabled person’s life experience” (p. 17). Furthermore, “there has been a virtual absence of studies that report, in people’s own words, the routine experience of living with chronic illness and disability” (Schneider, 1988, p. 63). Bearing in mind these indictments and admonitions, I sought to place persons with disabilities and their loved ones at the center of inquiry.

While asserting my well-intentioned interest and investment in seeking to explore some of the family and personal issues facing people with adult-onset disability, I was mindful and self-conscious of my position as an able-bodied researcher. Harkening back to the criticism of Fine and Asch (1988) about studies designed and conducted by scholars “outside the disability experience,” it had to be asked how I could responsibly engage in this research.

The answer is found partially in what Patricia Hill Collins (1986) describes as a dual vision that can emerge when one has *entre’* to multiple arenas--in her case Black culture, feminist womanhood, and academia--but is relegated to the margins due to some aspect of identity or experience. Referred to as “outsider-within” status, this can be a difficult and painful position, but it can also afford a special perspective on self, family,

and society. bell hooks (1984) captures the essence of this vantage point by explaining, “...we developed a particular way of seeing reality. We looked both from the outside in and from the inside out...we understood both” (p. vii).

In this research I claimed the “unique standpoint that the outsider within status can generate” (Collins, 1986, p. S15). My educational training and professional experience has been in the field of social work where, among other matters, I studied about and worked with persons with severe disabilities and their families. I participated with various agencies, programs, departments, and personnel as an insider-professional, though I was an outsider to the experience of my clients and their families. Then, seven years ago, this arrangement was abruptly altered: I became an insider-family member, entering the disability experience as a “well spouse” (Strong, 1988) when my husband was diagnosed with multiple sclerosis. Drawing from interviewing and advocacy skills acquired in professional training and experience, as well as from my association with disability through personal experience, I engaged in this research with a dual vision that I hoped would allow me to meaningfully explore the experiences of people negotiating disability at midlife. Following the example of Krieger (1991), “my discussion draws on both my experiences and the experiences of others, piecing these together, suggesting common themes and ultimately offering an argument” (p. 15).

The preceding articles report the findings, grounded in the data of informants’ direct accounts, about the processes of negotiating meaning of disability in various contexts and its outcomes for family life. Conversely, the present article presents my findings about the research experience, and issues that arose during the course of the

study, as they pertain to my experiences of listening to experience and “giving voice” in research.

In most discussions about qualitative methodologies, listening is a central concept, serving as a primary “tool of the trade” through which researchers gain insight into how people construct their realities and live their lives. It is a chief means by which we access subjective experience, deconstruct objective “truths” as not fitting the lives of marginalized people, and create new ways of knowing. Yet, what about the deconstruction of listening itself? Could it be that our listening, despite respectful and generous motivations, is another mechanism of coercion? Does our act of listening impose an expectation for others to speak at our whim and for our purposes?

These questions arose from two unrelated encounters that occurred 4 years apart during the course of my doctoral program. They have led me to examine my privilege as a scholar-listener, and to question the dynamics of power in the act of listening. The first came in the form of a reading assignment for an elective class I took during my second year of study, before I had given much thought to my dissertation. It included the following lines: “You come for oral histories, for your own agendas...You come to fill in some much needed data for a thesis...But you come not as equals. You fail to examine your oppressive attitudes” (MacDonald, 1991, p. 170). I was disturbed by this passage as it suggested that rather than empowerment, regard, and centeredness being the result of inclusive listening and qualitative research, the experience could be, and was, experienced as exploitive and disrespectful. I realized the difficulty in placing people in the center when, in actuality, my project occupied that location. For my own research, I

wanted to believe that my outsider-within status would help me avoid these problems as I sought to engage people in talking about their experiences while I listened. However, even with this safeguard, I recognized that any agenda would still be mine, and I struggled with how to discern and incorporate participants' agendas as well.

The second encounter that sensitized me to methodological issues related to qualitative studies came in the form of song during the early stages of my data analysis. Listening to music as I was making a preliminary review of my interview transcripts, the lyrics of a chorus that was barely audible worked their way into my consciousness and I found myself scribbling them in the margins of my notes: "Talk to me while I'm listening. Now...In voice that we both can hear...Won't you please talk to me while I'm listening?" (Griffith, 1994). I reflected on how I had presumed upon my informants to do just that, and wondered how they felt about their participation in the interviews and about having their voices audiotaped for my use. I wondered how it could be possible to develop a qualitative method that would correct for the listener-driven agenda of which I had become so acutely aware, and with which I had become acutely discomfited.

Other experiences of listening to experience arose over the course of the research. As stated earlier, in learning about qualitative research, I was taught that it is a "voice giving" endeavor. I believed in the importance of this, and sought, as a primary purpose of my study, to give voice to midlife adults with disabilities and their intimate partners. An interesting development occurred as I reviewed the interview transcripts. There was a considerable number of "inaudible" notations which took me back to the tapes in order to fill in the "gaps" on the transcripts, so that I could proceed with my analysis. In listening

to the tapes again, I was struck by the variation in tone, speed, inflection, accent, and other qualities of voice. One man had great difficulty speaking due to his disability, and expressed how he got frustrated when people completed his sentences, thereby stealing his voice. I realized that the transcripts also “stole his voice” by rendering his impediment both invisible and inaudible. On paper, his words were received according to the pace of the reader, not at his pace as speaker. Each word he utters is an effort; that reality was lost in a straight reading of the transcript. Another woman, who grew tearful at several points during the interview and whose voice quavered and caught when speaking about sensitive matters, was not accurately represented in the transcripts. Her voice, replete with emotion, was not “heard” even though her words were preserved. There are many examples of this disparity between registering words and giving voice. In a very real sense, the transcripts did not contain just a few inaudible gaps of some words; rather, all the voices were “inaudible” in the transcripts. I found myself drawn repeatedly to the tapes, and frustrated when shuffling through the transcripts. I found the tapes interesting and the transcripts boring. Again, I wondered how it could be possible to develop a qualitative methodology that would correct for the transcript-driven agenda for analysis that I had been taught, of which I had become so acutely aware, and with which I had become acutely discomfited.

Another experience of listening to experience in this qualitative study arose in the context of multiple interviews with different family members. I held initial conjoint interviews with couples in which one partner had a diagnosis of multiple sclerosis and conducted individual follow-up interviews with both partners separately. From the perspective of triangulating data sources and obtaining contextual and processual data,

this methodology was excellent. Yet, from my perspective, some issues arose around listening as an act of power and privilege in the process of conducting multiple and separate interviews.

As proposed earlier, the act of listening imposes a process of telling and this interaction can serve to construct realities for the parties involved. I did not find this listening dynamic problematic in the conjoint interviews, as both partners were present ensuring that any reality constructed would be shared. However, in the individual sessions, this was not the case. I was engaged in a listening process about a shared experience, but which excluded one of the actors.

Accompanying this process, was one in which I was coming to be “known” by the informants through repeated visits to their homes for follow-up interviews. This familiarity, along with the privacy of the interviews, seemed to create an atmosphere for the individual partners to be more forthcoming in their responses to my questions. Their voices were generally lower in tone and volume, and had a more serious and reflexive quality. The level of disclosure, the concealed nature of the individual interviews, and the participants’ changing regard for my presence, set me apart as being an expert about their own experience by having privileged information in and about the family system that was unavailable to both members. I discovered myself guarding against any nuance of exploitation, as I sensed that the informants were willing to talk about almost anything, making them vulnerable to unwitting disclosure. Simultaneously, and perhaps conversely, I wanted to acknowledge and participate in our burgeoning relationship of positive regard, as a way to give something back to the informants for their generous accounts

and expressions of experience. Again, I wondered how it could be possible to develop a qualitative methodology that would correct for the expert-driven research of which I had become so acutely aware and with which I had become acutely discomfitted.

I attempted my best resolution to the dilemma of agenda-, transcription-, and expert-driven research by seeking to convert interviews into data-infused conversations. I participated in, as well as conducted and directed, the conversations. I yielded to my respondents as they asked as well as answered questions. I followed the research in an unforeseen direction as the respondents gave voice to differing experiences. I listened to the audiotapes of the partners' voices as a primary analytical method, while reading their words in the the transcriptions as a secondary, less important, method. Using my outsider-within status, I believe I was able to do this in a way that honored both the producers and the product of listening, telling, and giving voice. Of knowing, being known, and making known. Of weaving story into science.

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## Literature Review

### Overview

This project involved the exploration of the personal, familial, and social experiences of people with adult-onset disability and those of their intimate partners. Emphasis is placed on the negotiated meanings of the disability experience and how it shapes the development of both individuals at midlife, as well as the couple as a family unit. I was particularly interested in how disparate meanings of disability are reconciled and incorporated at micro, meso, and macro levels.

Critics might ask, “Is disability in adulthood a ‘problem’ of sufficient magnitude to warrant specialized consideration?,” “Does adult-onset disability represent a salient confound in the established knowledge base of adult development?,” and “Is a study of disability more suitable for medical or rehabilitation disciplines than for family science?” To answer these questions and thereby establish a rationale for the study, I offer a presentation of literature on midlife adult development from a life span perspective. Introduced into that discussion is the phenomenon of adult-onset disability and the ramifications of that event on developmental processes. Included is an overview of the current state of thinking that moves disability beyond the purview of medical consideration at the micro level, and frames it as a social and political concern. Specific attention is given to disability related issues at social, familial, and individual levels of experience; connections and interactions among and between these levels are also assessed.

### Adult Development

Much research, especially that grounded in psychoanalytic and life script theories, advances “early formation” conceptions of personality development (Wrightman, 1988). These models, with an emphasis on biopsychological dynamics, suggest that childhood is active, progressive, and chocked full of preparatory experiences and challenges that serve to govern the future behavior, adjustment, and world view of an individual at maturity. Adulthood, on the other hand, is perceived as relatively static; that part of life in which people simply live out the dispositions acquired in childhood. This thinking has been vigorously challenged on many fronts by scholars, philosophers, and practitioners who agree with Leonard Pearlin's (1980) assessment of “adulthood as a period in which newness is more commonplace than stability. Adulthood is not a quiescent stretch interspersed with occasional change; it is a time in which change is continuous, interspersed with occasional quiescent interludes” (p. 174).

Fiske and Chiriboga (1990) concurred with Pearlin's assessment and summarized additional observations and caveats regarding the study of adult development dating back to the early work of Bernice Neugarten (1969):

She pointed out several vital but often ignored differences between studying adults as compared with the well established fields of infant and child development...The study of adult lives is inherently more complex because adults have a longer experiential history...requir[ing] a multidisciplinary orientation embracing not only psychology but social psychology, sociology, anthropology, and social history as well. (p. 20)

The view of adulthood as a period of continuing and complex development has been

captured in the work of stage theorists and life span developmental psychologists.

Stage theories of adult development fit within the purview of a life span perspective, in that human development is viewed as an ongoing process, never “fixed”, and one that continues for the duration of a person’s life. Erik Erikson, perhaps the best known stage theorist, rejected purely biological or psychological orientations, believing instead that growth and development emanate from the combination of biology and psychology, influenced by *social* factors. Stage theorists purport that these biopsychosocial forces guide individuals to and through an ordered series of critical life tasks, each being qualitatively different but progressive inasmuch as a successful resolution of the task at one stage equips the person with the capabilities necessary for the next stages. Thus, each new stage provides an entirely new level of structural integration (Wrightsmann, 1988). This feature of stage theories--that “a solution at any stage...has its effects on all subsequent stages” (Neugarten, 1968, p. 86)--is known as the epigenetic principle. It specifies that each aspect of development has a particular time of ascendancy until all parts culminate to form a functioning whole and is an important component of stage-based formulations of human development throughout the life span (Ryff & Seltzer, 1995).

The critical tasks, or crisis points, identified as being relevant to adult development at midlife vary depending on the particular theory under consideration. Despite the similarities found in these models and the usefulness of a stage approach in capturing the idea of continuing development throughout adulthood, there are significant limitations in approaching a study of adult development and aging from a stage-based

formulation.

Some criticisms of stage modeling include its uni-directionality, its grounding in bio-chronology, its heterosexist bias toward marriage-based family life and homemaking practices (Cornett & Hudson, 1987), its overtly normed view of developmental processes in adulthood, and finally, its male perspective of normal development (Gilligan, 1982). For the purposes of the current study, stage models are inadequate in addressing biological disruptions related to disability onset; neither do they provide for the “constitutional givens” of individuals--such as resilience--as they move through the life course.

In contrast, life span psychology represents a perspective that includes the strengths of stage models while overcoming their significant limitations. Life span psychologists view development as a life-long process that involves the interaction of factors at biological, psychological, and sociocultural levels (Featherman & Lerner, 1985). In a similar vein, Baltes, Reese, and Lipsett (1980) described the life span perspective as an approach that considers the joint impact of ontogenetic, historical, and nonnormative events, as mediated by the individual, in accounting for behavior. Because the potential for variability in events along these three axes is vast, and because the interaction of bio-chronological, cohort, and idiosyncratic forces is filtered through, rather than imposed upon, the individual, “there is an explicit rejection of the notion of any universal kinds of experiences, particularly during the middle years” (Huyck, 1989, p. 24). Instead, the life span perspective provides a more open orientation that considers human phenomena that entail change processes, by viewing them in the context of chains

and patterns of diverse antecedent and subsequent events (Baltes, Reese, & Lipsitt, 1980).

The life span conceptual framework is predicated upon four major assumptions. Like the stage models, it assumes that development is a life-long process. Unlike some other theoretical approaches to human behavior which conceptualize the human personality as being formulated in early childhood (e.g., Freud, Piaget), life span theorists advance the idea that development continues throughout the entire lifetime of a person. Thus, the view of aging as a process of degeneration and deterioration is reframed to consider retrogression as development. For instance, Troll (1975) observed that some adults restrict the variety of their experiences, become less open, and “probably develop ‘backward’ instead of ‘forward’ ” (p. 4). Within the life span orientation, change, whether forward or backward, progressive or retrogressive, generative or degenerative, is viewed as continued development rather than decline. This is closely related to another assumptive underpinning of the life span orientation: development must be conceived as a pluralistic, multidirectional process.

Many theories, including the stage models discussed earlier, hinge on the epigenetic principle and view development as occurring in a sequential, irreversible, age-bound manner; development is a process that results in an end-state that builds, in a quantitative and incremental manner, on growth achieved at an earlier point in a maturation. In contrast, life span developmentalists view development in more discontinuous manner. Both increases and decreases of certain potentialities are viewed as developmental. Individuals are viewed as possessing great plasticity, capable of development at any point along the life course.

A third assumption is that development involves the interplay of ontogenetic and evolutionary processes, rather than simply being described or explained by individualistic ontogenetic factors, especially amongst adults in midlife and old age. Elaborating on this aspect of the life span perspective, Wortley and Amatea (1985) discussed how ontogenetic factors interface with sociocultural, historical, environmental, economic and epochal events to shape human behavior and development. Indeed, Baltes, Reese, and Lipsett (1980) proposed that these differing factors (ontogenetic, history-graded, and nonnormative events) fluctuate in salience over the life course, with biological aging becoming less, and nonnormative events--such as unexpected disability--becoming more, influential in adulthood and old age.

A final assumption of the life span framework is that any study of development requires an integrative, multidisciplinary approach. Because it focuses on the complex interplay of so many factors, life span research must attend to issues of history, the sociocultural milieu affecting informants including economic and social trends, news events, popular culture, political climate, and significant world phenomena such as wars, natural disasters, famines, and epidemics. Added to the consideration of ontogenetic and environmental influences is recognition by life span researchers of nonnormative events, such as unexpected disability at midlife, and their increasing salience to developmental processes during the adulthood.

Having looked at life span development and the application of the four key assumptions to the broad study of adult development and aging, the discussion will now focus on a more narrow period of adulthood known as midlife.

## Midlife

Unlike some models of adult development which define midlife by chronological age, life span developmentalists argue that the shift of markers which signify the onset and the end of middle age from culture to culture and over historical periods makes it impossible to attempt some summary characterization of the period in the life course (Huyck, 1989).

This view is supported by Brooks-Gunn and Kirsh (1984) who studied the midlife transitions of well educated career women. Their findings suggest that the period denoted as midlife has shifted further along the life course with the protraction of young adulthood, improvement in health care and status, increased life expectancy, discontinuity of family life cycle staging related to divorce, blended families and other reconstitutions of family structure, childbearing and rearing practices, and changes associated with career paths and work-life events. The Brooks-Gunn and Kirsh study points out that these factors, and others associated with midlife processes and transitions, vary according to an individual's gender, class, culture, previous experience, family constellation, socioeconomic status, educational attainment, and other ontogenetic, history-graded, and nonnormative experiences. They further noted that many of the events associated with midlife are not experienced by all individuals in the same way or sequence, concluding that the variability of midlife markers and the lack of cohesion among them makes it difficult to discuss transitions.

Even so, Chiriboga (1989), in support of early contributions made by Neugarten, Moore, and Lowe (1965) and Neugarten and Moore (1968) who were among the first to

frame midlife as movement to and through culturally constrained, age-normed life events, proposed that many so-called life events do occur more often at some stages of life than others and remain helpful in charting the trajectory of the life course of specific individuals.

These two positions--one focusing on discontinuity and variability and the other on predictable, somewhat normative life events--give witness to the problematic study of adult development as a whole and midlife adulthood in particular. To gain an understanding of the events, issues, and concerns associated with the phase of human development referred to as midlife and attempt some sort of coherent conceptualization of the experiences of people at this location in the life course, I will briefly trace a chronology of the research findings of the past several decades.

Chronology of midlife research. One of the largest scale investigations of middle age, associated life events, and personality development was carried out under the sponsorship of the Committee on Human Development of the University of Chicago between 1952 and 1962. This project gathered cross-sectional data on more than 700 people from Kansas City, aged 40 to 70, representing all socioeconomic levels. Under the auspices of the National Institute of Mental Health, another set of studies was conducted in conjunction with the Kansas City research in 1953 and 1954. Other longitudinal studies, most notably the Oakland Growth Study and the Guidance Study of Berkeley, have also rendered volumes of data for the study of human development through the life span. Much of what is known about midlife has emerged from the data generated in the Kansas City, Oakland, and Berkeley studies, or has evolved from questions first raised by

those early investigators who piloted inquiry into this previously neglected area of human development.

1950s & 1960s. Since the late 1950s and early 1960s when the Kansas City project was being completed, a surfeit of studies has been conducted to identify life events and psychological phenomena that serve to define, mark, or otherwise chart the phase of development known as midlife. According to Levine (1957), middle age is marked by a change in tempo and rhythm. The value of mental alertness and speed is replaced by “the assurance of reflective thinking” (p. 43), in which stimuli is filtered selectively. Earlier focus on physicality is replaced by an integration and appreciation of the whole person--mind, body, personality--for one’s self and others.

In their study of personality and adjustment in middle age, Peck and Berkowitz (1964) identified and tested seven psychological attributes purported to be meaningful variables for studies of personality and adjustment in the second half of life. The attributes were: (a) cathectic flexibility which is “the capacity to invest strong, meaningful emotion in new activities, new relationships, new experiences” (p. 16); (b) mental flexibility which “implies open-mindedness, as opposed to dogmatic, opinionated, or passive closed-mindedness” (p. 17); (c) ego differentiation which refers to the ability to pursue and to enjoy a varied set of major activities and not rely entirely on one or two roles for a sense of self-worth or enjoyment; (d) body transcendence which is feeling whole, worthwhile, and happy; (e) body satisfaction which is “the degree of satisfaction one subjectively feels with one’s body” not necessarily related to one’s “actual state of health, vigor, or physical attractiveness” (p. 19); (f) sexual integration of desire with

affection for the sex partner, a sense of responsibility for offspring. Relevant for the study of unexpected disability are a number of these variables which speak to a person's changing regard for a changing physicality.

Another study of midlife experience from the 1960s that raises an important issue for an investigation of adult-onset disability was conducted by Gutmann (1964). He noted that the concept of mastery is particularly salient in the midlife period. According to Gutmann, mastery refers to one's sense of competence in handling the stresses presented by the environment, interpersonal relationships, as well as internal conflicts. The ecological perspective represented in Gutmann's study is reflected in the present study of the individual, familial, and social aspects of one's disability experience.

Social role changes in middle age were investigated by Sussman (1965) whose research involved interviews with 57 post-parental married couples. This study provided an interesting integration of life span and symbolic interactionist conceptualizations of aging and adult development, much like that being utilized in the present research. Changes in the meanings and processes of intergenerational and marital relationships were noted, with decreased attention given to parenting and increased importance being placed on the marital relationship. Increases in leisure pursuits and involvement in religious activities were found among midlife couples, perhaps due to an easing of time and financial constraints, coupled with clarified values. No changes were evident in worker roles for men, suggesting career stability, while women reported decreases in domestic responsibilities and the need to reconstruct who they are as their interactional patterns and contexts change.

Other mileposts of middle age marked during the 1960s by Neugarten (1964; 1968) include an emerging awareness of being set apart from both younger and older generations, and a change in the perception of time. “Life is restructured in terms of time-left-to-live rather than time-since-birth” (p. 97). Neugarten corroborated Gutmann’s concept of mastery by stating that a prevailing theme of midlife is a heightened sense of competence for dealing with life. While this competence is expressed in terms of external demands, midlife ushers in a period of increased salience of the inner life with a lessened sense of concern for accommodating the reaction of others.

1970s. Johnson (1971) described middle age as the most creative period of life, during which people reach a peak of capacity and achievement. Johnson also noted that there is a sense of urgency and foreboding in midlife with a realization of “vanishing youthfulness that betokens a critical turning point from ascending into descending life” (p. 4). More specifically, Johnson identified practices and attitudes that correlate with being stationed in midlife: giving to others in interpersonal relationships, taking time for spiritual “in-searching” (p. 13), and caring for, but not obsessing about, one’s body, physical strength, aches, and illness.

Diverging from studies that have focus primarily on psychological phenomena, Troll (1975) reviewed and reported the findings of many cross-sectional studies regarding physical, intellectual, and social changes associated with midlife, as well as family and occupational careers. She noted that aside from menopause or climacterium, adulthood is a phase of life marked by relative stability, especially when compared with other periods of life (e.g. infancy, adolescence, late senescence). Additionally, Troll reported that the

important starting signals for middle age seem to be social, such as the experiences of marriage, parenthood, and being at the peak of a career, or seeing the youngest child move out of the home. It should be noted that the social experiences of family-making and employment, as well as the physical stability that typically characterizes this phase of life are often violently disrupted by the experience of adult onset disability, necessitating consideration of its impact on developmental processes at midlife.

In the late 1970s, Levinson (1978) reported his findings of a study of 40 men between the ages of 35 and 45 from various occupational groups. He identified several core components of midlife development. He found that middle aged men undertake a life review and reappraisal which is spurred by a realization of mortality and increased individuation. Individuation is described as a process which requires a person to integrate dichotomies of young/old, destructiveness/creativity, masculinity/ femininity, and attachment/separateness. According to Levinson, the central issue facing people at midlife is bringing into balance these countervailing forces and thereby establishing a renewed, integrated value system; one that will bring the midlifer greater satisfaction and meaningfulness in personal and social relationships. Again, this study failed to include the experiences of disabled people. If and how they undergo the life review and individuation processes remains unknown.

1980s. Haan (1981), a champion of abstract conceptualizations of developmental processes in adulthood reported that midlife brings about a move toward greater self-reflexiveness and self-liberation. Reminiscent of Levinson's study, she suggested a dynamic involving the masculine-feminine dichotomy, reporting that women become less

feminine, men more feminine. Some inferences could be made, perhaps, that this finding lends support to Sussman's early study of the shifting social roles for women away from domestic obligations to personal agency with the launching of grown children.

Haan reported that "'generalized' middle-aged persons appear to be equipped by reason of past experiences both to savor and deal with themselves effectively and comfortably" (p. 151). Savoring such effectiveness and comfort is indicated by increased nurturance, self-confidence, openness, and personal and sexual expressiveness. Because her conclusions are predicated upon the assumption that people at midlife are equipped "by reason of past experiences," one must ask what happens to the person at midlife whose current experience is so suddenly, unexpectedly, and profoundly disrupted by a diagnosis of disability as to render past experiences insufficient for current effectiveness and comfort? On what basis can such an individual hope to increase in nurturance, self-confidence, openness and expressiveness?

Moving into the realm of health and health-related midlife research, Donald Donohugh (1981), a physician who worked for 25 years with middle aged patients, found that reevaluation of personal values and a quest for meaningfulness is a hallmark of midlife. In line with this claim, and with the many other scholars who have alluded to the midlife processes of in-searching and value clarification, the premise of the current study was that the meaningfulness of disability is worked out and incorporated on individual, familial, and social levels.

Chiriboga (1989) discussed the concept of midlife crisis, indicating that while most adults in midlife can expect stability in personal and mental health, changes in work

trajectories and household arrangements can bring developmental, stress-related, and clinical issues to the fore. Closing career options and career plateauing offer stability and the experience of executive expertise, while at the same time, they point to career closure and the realization of encroaching retirement. On the homefront, movement away from childcare can indicate a movement toward the need to care for aging parents.

These events tend to bring persons to a realization that they are in the middle of the generations, and usher in a period of self-examination and attempts to balance life choices with values. Work- and family-related events at midlife can also usher in a series of loss-related demands that have the potential of creating an identity vacuum. Finally, and particularly germane to the current investigation, Chiriboga discussed “clinical-level losses” in the personal world and/or physical status of people at midlife that have the potential for completely disrupting one’s life.

On a more humorous level, Kalish (1989) noted several “signposts signifying arrival in the land of middle age” (p. 301): a disturbing increase in being addressed as “sir” and “ma’am;” not recognizing names of contemporary icons; discovering that one’s lived experiences are now the content of children’s history classes; and being startled by an aging, oddly unfamiliar, face reflected in one’s mirror. More seriously, Kalish commented that middle age brings the optimum balance of years behind and years ahead, that is, of experience and potential. Middle age is marked by coming to know one’s self and what is important in the grand scheme. Middle aged people are seen as engaging in decisive action. Finally, Kalish noted that midlife is the period of life which lends itself to power and leadership.

In his chapter entitled “Productive Aging,” Butler (1989) identified several myths surrounding the process of adult development and aging. Although the focus of his discussion was on people beyond midlife, it is included here for its relevance to the understanding of disability. Among the many myths and stereotypes related to aging were noted the deterministic and defining power attributed to chronological age, inevitable unproductivity and senility, and the notion of older people as asexual. “These myths directly and indirectly affect the public’s perception of older people’s productivity and negatively influence older people’s images of themselves and the contributions they can make to society” (p. 56). I suggest that the same myths exist for people who become disabled and with equally harmful results. Indeed, the concerns of disabled and aging people overlap (Shapiro, 1993), supporting the congruence of gerontology and disability studies, and suggesting the potential for them to be mutually informing.

1990s. In the design of a 12-year longitudinal study of adult development, Fiske and Chiriboga (1990) identified a sense of personal continuity along with ubiquitous stress as telltale signs of an individual at midlife.

Another writer, Mary Carlsen (1991), advanced an interesting conceptualization of adulthood as the span of life in which meaningfulness is sought in the entirety of experience, both good and bad, through a creative process. Carlsen’s paradigm incorporates concepts such as crisis points, questioning value systems, increased introspection, work, mastery, and self-acceptance.

Research on midlife development is taking root in the 1990s, though there is still a dearth of knowledge on this phase of the lifespan when compared to that on childhood,

adolescence, or old age. And still, more often than not, it seems that midlife studies focus on chronological age, traditional family life events, and that they continue to be framed and guided by stage models. Several recent studies have opened up the field to consider midlife experiences among minority populations (Silverstein & Waite, 1993) and the impact of nonnormative events such as ill health (Kuuire, 1993) and combat trauma (Scaturo & Hayman, 1992).

The inventory of midlife phenomena is vast, indeed. In response to the difficulty attendant to disentangling the presenting morass of life events and psychological processes, Haan (1981) stated that satisfactory conceptualizations must be relatively abstract and must rise above the concrete details of ever-changing individual lives and situations because it is impossible to control or otherwise “systematize the complex, intimate details or the sociohistorical contexts of persons’ lives” (p. 118). Likewise, Smelser (1980) believed that rather than attempting a theoretical synthesis, research efforts should focus on identifying the central issues that have emerged to dominate the study of the adult phase of life. He suggested that the two issues purported to be “the most important life phenomena that play themselves out during these years” are work and love (p. 4).

The task of identifying the central issues for study of middle adulthood was substantiated by Hale (1980) who observed that it was originally undertaken by Freud who reflected on work and love not as a systematic social philosopher but as a physician. “Freud’s clinical practice was overwhelmingly devoted to young adults between twenty and forty for whom the problems of work and love were poignantly acute” (p. 30). The

love and work paradigm allows for all the various issues, matters, and tasks attendant to maturity to be, in their essence, subsumed under a simple yet comprehensive framework for the study of adult development. Smelser (1980) argued that the selection of these two issues as the central matters in adulthood is validated by looking to the major social institutions constructed to establish, regulate, and maintain practices related to the expression of love and work: “the occupational-bureaucratic complex, provid[es] the locus of most ...work activities. ...and the family [is] the preferred...arena for the cultivation and expression of love and related affects” (p.4). The love and work conceptualization of adulthood has been used in several studies regarding life in the middle years (Hale, 1980; Merriam & Clark, 1993; Veroff, Reuman, & Feld, 1984).

As indicated in the preceding chronology of research, there are infinite derivatives of the love and work constructs (e.g. courtship, mate selection, parenting, employment, career development, shifts in interpersonal and family relationships, etc.). These operationalizations are helpful and useful in specific investigations. But using the more abstract concepts of love and work as the central, unifying themes of adult life and growth helps to frame a more meaningful examination of the overarching processes of midlife development and the influence of disability upon it.

By approaching the study of disability from an “implications for love and work” perspective, one is better able to focus on issues beyond physicality and to frame age-appropriate inquiry. The love and work paradigm is of further value in the study of adult-onset disability as it compels one to acknowledge not only the individual biomedical status of a person at midlife, but one’s social and occupational status, thereby including

salient environmental and cultural aspects of disability as well. This vantage point is congruent with the multidisciplinary orientation of the life span perspective, and holds promise for making real inroads in grasping the effects of disability on the growth and adjustment of disabled adults and their families.

### Disability Overview

The focus of much inquiry into disability has been couched in measurement of performing activities of daily living, mobility, and functional capacity; in other words, rehabilitation. Further, much of the rehabilitation literature establishes comparisons of disabled people with able-bodied standards, inevitably rendering deficit models of disabled adulthood. Little attention has been given to find how disability is related to, and what meaning it has for, disabled people and their families, in experiencing love and work.

Historically, the study of disability has been firmly situated in a medicalized, individualized, isolationist perspective, and has concentrated on issues of greater importance to medical professionals than to disabled persons (Chappell, 1992). Referred to as the individual impairment model (Sheer & Groce, 1988), this approach has come under great scrutiny and criticism by social scientists in recent years. Many researchers are now calling for the discipline to be reframed to include sociocultural and economic considerations of disability (Atkin, 1991; Biklen, 1988), as well as psychosocial aspects of disability within the purview of relationships and family life (Hammell, 1992; Hill & Zimmerman, 1995; Rolland, 1994). It has become apparent that the focus of disability research must be broadened from a strict biological approach that examines physical

functioning to one that also includes consideration of health care systems, cultural dynamics of discrimination and stigmatization, and political and legislative machinations related to civil rights, education and transportation (Scotch, 1988; Shapiro, 1993; Wang, 1992). After all, disability ranks as the nation's largest public health problem, affecting not only individuals with disabling conditions and their immediate families, but also society at large due to lost wages, and enormous impacts on the health care and insurance industries (Pope & Tarlov, 1991). Exacerbating the reality of disability as an enormous and costly public health concern, Scotch (1988) noted that the incidence of disability is concentrated among the least powerful members of American society--those with low incomes, low education, and low work-force participation. This dynamic of disenfranchisement has rendered a minority status model for understanding and describing the life experience of many with disabilities.

Minority status model. Using federal health survey data, the Institute of Medicine concluded in 1991 that 35 million Americans--one of every seven--have a disability that interferes with daily activities such as work or keeping a household. This staggering incidence of disability and the concomitant socioeconomic ramifications of being disabled have led to the suggestion that the disabled constitute the largest minority group in the United States (Fine & Asch, 1988). Certainly, the disabled, like other marginalized groups in our society, experience stigmatization (Goffman, 1963), stereotyping (Wright, 1960), discrimination in housing and employment (Ravaud, Madiot, & Ville, 1992), lower wages (Pfeiffer, 1991), unusual barriers when accessing educational opportunities (Scotch, 1988), and live under others' assumptions of biological inferiority (Hahn, 1988).

However, unlike other minority groups, most disabled people do not have meaningful connections and affiliation with other people who share their devalued status (Scotch, 1988). Their lives are embedded in the world of the able-bodied (Meyerson, 1988), creating an isolated experience of disability, and preventing the formation of and participation in disabled culture, group consciousness, and political activism (Fine & Asch, 1988; Hahn, 1988; Percy, 1989; Scotch, 1988; Shapiro, 1993).

People with disabilities have been a hidden, misunderstood minority, often routinely deprived of the basic life choices that even the most disadvantaged among us take for granted (Shapiro, 1993). In the last twenty to thirty years the civil rights struggles of African-Americans, women, gays and lesbians, and other minorities have brought to the fore the experiences of oppression and exclusion, with a demand for recognition, inclusion, and fair treatment. Offering a commentary on the difference between societal response to various minority groups, Oskamp (1988) observed, “most of us have learned not to treat a person of a different race or nationality or language as inherently inferior-- When will we learn the same lesson about people who are physically different?” ( p. 3).

Continuing the minority status conceptualization of the disabled population, Shapiro (1993) reminds us that disability is the one minority that “anyone can join at any time, as a result of a sudden automobile accident, a fall down a flight of stairs, cancer, or disease” (p. 7). Indeed, remarkable advances in medical, surgical, and rehabilitative technologies have dramatically increased the survival rates of persons following major trauma and illness (Hammell, 1992; Meyerson, 1988). However, survival does not indicate full recovery and resumption of normalcy; rather, the outcome of medical

advances has been a growing number of ill and injured people who survive their infirmities to face challenges of life-long disability (Hammell, 1992). Many of these people, especially those whose disabling conditions occur during adulthood, do not incorporate a self-concept of being disabled; they retain expectations of full economic and social participation, and to live as normal adults (Scotch, 1988).

Disability as a social construction. To appreciate the magnitude of disability phenomena, and the complexity of estimating its incidence, it is helpful to consider how disability is defined and how these definitions shape the understanding of human impairment. Whereas definitions of disability have historically been contrived and advanced by medical personnel (Chappell, 1992), a contemporary theme among disabled persons and among researchers exploring their experiences is to define disability in sociological terms (Atkin, 1991; Biklen, 1988). Meyerson (1988) notes that, while there is a “salient biological component” (p. 179) to the perception, experience, and definition of disability, biology alone is not sufficient in explicating the phenomenon. Instead, as Hahn and Longmore (1983) point out, the definition of disability is determined by public policy through the creation of laws and implementation of regulations pertaining to human impairment (p. 5).

Two statutory definitions of disability have emerged over the past two decades in the wake of political action by, and on behalf of, disabled persons. The first definition, considered a categorical one, was utilized in Public Law 94-142, Section 121a.5. It defines a disabled person as one who is

evaluated as being mentally retarded, hard of hearing, deaf, speech impaired,

visually handicapped, seriously emotionally disturbed, orthopedically impaired, other health impaired, deaf-blind, multihandicapped or as having specific learning disabilities.

It is noteworthy that this definition requires an “evaluation” of disability, implying that disability is located within the individual on whom the evaluation is being conducted.

The second, considered a functional definition, was utilized in the Rehabilitation Act of 1973, Section 504. It defined a handicapped individual as

any person who has a physical or mental impairment that substantially limits one or more major life activities, has a record of such an impairment, or is regarded as having such an impairment.

This definition, in its final two clauses, makes a slight move away from locating disability within the individual and toward viewing it in context as an individual attempts to live a social life, working, interacting, and being regarded by others.

This trend toward social construction of disability is further advanced by Hahn (1988) who noted significant shifts in the definition of disability. She identified three major models for understanding and defining disability: (a) the historical medical model that focuses on functional impairments, (b) the economic models with their focus on vocational limitations, and (c) the socio-political models which “regard disability as the product of interactions between individual and environment” (p. 40). In the economic and socio-political models one can discern that disabilities are not ‘givens’ in nature, but rather socially constructed categories that emerge from the interpretive activities of people interacting in social situations (Schneider, 1988).

Embedded in these definitions and models are important distinctions between the concepts of impairment, disability, and handicap. These distinctions speak to the interplay and overlap of individual and societal factors in the understanding of disability.

According to Sheer and Groce (1988), impairment is the loss of some physical or cognitive capacity due to illness, injury, or genetic condition. Disability, a related yet distinct concept, refers to the impact of impairment on one's ability to carry out the functions of daily living. Conversely, handicap refers to those social conditions that interact with an impairment or disability in such a way as to limit, segregate, or deny involvement and participation of the person with the impairment in social living.

#### Convergence of Adult Development, Disability, and Family Studies

As suggested in the preceding discussion, disability is viewed as an experience of person and social interaction, embedded in, or filtered through social contexts, the most salient of which is the family system. Despite the fact that most disabled people's lives are lived out within "nondisabled families," the study of disability and family have been treated as separate entities. Attention to the interrelationship between family and disability, particularly adult-onset disability at midlife, has been sparse. Similarly, in studies of adult development, including midlife transitions, "little systematic research has been carried out on the internal dynamics in the households" (Haraven, 1995, p. 28). But at this time, several trends are converging: Rapid advances in medical technology are resulting in growing numbers of people surviving disabling conditions. Sweeping legislative action related to civil rights of disabled citizens is beginning to alter social and physical environments throughout our society. Changes in health care delivery systems

and reimbursement mechanisms are raising questions about necessary and effective medical care and quality of life issues. The maturation of baby-boomers into middle and old age is having significant impacts on family structure and function. Conservative social agendas are positioning “the family” to assume greater responsibility with fewer supports for meeting the biopsychosocial needs of its members across the lifespan. The effects and influences of these converging trends are not easily disentangled.

Understanding human experience in the social world will require attention to the processes by which these complex arenas connect and interact to inform and shape people’s lives.

## Methodology

### Overview

The number of social scientists interested in disability phenomena has grown steadily over the last 40 years. However, the number of investigations that are flawed from inception by prejudicial assumptions, by theoretical bias, or by methodological error remains high (Meyerson, 1988). Much of the current knowledge base about the lives of people with disabilities is flawed in its very development, being designed to advance social theories rather than to advance knowledge of the experience of disability. Most research has not focused on the lives of people with disabilities, and it has often been conducted without substantial contact with them (Fine & Asch, 1988).

It was my intention in this study to capture the meanings of adult-onset disability and the individual, family, and social processes of disabled persons and their intimate partners by focusing the research on their lives. I sought to place persons with disabilities at the center of inquiry, to hear their stories, and to learn from them rather than “to impose... definitions of reality on those researched” (Acker, Barry, & Esseveld, 1983, p. 425). This was congruent with postmodern approaches that seek to generate and refine more interactive, contextualized methods in the search for pattern and meaning rather than for prediction and control (Lather, 1991).

### Guiding Theory

Research design, data collection and analysis were guided by symbolic interactionism and human ecology. Within these theoretical frameworks, I took a life span perspective and sought to correct both the *invisibility* and *distortion* of experiences

of people with disabilities (Lather, 1991). Like Hewitt (1994),

I work from [this] perspective because I think it offers the best hope of a humane science--one that avoids distorting our diverse human natures into particular and narrow caricatures, but also one that respects and emphasizes the value of theoretically guided empirical inquiry as one of the best hopes of humankind for creating a better world. (p. 262)

Symbolic interactionism acknowledges the ongoing processes involved in the acquisition, ascription, and achievement of selfhood within and across various social contexts, delineated by human ecology theory. These theories also recognize persons multiple identities--that is, the variety of ways in which people experience themselves and take locations in social life (Hewitt, 1994). Taken together, these factors make the combination of symbolic interactionism and human ecology, undergirded by a life span orientation, an especially fitting choice for the proposed study of adult-onset disability and the associated "connections between changing life circumstances and changing views of self, others and the larger world" (Acker, Barry, & Esseveld, 1983, p. 427).

My underlying assumption in this research, supported by the literature, was that receiving a diagnosis and becoming disabled is not singularly defining nor inherently negative for the people who have this experience or for their loved ones. Disability is neither a homogeneous nor static condition. Rather, the *meanings* of diagnosis and disability for one's development are negotiated over time through interpretive processes that involve self, family, and society. Researchers "interested in questions of meaning have increasingly recognized the suitability of qualitative work that uses symbolic

interactionism as its organizing domain because [it]...ask[s] questions of agency and action...[and]deconstructs traditional patterns of thought” (Ramsey, 1995, p. 63). Taken together with human ecology, it is possible to see the contexts in which those questions of agency get asked and answered.

This investigation reflected my commitment to and insistence upon placing people dealing with disability in the center, to hear their stories in context and capture their views. It was also my endeavor to overcome some shortcomings of previous disability research, particularly the ablist notion of disability-as-devastation (Meyerson, 1988; Wright, 1987), and studies that are undertaken by researchers removed from people with disabilities (Fine & Asch, 1988). In an effort to fulfill these commitments without abandoning theoretical and empirical integrity the following methodology was adopted.

#### Rationale for a Qualitative Design

I conducted this study using qualitative methods for data collection and analysis, deeming it most appropriate for a study focusing on negotiating the meaning of a life event. This position is consistent with the trend in family sociology that challenges monolithic presentations of family structure and processes. Qualitative methods focus on identifying the ways by which families create their own realities (Daly, 1994). Further, qualitative methodology lends itself well to meeting the challenge of Lather (1991) for achieving more interactive, contextualized means of collecting and analyzing data, of Fine and Asch (1988) for having substantial contact between the researched and researcher, and of Schneider (1988) for including the voices of disabled people in studies of disability. There has been a “virtual absence of studies that report, in people’s own

words, the routine experience of living with chronic illness and disability” (Schneider, 1988, p. 63).

Although “indepth qualitative studies can reveal much about social processes...like all research methods, they have limitations” (Cannon, Higginbotham, & Leung, 1988, p. 449). Potential problems related to small sample size, participant homogeneity, questions of external validity (Cannon, Higginbotham, & Leung, 1988), infusion of researcher bias and interpretation in data collection as well as analysis (Daly, 1992), and poor representation and overgeneralization (Jayaratne & Steward, 1991) must be carefully considered when selecting a qualitative approach. Arguments have been made that these concepts are anchored in positivist philosophies of science and do not translate to post-positivist and postmodern philosophies and qualitative designs.

I chose a qualitative design because my interest was in discovering the **meanings** that midlife development and disability onset had for people, rather than in explaining or predicting experiences (Snyder, 1992). By using multiple sources of data (couples, well partners, ill partners, myself), collecting data to the point of theoretical saturation, and confirming my initial findings in subsequent interviews with the participants (Gilgun, Daly, & Handel, 1992), I maximized the precision of my analysis and the rigor of the method.

In the selection of this method, I placed overt value on hearing direct accounts, and joining with disabled adults and their well partners as they spoke of themselves, rather than removing and positioning myself for the purpose of speaking about them from a distance.

## Target Population

To this point I have referred to my target population as midlife couples in which one of the partners has encountered unexpected disability. Quite obviously, the population is huge and extraordinarily diverse. Men and women of all races, educational and socioeconomic levels, medical backgrounds and treatment options with histories of cancer, heart disease, diabetes, traumatic injury, any number of chronic and chronic-progressive illnesses, stroke, and a host of other diagnoses make up the population of interest. For the purposes of this study, I chose to restrict the target population on the basis of diagnosis. I conducted the study of adult-onset disability and related phenomena in individual, family, and social spheres, and the sum total of these matters on adult development by focusing on middle aged people diagnosed with multiple sclerosis (MS) and their well partners.

This decision was made at once on personal and conceptual bases. At the personal level, MS is of particular importance and interest to me as it was discovered in my family seven years ago. Since then, my knowledge of this chronic, disabling illness has become quite substantial. Coincidentally, the daily experience of the symptoms, treatment and course of the disease, as shared with my spouse, has had an “important bearing on my interest in the topic and what I thought was important to ask” (Daly, 1992, p. 9). Similarly, Krieger (1991) stated that social science usually does not include or describe the internal, but is focused on “grasping an external reality” (p. 81), yet “to be of value, [research] must be a statement of truth, not abstract or general truth, but particular truth, sourced in the specific experience of a knower” (p. 77).

Conceptually, limiting the population on the basis of diagnosis helped establish manageable parameters while still allowing heterogeneity in the focus of the study. The diagnosis, experience, and disease course of this illness is widely variable and unpredictable. More women than men get the disease, but the prognosis for men tends to be less favorable. People of all races can be affected, though Caucasians, especially those from northern European extraction, comprise the largest ethnic group of MS people.<sup>2</sup> MS does not have class, education, or lifestyle correlates. The etiology is unknown, and currently there is no cure. Once believed to be a rare disease MS “is now known to be the most common neurological disease of young and middle-aged adults--affecting a third of a million Americans and an estimated 1.1 million people worldwide” (National MS Society, 1996, p.3).

### Sample Selection

It has been suggested that qualitative research is most amenable to the use of small, homogeneous samples because extreme diversity makes the process of identifying common themes and patterns almost impossible (Cannon, Higginbotham, & Leung, 1988). Indeed, the argument has been made that, in terms of the economic, time, and personal costs to the researcher, the process of qualitative research necessitates the selection of small samples (Judd, Smith, & Kidder; 1991). Further, the point of theoretical saturation at which increased sample size does not render new data is considered the methodological convention in determining sample size in qualitative

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<sup>2</sup> "MS person" is the term of preference for people with this diagnosis, outside of medical contexts where "patient" is considered appropriate.

research, rather than using other formulae to determine and impose a sample size for a particular study (Strauss & Corbin, 1990).

In line with the counsel of Cannon Higginbotham, and Leung (1988) to draw a small, useful sample, the participants in this study were 18 midlife individuals comprising 9 intimate dyads all of which had one partner with a confirmed diagnosis of multiple sclerosis. The foci of the study, which included the negotiations and incorporation of disability onset within individual and family life, required that the diagnosis occurred after the couple was established.

As the research involved an investigation of disability onset within the context of adult development at midlife, participants were selected on the basis of their midlife status as measured by chronological age (31-57 years). Beyond chronological age, participants were further assessed via a screening form (see Appendix C) for characteristics and indicators of midlife development identified in the literature such parental status, career status, and length of relationship.

### Participant Recruitment

Participants were recruited on a volunteer basis from a regional chapter of the National Multiple Sclerosis Society, from area MS support groups, and from snowball sampling (Fonow & Cook, 1991; Strauss & Corbin, 1990).

Regional chapter. I contacted the executive director of the Blue Ridge Chapter of the National Multiple Sclerosis Society, informing her of the study. We scheduled a meeting at the chapter office to further discuss the research and the possibility of her assistance with participant recruitment. During the course of that conference, the

executive director agreed to distribute a letter of support (see Appendix A), accompanied by an informational flyer (see Appendix B), to chapter members.

Support groups. During my conference with the executive director, I obtained names and telephone numbers of the facilitators of the local MS support groups. I contacted the leaders, gave a brief overview of the research project, and asked to be placed on the agenda of the next meeting of the groups. I attended the meetings, explained the purpose and methodology of the study and distributed informational flyers (see Appendix B) for members to complete and return if interested in participating.

Snowball method. A local counselor who was conducting a therapy group for MS patients learned of my study through the executive director of the local chapter office, and through personnel at Virginia Polytechnic Institute and State University. She contacted me, offering to inform her clients of my study for possible participation. I met with her, explained the study, brainstormed possible questions that her clients might have, and provided her with copies of the informational flyer (see Appendix B) to distribute. The flyer contained a phone number and address for use by those interested in volunteering for the study, or desiring more information about it.

For all three methods, I called each person or couple whom had returned the form indicating an interest in participation. Introducing myself, I provided a brief synopsis of the study, completed an initial screening (see Appendix C), and answered questions regarding the timeframe for the project. Persons who met the criteria for participation were scheduled for conjoint interviews at a time and location convenient to them. The subsequent individual interviews were scheduled at the close of the conjoint interviews,

and again were held at a time and location convenient to the informants. No inducements for participation will be extended other than an offer to provide copies of the results of the study.

### Data collection

In social research, findings gathered from multiple sources are considered more valid than findings from a single source (Gilgun, 1992). It is particularly critical to have data from multiple points of view in research that seeks to link individual and family experiences (Ryff & Seltzer, 1995). The use of multiple sources, referred to as triangulation (Denzin, 1978), allows the researcher to come at a single point from a number of directions. Accordingly, I used triangulation of data sources and data collection techniques in this study to “achieve a multidimensional, contextualized view” (Sandelowski, Holditch-Davis, & Harris, 1992, p. 314).

Triangulation of data sources. The stated purpose of this study was to capture the meanings of adult-onset disability in the individual, familial, and social processes of MS people and their intimate partners. To accomplish this, data was gathered from three identified sources: a) the MS persons, b) their well partners, and c) the couples as family units. A fourth source of data, the researcher, is also included in the triangulation method, as I wanted to remain cognizant and cautious of not “underestim[ing] my own influence on my work” (Krieger, 91, p. 153).

Triangulation of data collection techniques. In her analysis of symbolic communication in culturally constructed systems of meaning, Hertzler (1965) argued that the spoken word is the “only all-inclusive...medium of communication” (p. 43), but,

noted that as people and societies develop their language to the point of literacy, the spoken word is supplemented by the written word which emerges as an important medium of symbolic interaction in the production, “recording, and perception of meanings...across time and space” (p. 43). The techniques of data collection triangulated in this study followed Hertzler’s spoken-written progression of symbolic communication. **Spoken** words were collected via two methods: first, in conjoint interviews to capture couples’ shared meanings, and second, from each participant individually, to discover private interpretations of adult-onset disability. The indepth, semi-structured interviews followed a general question guide (see Appendix F), and ranged from .5 to 3 hours in length, for a total of more than 40 hours of interview time. I customized the order and phrasing of questions to maximize the informants’ participation in telling their own stories in their own words. **Written** data was “collected” in the form of field notes, memos, and entries in my research journal reflecting on the research process, my preliminary observations, interpretations, and analyses of the project, the participants, and my own experiences. Finally, spoken words were converted to written data in the verbatim transcription of the interviews, and in the final report of the findings.

### Data Analysis

The process of data analysis in qualitative research consists of carefully sifting through data to find key issues, significant themes, and categories of meaning among and between the informants while respecting and reflecting diversity and individual uniqueness (Snyder, 1992). For the purposes of this study, I adopted the constant comparative method, as it is particularly usefule in studies with multiple sources of data

(Snyder, 1992). Constant comparison requires the researcher to strike a creative balance between generalizing from data in the establishment of common categories and remaining aware of the distinctiveness of individual experiences. It involves working back and forth between the various forms of data to see differences and similarities in experience.

Although data analysis in qualitative research begins “the first moment of first contact with the informants” (Ramsey, 1995, p. 99), the formal analytic work began by reviewing the tapes from the conjoint interviews in preparation for the follow-up interviews with individual partners. Questions and issues raised in each conjoint interview were incorporated into the individual interviews of all participants, honoring the tenet of constant comparison for “each new family’s data [to] illuminate the previous family’s data” (Murphy, 1992, 155). Analysis continued with multiple readings of the interview transcriptions, and additional reviews of the audiotaped recordings of interviews. During this process, I identified key issues, categorized them into themes, and consistent with the constant comparison technique, collected many illustrative examples, in the form of transcript excerpts, for each theme. The test of relationships among categories (Gilgun, Daly, and Handel, 1992) was conducted in the formulation of the processual models offered to describe and capture the informants’ experiences and creation of meaning.

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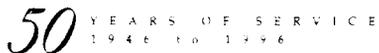
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**Blue Ridge Chapter**



**Appendix A: Support Letter**

**Branch Office**

3959 Electric Rd., SW, Ste. 310  
Roanoke, Virginia 24018  
Telephone 540-776-0985  
FAX 540-772-4397

**7  
of Trustees**

- Baker
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- D. Sandridge
- V. Seagle, Ph.D.
- ehring
- ie R. Walker
- tterson
- Vatterson
- D. Wortman

Dear \_\_\_\_\_,

I want to inform you of a research project being conducted locally by Nancy Wingfield, a doctoral student at Virginia Tech. She is seeking couples who are living with MS to interview for her dissertation.

The purpose of the study is to go beyond the medical aspects and examine what MS means to you as you go about your daily life. After discussing the research with Ms. Wingfield, I believe her study, with your input, has the potential to benefit families who will be diagnosed with MS in the future.

I endorse this research and encourage you to consider participating. I have enclosed a flyer that provides all the information you need about how to contact Ms. Wingfield to be included in the study.

If you have any questions, please give me a call at the chapter office.

Sincerely,

Katherine Garvin  
Executive Director

nter  
nt and  
rofessional Officer

## Appendix B:Recruitment Flyer

### WHAT DOES MS MEAN TO YOU?

If you are a person with MS,  
or  
the partner of a person with MS,

You are invited to participate in a study that seeks to find out how you live, grow, work, play, and love with MS as a part of your life.

This is an opportunity to inform others by sharing your story.

### WHAT'S INVOLVED?

Participating in two interviews--one as a couple, one as an individual--at a time and location convenient to you.

All interviews are confidential.

### WHO'S DOING IT?

Nancy P. Wingfield, Doctoral student at Virginia Tech,  
Department of Family and Child Development.

Nancy is a member and peer volunteer of the Blue Ridge Chapter of the MS Society, has served on the Branch Services Committee for the chapter, and has been a volunteer for the Bike Tour fund raisers for MS research. Her interest in MS began in 1990 when her spouse was diagnosed.

The study has been approved by Katherine Garvin, Executive Director of the Blue Ridge Chapter of the National MS Society.

### HOW TO PARTICIPATE or OBTAIN MORE INFORMATION?

Call Nancy at (540) 774-2218  
OR, clip and return the response card below.

---

Yes, we are interested in participating in your study about living with MS.

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Phone: \_\_\_\_\_

Return to: 7618 Mt. Chestnut Road / Roanoke, VA/ 24018

Appendix C: Initial Screening Form

Name: MS person: \_\_\_\_\_ Sex: \_\_\_\_ DOB: \_\_/\_\_/\_\_\_\_

Well partner: \_\_\_\_\_ Sex: \_\_\_\_ DOB: \_\_/\_\_/\_\_\_\_

Years together in relationship: \_\_\_\_\_ Date of diagnosis: \_\_\_\_\_

Composition of household:

Name of Resident	Relationship to Participants	Age	Employment Status

Current status of MS symptomology:

- \_\_\_\_ one episode
- \_\_\_\_ relapse/remitting
- \_\_\_\_ primary progressive
- \_\_\_\_ secondary progressive
- \_\_\_\_ profoundly incapacitated

Employment status:

Of MS person:

Of well partner:

---

Comments/Notes:

---

Date for initial interview: \_\_\_\_\_ Phone: \_\_\_\_\_

Location/Address: \_\_\_\_\_

Directions (over)

## Appendix D: Informed Consent

### Informed Consent for Participation in Investigative Research Projects

Title of Project: Disability-Onset in Midlife Unions: The Meanings of Multiple Sclerosis as a Personal, Familial, and Social Experience

Investigator: Nancy Poe Wingfield, Doctoral Student

#### **PURPOSE**

The purpose of this study is to examine the phenomenon of unexpected, adult-onset disability in midlife within a family context. The study seeks to shed light on the personal, family, and social experiences of people with multiple sclerosis (MS) and their loved ones; it focuses not only on the medical aspects of being a patient, but on what diagnosis and disability has meant and does mean for living adult life. 16 to 20 participants are involved in the study.

#### **PROCEDURES**

The study requires that participants take part in two interviews with the investigator. The first interview will include both members of an intimate couple. Individual follow-up interviews will be held separately with each member of the couple. Interviews will last approximately one hour, and will be held at times and locations convenient to the participants.

#### **RISKS**

The foreseeable risks for participating in this research are minimal and are limited to possible distress caused by thinking and talking about unpleasant experiences related to MS. Safeguards to minimize these risks include referral to the Blue Ridge chapter of the National MS Society for peer counseling or other services, and referral to local support groups.

#### **BENEFITS**

The benefits for participating in this research include the opportunity to inform others who may be facing a diagnosis of MS, to offer a corrective for erroneous beliefs and assumptions about MS, to gain new insights by speaking about the experience of receiving a diagnosis of disability in adulthood, and to broaden the medical focus of disability as a biological experience to include personal, family, and social experiences as well.

No promise or guarantee of benefits are made to encourage you to participate.

## **CONFIDENTIALITY**

The researcher will not divulge information regarding your participation in this project without your written consent. The interviews will be audiotaped and transcribed. Pseudonyms will be used in the transcripts and the tapes will be destroyed after the project is finalized.

The tapes will be stored in the investigator's home file cabinet. The transcriptionist is a professional secretary employed as a clerk for United States District Courts, with eight years of experience working with confidential and sensitive material. Her involvement with this research project is privately contracted by this investigatory on the basis of her skill and expertise in transcription. In no way does her involvement overlap with her work as a federal employee and Clerk of Court.

In some situations, it may be necessary for the investigator to break confidentiality. Those cases include but are not limited to reports of child abuse, or belief by the investigator that the participant is a threat to him or herself or others.

## **COMPENSATION**

No compensation in the form of cash, redeemable coupons, other currency, or services are being given for participating in this study.

## **FREEDOM TO WITHDRAW**

Participants are free to withdraw from the study at any time. Likewise, participants are free to not answer any questions that they choose.

## **APPROVAL OF RESEARCH**

This research has been approved, as required, by the Institutional Review Board for Research Involving Human Subjects at Virginia Polytechnic Institute and State University, and by the Department of Family and Child Development in the College of Human Resources.

## **SUBJECT'S RESPONSIBILITIES**

I voluntarily agree to participate in this study. I have the following responsibilities:

1. participate in a conjoint interview with my partner;

2. participate in an individual follow-up interview.

**SUBJECT'S PERMISSION**

I have read and understand the Informed Consent and conditions of this project. I have had all my questions answered. I hereby acknowledge the above and give my voluntary consent for participation in this project.

If I participate, I may withdraw at any time.

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

## Appendix E: Disease Classifications

To develop standard definitions and terminology for MS types, the National Multiple Sclerosis Society conducted a survey among 215 medical scientists throughout the world whose work focuses on clinical research and care of people with MS. Analysis of survey responses, and subsequent discussions by the Society's Advisory Committee on Clinical Trials of New Agents and the National Medical Advisory Board resulted in four redefined categories of disease. They are:

1. Relapse-remitting. Clearly defined disease relapses with full recovery or with sequelae and residual deficit upon recovery. Periods between relapses are characterized by a lack of progression.
2. Primary-progressive. Disease progression from onset, with occasional plateaus.
3. Secondary-progressive. Initial relapse-remitting course followed by progression with or without occasional relapses, minor remissions, and plateaus.
4. Progressive-relapsing. Progressive disease from onset with clear, acute relapses, with or without full recovery. Periods between relapses characterized by continuing progression. This is a rare clinical course.

---

Information provided by Katherine Garvin, Executive Director of National Multiple Sclerosis Society, Blue Ridge Chapter, Roanoke, Virginia.

Appendix F: Interview Schedule  
(Conjoint Interview)

(Individual interviews will clarify points raised during conjoint interviews, asking participants to answer as individual rather than as a couple)

---

**I. BACKGROUND**

1. How long have you been together as a couple?

(PROMPTS: What's your anniversary?)

2. And before that, how long did you know each other?

(PROMPTS: When did you first meet? How did you first meet?)

3. How long did you court/date between meeting and getting established?

(PROMPTS: Did you start dating as soon as you met?)

4. Tell me about your courtship.

(PROMPTS: What kinds of activities did you do when you dated? Where were you living during your courtship? What was your most memorable time during courtship?)

5. How long were you together before s/he got MS?

(PROMPTS: When did you get diagnosed with MS?)

6. What were those years like?

(PROMPTS: Where did you live when you first got together? Work? Who did you spend time with as a couple? How would you portray your relationship before you go MS?)

7. Tell me about your diagnosis.

(PROMPTS: When did you first suspect something was wrong, in terms of your health? What were your symptoms? What happened that made you go see a doctor? What did your doctor do/say when you reported your concerns?)

8. What were your initial thoughts, feelings, questions when you found out?

(PROMPTS: What went through your mind when you heard, “You have multiple sclerosis”?)

9. What are your thoughts, feelings, questions now?

---

## II. STIGMA

10. Who did you tell about the MS when you found out?

(PROMPTS: Family? Friends?)

11. What did they say/do?

(PROMPTS: What was their reaction? How did they act when you told them?)

12. How did their response affect you?

(PROMPTS: When they \_\_\_\_\_ (fill in response from #11) \_\_\_\_\_, how did you feel? What did you think?)

13. Who didn't you tell?

(PROMPTS: Family? Friends? Neighbors? People at work?)

14. Why?

(PROMPTS: What made you decide not to tell them? How is it that you chose to tell some people, like \_\_\_\_\_ (fill in response from #10) \_\_\_\_\_, but not \_\_\_\_\_ (fill in response from #13) \_\_\_\_\_)

15. Do they know now?

If so, when did you tell them?

(PROMPTS: How long have they known?)

16. How did you decide to tell them?

(PROMPTS: What changed between not telling them and telling them? What

made you change your mind about telling them?)

17. What do you think most people believe about MS and the people who have it?

18. Is that hard?

(PROMPTS: Difficult? Troubling?)

19. What do you wish people knew about MS?

---

### **III. CAREGIVING**

20. Are there things that you do/can't do for yourself because of MS?

21. Like what?

22. What about for each other?

23. How has that been?

---

### **IV. WORK**

24. What about work? Has there been any impact on work from MS?

(PROMPT: Are you still doing the same job(s)--paid employment/household labor? Has income been affected?)

25. Have you had to make any work-related changes or decisions since being diagnosed?

26. How might your work be different if MS hadn't come into your lives?

(PROMPTS: Would you be doing something different? Would your achievements be any different?)

---

## V. RESILIENCE

27. How do you deal with MS?
28. Many people think of diagnosis or disability as devastating. What keeps you going?
29. When times are tough, what do you tell yourselves?
- (PROMPTS: How did you get through the last flare-up?)
- 

## VI. LOOKING AT CHANGE OVER TIME

30. How did/has MS changed your lives as a couple (as an individual)?
- (PROMPTS: Earlier (in questions #4 and #6), you described your life before MS as \_\_\_\_\_. Are those things different now? How would you describe your life now?)
31. Are you any different than people you know who are at the same age and station in life as you because of MS?
- (PROMPTS: Do you share the same cares and concerns, or are yours different?)
32. How do you see yourselves/self as a couple/person dealing with midlife?
- (PROMPTS: Are your experiences any different than what you expected because of MS?)
- 

## VII. MEANING

31. What does MS mean to your life?
- (PROMPTS: What is the significance of MS for you? What sense do you make of having MS in your life?)
32. What lessons have been learned from MS?
- (PROMPTS: Learned about each other? Relationships? Family? The world? Life?)

## NANCY POE WINGFIELD

7618 Mt. Chestnut Road, SW  
Roanoke, Virginia 24018  
540/774-2218

Department of Social  
Work, Sociology &  
Anthropology  
Mansfield University  
Mansfield, Pennsylvania 16933  
717/662-4494

Date of Birth: 6/28/60

---

### Education

#### DOCTOR OF PHILOSOPHY

Family Studies  
Certificate in Gerontology  
Virginia Tech  
Blacksburg, VA  
May, 1997

#### MASTER OF SOCIAL WORK

Family & Child Welfare  
VA Commonwealth Univ.  
Richmond, VA  
May, 1989

#### BACHELOR OF ARTS

Sociology  
Roanoke College  
Salem, VA  
December, 1983

### Professional Experience

#### ASSISTANT PROFESSOR (tenure-track)

Mansfield University  
Department of Social Work, Sociology, & Anthropology  
Mansfield, Pennsylvania  
1996 - Present

Taught courses and advised students within the Social Work program of the Department of Social Work, Sociology & Anthropology. Served as Director of Field Instruction for Social Work majors. Faculty sponsor of Social Work Club. Drafted proposal for campus-wide multi-disciplinary gerontology certificate program. Courses taught:

- Family Practice
- Communities: Macro Practice
- Field Placement
- Human Behavior and the Social Environment
- Social Work: Professional Responsibilities
- Issues in Professional Practice
- Program Orientation
- Senior Seminar

#### COORDINATOR OF ADMISSIONS

Radford University School of Social Work  
Radford, Virginia  
1993 - 1996

Developed and implemented admissions policy for new Master of Social Work program and existing baccalaureate program. In coordination with University's Graduate College, insured compliance with University policy and standards of accrediting body (Council on Social Work Education). Created program informational materials and screening instrument for applications. Recruited applicants and

processed all program inquiries and applications. Set up uniform filing system for undergraduate program, consisting of 200+ majors. Chaired and facilitated Admissions Committees and Graduate Student Mentoring & Assistantship Committee. Supervised Graduate Teaching Assistant.

**INSTRUCTOR**

Radford University School of Social Work  
Radford, Virginia  
1987 - 1989; 1992 - 1996

Taught courses and advised majors in the School of Social Work. Served as Faculty Liaison to agencies involved in community-based internships. Assisted students in developing learning contracts and resumes.

Courses taught:

- History of Social Welfare
- Interventive Methods
- Field Instruction
- Community-based Internship
- Introduction to Fields of Practice
- Introduction to Professional Practice
- Gerontology

**PROGRAM  
COORDINATOR**

Virginia Baptist Children's Home  
Salem, Virginia  
12/90 - 9/92

Managed Specialized-Care cottages within a residential facility for adolescents. Designed, implemented, and opened new cottage program for girls with histories of sexual abuse. Supervised Social Worker and 12 direct care staff. Organized on-going staff training and development. Conducted weekly case staffings. Facilitated weekly group counseling with residents. Wrote parent's handbook and program manual.

**SOCIAL WORKER**

Connections (Catholic Charities)  
Roanoke, Virginia  
7/89 - 12/90

Intensive case management for abused, neglected, and emotionally disturbed children within a special needs foster care program. On-call crisis support for foster and birth parents. Conducted foster parent training sessions. Testified in custody hearings. Worked in partnership with public child welfare departments.

**BEHAVIOR  
SPECIALIST**

Blue Ridge Community Services  
Roanoke, Virginia  
9/88 - 7/89

Co-developed residential program for adults with a dual diagnosis of mental retardation and mental illness. Wrote policy manual in accordance with licensure regulations. Conducted assessment and screening of clients for admission to program. Interacted through home and office visits with parents,

case managers, school and hospital personnel in determining appropriateness of applicants for program. Gathered, documented, and presented pertinent client data to Residential Selection Committee. Coordinated staff training. Supervised residents. Developed behavioral programming to reduce incidents of aberrant behavior and to enhance social functioning.

ADMINISTRATIVE  
ASSISTANT

Virginia Office of Supported Employment  
Roanoke, Virginia  
8/87 - 9/88

Coordinated workshops and forums for service providers regarding employment initiatives for disabled persons in southwestern Virginia. Also provided clerical support and general assistance to regional consultant.

SUPPORTED  
EMPLOYMENT  
SPECIALIST

Association for Retarded Citizens  
Roanoke, Virginia  
2/85 - 8/87

Case management for clients with mental retardation and severe disabilities within a program of supported employment. Educated clients, families, and business persons in regard to the supported employment model. Individualized job training, assessment, and counseling. Acted as liaison to outside agencies to ensure continuity of services. Program evaluation. Developed and led Parent Advisory Committee (support group). Moved program from grant to vendor status.

### **Internships/Practica**

Center for Gerontology  
Virginia Tech  
Blacksburg, VA

1/94 - 5/94

Focus: Curriculum design and pedagogy in gerontology.

Blue Ridge Community Services  
Division of Mental Retardation  
Roanoke, VA

10/88 - 4/89

Focus: Residential services and community integration for clients with dual diagnosis of mental retardation and mental illness.

Council of Community Services  
Roanoke, VA

1/88 - 8/88

Focus: Community organization and macro planning for social service delivery systems.

Sanctuary Adolescent Crisis Center  
Roanoke, VA

Summer, 1983

Focus: Residential treatment with adolescent offenders.

### Honors

- |                  |  |
|------------------|--|
| Phi Kappa Phi    | National Honor Society for Academic Excellence                               |
| Kappa Omicron Nu | National Academic and Professional Society for Excellence in Human Resources |
| Sigma Phi Omega  | National Academic and Professional Society for Excellence in Gerontology     |

### Research

1997 **Midlife Development and Disability-Onset in a Family Context: A Qualitative Integration**

Study with individuals and intimate dyads who have experienced adult-onset disability. Utilized multiple in-depth interviews to discover the psycho-social aspects of becoming disabled in micro, meso, and macro contexts.

1989 **Family Caregiving and Alzheimer's Disease**

Study with family caregivers of patients with Alzheimer's disease. Utilized mail surveys and telephone interviews with caregivers to discover the stressors and support needs of family providers.

1988 **Community Analysis: Southern Baptist Life at the Local Level**

Study of the Roanoke Valley Association of the Southern Baptist National Convention. Utilized mail surveys, telephone interviews, key informant interviews, and extant data analysis. The purpose of the study was to analyze the structure and function of the local Southern Baptist community, and to assess local support for the initiatives and positions of the national convention.

1983 **Resettlement of Laotian Refugee Families in Southwestern Virginia**

Interviewer for study of Laotian refugee families in the greater Roanoke Valley area. Conducted home-based interviews with refugee families being sponsored by the Office of Refugee Resettlement. The purpose of the study was to determine the families' adjustment in their new communities and to assess gaps in service delivery. Worked under the auspices of Roanoke College Community Research Center and Department of Sociology.

**University Committees**

**MANSFIELD UNIVERSITY**

Faculty Senate (alternate)	1996 - Present
Social Work Curriculum Committee	1996 - Present
University Assessment Committee	1996 - Present

**RADFORD UNIVERSITY**

MSW Admissions, Chair	1993 - 1996
BSW Admissions, Chair	1994 - 1996
Graduate Assistant Selection, Chair	1994 - 1996
Transition & Retention Project for Office of Disabled Students	1995 - 1996
Program Assessment for Accreditation	1994 - 1995
Student Review	1994 - 1995
Social Work Graduate Curriculum	1993 - 1994

**Community Service and Affiliations**

Present	National Association of Social Workers
Present	Council on Social Work Education
1996- Present	Participant National Institute of Mental Health Genetics of Schizophrenia: Sibling Study
1988 - Present	National Alliance for the Mentally Ill
1995 - 1996	Training Consultant and Coordinator Total Action Against Poverty Family Development Program
1993 - 1996	Branch Services Committee National Multiple Sclerosis Society (Blue Ridge Chapter)

1993 - 1996	Volunteer Counselor National Multiple Sclerosis Society (Blue Ridge Chapter)
1992 - 1993	Student Representative Virginia Tech Departmental Graduate Curriculum and Policy Committee
1989 - 1990	Secretary National Association of Social Workers (Blue Ridge Chapter)
1986 - 1989	Alumni Council of Stuart Hall School

### Presentations

March, 1997	<u>Presenter</u> : "Songs of Social Consciousness" (Arts Festival) ● Council on Social Work Education: All Programs Meeting, Chicago, IL
February, 1996	<u>Exhibit</u> : "Radford University School of Social Work" ● Council on Social Work Education: All Programs Meeting; Washington, DC
January, 1996	<u>Presenter</u> : "Guiding Principles of Family Development Work" (1/22/96) <u>Presenter</u> : "Thinking in Family Terms" (1/24/96) <u>Presenter</u> : "Expert Families" (1/24/96) <u>Presenter</u> : "What's a Case and How Do I Manage it?" (1/31/96) ● Total Action Against Poverty Staff Development; Roanoke, VA
October, 1995	<u>Panelist</u> : "Graduate Study in Social Work" ● Statewide Conference for Undergraduate Social Work; Massanetta, VA
October, 1994	<u>Presenter</u> : "Disability and Sexuality: Ablast Misconceptions" ● Statewide Conference for Undergraduate Social Work; Massanetta, VA
1992 - 1996 (each semester)	<u>Panelist</u> : "Diversity in Family Forms" ● Virginia Tech: Family & Child Development; Blacksburg, VA

- June, 1991                      Guest: “Service Options for Girls With Histories of Sexual Abuse”  
 ● WFIR Radio. Community Call-In Program; Roanoke, VA
- May, 1989                      Presenter: “Essentials of Community Integration for Persons With Long Term  
 Mental Illness”  
Discussant: “Challenges in the Care of Mental Illness: Family Perspectives”  
 ● Virginia Alliance for the Mentally Ill & Western State Hospital  
 Symposium Caring for Persons with Serious Mental Illness; Staunton, VA
- September, 1986              Presenter: “Dignity of Risk & Quality of Life:  
 Competitive Employment for Persons With Severe Disabilities”  
Poster: “Project EMPLOYEES: Transitioning From Workshop to Work”  
 ● Virginia Commonwealth University Research & Training Center:  
 National Symposium on Supported Employment; Virginia Beach, VA

### **Professional Development**

Selected conferences, workshops, lectures attended: Last five years

#### **1997**

- |   |      |
|---|------|
| Council on Social Work Education Annual Meeting<br>Navigating the Winds of Change | 3/97 |
| From Cradle to Grave: Outcomes Assessment   | 1/97 |

#### **1996**

- |   |       |
|---|-------|
| Role of Department Chair in Outcomes Assessment                                       | 10/96 |
| Baccalaureate Program Directors Annual Conference                                     | 10/96 |
| Academic Advising at Mansfield University   | 10/96 |
| Pennsylvania Association for<br>Undergraduate Social Work Education Annual Conference | 10/96 |

#### **1995**

- |   |       |
|---|-------|
| Social Science Paradigms  | 10/95 |
| Family Theory and Practice: Feminist Critiques                        | 3/95  |
| Family Rituals & Family Stories                                       | 3/95  |
| Coping and Adaptation: Professional Understanding of Family Strengths | 3/95  |
| Coping & Adaptation: Strengths of Families and Consumers              | 3/95  |

**1994**

Ethical Issues in Aging	4/94
Clothesline Project Workshop	4/94
Media Images of Gender, Sexuality & Violence	3/94
Reproductive Freedom in Virginia: Recent Developments & Future Concerns	3/94
Pleasure Travelers: The Mature Market	3/94
Health Related Moves	2/94

**1992**

Uncommon Therapy: Creative Interventions in Family Therapy	10/92
The Struggles of Democracy: An Agenda for America's Children and Families in the '90s	10/92
The Paradox of Permanence: Women, Families, & Feminism	9/92
That's What Friends Are For: Friendship Research	9/92
Working with Aggressive Adolescents	4/92
Prevention of Childhood Sexual Abuse	3/92
Rape: Prevention and Defense	3/92

*Nancy Poe Wingfield*  
*May, 1997*