Home Environmental Modifications: Consumer Experience and Satisfaction

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HOME ENVIRONMENTAL MODIFICATIONS: CONSUMER EXPERIENCE AND SATISFACTION

By

Linda L. Mohney

THESIS

Submitted to the Occupational Therapy Program at Grand Valley State University Allendale, Michigan in partial fulfillment of the requirements for the degree of

MASTER OF SCIENCE IN OCCUPATIONAL THERAPY

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Abstract

This study investigated consumer experience and satisfaction in choosing home modifications to accommodate a disability. This study used semi-structured individual interviews and qualitative analysis to gather information from six people with disabilities concerning their experience with and opinion of home modifications. Seven significant themes emerged: a.) the importance of an adviser and self-agency in the modification process; b.) the inability of participants to distinguish OT’s contributions; c.) participant’s perception of OTs as part of a uni-disciplinary team; d.) ineffective execution of environmental interventions; e.) inadequate knowledge of applicable laws, standards, and codes; f.) a disability vs. client-centered perspective, and g.) the importance of meaning in the choice of and satisfaction with modifications. A gap exists between the participant’s expressed needs and OT interventions. Client-centered practice is presented as a framework for closing this gap and expanding OT’s scope of practice.
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CHAPTER 1

INTRODUCTION

Background

Significant shifts are occurring in health care that re-focus health care service from a disability perspective to a participation perspective. First, a thorough examination of this shift requires clarification of several important ideas concerning health. Secondly, several important terms pertinent to the shift in health care will be defined.

The World Health Organization (WHO) and the Ottawa Charter for Health Promotion characterize health as more than the absence of disease. It also includes life satisfaction and a sense of well being even with the presence of chronic illness (Law & Mills, 1998). Furthermore, the Ottawa Charter stresses the need for creation of supportive and ecological environments, community action programs, and health services that promote health and wellness (Law & Mills, 1998). This definition of health and well being expands the execution of health practice from a purely personal perspective to a community perspective.

The World Health Organization recently revised its 1980 classification of impairments, disabilities, and handicaps to a classification of impairments, activities, and participation (WHO, 1980, 1997). Defining these classifications begins the process of understanding how people functioning in their chosen environments execute this contemporary definition of health. It also forms the framework for the current paradigm shift in health care.

The World Health Organization system of classification defines impairments as the physical aspect of body structures or functions (WHO, 1997). This definition is
 congruent with the definition of occupational therapy performance components under the American Occupational Therapy Association’s (AOTA) uniform terminology. Impairments include but are not limited to components such as visual perception, fine motor ability, or postural control.

*Activities* are one step higher functionally and apply to functioning at the level of the person. Activities can include basic physical functions of a person as a whole (grasping an object, seeing a person, or moving a limb), basic and complex cognitive functions (learning or remembering information), and groups of physical and/or mental activities at varied levels of complexity (interacting with people, preparing a meal).

*Participation* refers to the transaction between the person and their environment as they perform an activity in daily life situations. It is unique from the other two definitions in that it includes the *context* of performance in addition to the person and the activity performed. “Participation is the interaction of impairments and disabilities and contextual factors, that is features of the social and physical environment, and personal factors” (WHO, 1997. p.21). Using this classification, a person with a C-6 spinal cord injury performing grooming activities in an electric wheelchair, using an assistive device with the help of a personal assistant in his own home, is an example of participation.

Occupational therapists may intervene at any of the three WHO classification levels. At the *impairment* level, occupational therapists would concentrate on remediating prerequisite or component skills for occupational performance activities. Occupational performance is defined as the dynamic experience of a person engaged in purposeful activities and tasks within an environment (Law et al., 1996). More simply, it is the “doing” of activities (Christiansen & Baum, 1997). An example of intervention at
The *impairment* level is range of motion (ROM) activities to increase joint motion and facilitate activities of daily living (ADL) performance.

Instruction in occupational performance activities such as one-handed grooming and bathing would be an example of intervention at an *activity* level. Finally, removing physical or social barriers to facilitate independence in ADL tasks in a person’s home environment or public facility would be an example of practice at the level of *participation*.

The WHO classifications and examples of occupational therapy interventions demonstrate that health care in general and occupational therapy practice specifically is transitioning from a focus on a person’s disability to a focus on enhancing participation in one’s chosen roles within an enabling environment.

Consequently, moving from an impairment framework to a disability paradigm consists of three increasingly complex practice levels: the organ or pathological level (impairment/performance components) to a person or behavioral level (activity/occupational performance) to a societal or role level (participation/role performance) (Ottenbacher & Christiansen, 1997). This gradual expansion of practice culminates in what the WHO describes as a rehabilitative focus—"the combined and coordinated use of medical, social, educational, and vocational measures for training and re-training the individual to the highest level of function (WHO, 1980).

Consequently, occupational therapy practice does not necessarily or exclusively *cure* illness or replace lost function. However, it can *facilitate* performance of self-care, work, and leisure activities (Seidel, 1995). When occupational therapists use the 1997 WHO classification of impairments, activities, and participation, practice can be
expanded beyond medicine’s ability to cure disease or replace lost ability. The occupational therapy profession can expand its intervention from a pathological focus to a more inclusive environmental perspective focused on increasing a person’s quality of life and participation as a member of society.

The Shifting Model of Occupational Therapy Practice

What is the catalyst for this widespread change in health-care practice? Several factors affect the shift from a biomedical to a transactional approach to practice. Law et al. (1996) suggest that societal changes and legislation [i.e. the Americans with Disabilities Act] are driving the need to re-evaluate occupational therapy models and adjust therapist’s roles. Additional factors include rising costs, changing definitions of health, increased interest of consumers in directing their health care, and the prevalence of chronic disabilities as important antecedents of change (Law, et.al., 1996).

The transactive model characterizes occupational performance as the product of a dynamic, interdependent relationship existing among people, their occupations and roles, and their environments. In a biomedically-based practice, occupational therapists generally limit their assessment to measurement of a patient’s functional components or impairments (Christiansen & Baum, 1997). Examples of this type of assessment model include elements such as manual muscle testing, ROM measurement, and visual/perceptual testing. Treatment goals are based upon the assessed impairments and subsequent remediation or compensation follows therapist-driven goals and treatment plans designed to remediate the patient’s problem.

In a transactive model of practice, the focus is not based exclusively on treatment plans designed to remediate a patient’s disability. Using a transactive model,
occupational therapy is viewed as a collection of integrated strategies that encourage a patient to discover and use chosen resources to enable successful performance of their self-selected occupations and roles (Christiansen & Baum, 1997).

The specific impact on occupational therapy is the broadening of practice from institutions to community intervention (Law & Mills, 1998). Expanding the scope of practice includes fostering relationships with other professions which are more attuned to the transactional focus of health and well being as compared to those within the medical community. These new relationships include social scientists, human geographers, architects, and interior designers. All of these professions have a vital interest in creating and facilitating enabling environments (Law et al. 1996). In summary, traditional occupational therapy practice has focused almost exclusively on the therapist as the agent of change. The shift to community based practice highlights the importance of two vital but often forgotten occupational therapy practice modalities—a person's relationship with the environment and the therapists as consultant versus expert.

In spite of this transition from institutional based practice to community practice, there is very little information in the allied health literature in general and the occupational therapy literature specifically from the consumer's point of view concerning a person's relationship with their environment. Several articles address concepts such as universal design and public policy (Duncan, 1998; DeJong & Lifchez, 1983), and include prescriptive advice on how to create an enabling environment. However, able-bodied professionals (Mueller, 1990; Cannava, 1994; Ahmadi & Arch, 1997; Kose, 1996) generate most of these recommendations. Few studies survey the opinions and needs of the end user—the disabled person who must live in these environments. This literature
gap was the catalyst for investigating environmental modifications—specifically in the home—from the consumer’s point of view.

Research Questions

What is consumers’ experience in choosing home environmental modifications to accommodate and/or compensate for a participation limitation? Are consumers who have existing modifications in their homes satisfied with them? What factors influenced their choice of existing modifications? What changes would each consumer make in their existing home environment given sufficient resources? What are the barriers to implementing environmental modifications in the home?

Purpose

The purpose of this study is to a.) investigate consumer experience in choosing home modifications to accommodate or compensate for a chronic disability and b.) explore the satisfaction with existing modifications. Using a qualitative process, the effectiveness and meaning inherent in modifying a home environment can be more fully understood from the paradigm of a person with a chronic disability.

A review of current literature shows a significant gap in research on home environmental modifications from a consumer’s perspective. Prevalent research is more prescriptive and often details the benefits of modified environments from an outsider’s view, typically a health care professional, builder, or architect. Universally designed environments are the most popular archetype for this type of investigation. However, there is little, if any, information regarding the consumer perspective on universal design, specifically, and environmental modifications in general. Therefore, this study will use
semi-structured interviews and qualitative analysis to explore the consumer’s experience with and opinion of home environmental modifications.

Significance of the Problem

Occupational therapists are trained to intervene at any or all of three areas of occupational performance: person, task [occupation], and environment (Law, et. al., 1996). However, there are few practice models emphasizing the transactive relationship between a person and their performance environment (Law, et. al., 1996).

A study examining the extent of occupational therapy intervention at the environmental level revealed that therapists not only selected simulated over real activities more often, they also preferred activities aimed at changing the person over those changing the environment (Brown & Bowen, 1998). Additionally, only a small percentage of consumers choose to modify their environments and suggested modifications are often incongruent with the preferences of the end user (Wylde, 1998).

These facts take on added significance when one considers that elderly and disabled populations are increasing at a significant rate. One source estimates that 49 million Americans currently have a disability. By the year 2000, 75-85 million Americans will be disabled in some way—50% of them age 55 and older (Liebig & Sheets, 1998). These statistics reveal a convergence between the aging and disabled populations: more elderly adults are experiencing disability later in life and people who are already disabled are living longer (Liebig & Sheets, 1998). In fact, by the year 2030, one in five Americans will be 65 years of age or over (Gambill & Scott, 1997).

Considering these factors, it is prudent that occupational therapists begin using their environmental expertise to encourage and create enabling environments that
facilitate independence, productivity, and community participation (Liebig & Sheets, 1998). The alternatives to an enabling environment include assisted living centers and long-term care facilities. Both require significant financial resources and assisted living is not a covered Medicare expense. Increased use of environmental modifications and accessible/negotiable design benefits both the consumer and society as a whole by conserving limited resources and facilitating the productivity and independence of this converging cohort.
A comprehensive understanding of the interdependence between environment and occupational function centers on four basic concepts: a.) environment as a modality, b.) adaptation to the environment, c) environmental press, and d.) arousal.

Environment as Modality

Using the environment as a modality or tool to facilitate function is often ignored not only by occupational therapists but also by other health care and social service professionals as well. Kiernat (as cited in Corcoran & Gitlin, 1997) theorized that the environment could be used as a treatment modality and purposefully manipulated to either challenge or support a person's competencies. For example, environmental control systems (ECU's) have enabled people with severe physical disabilities to live more independently and with increased community participation (Dickey & Shealey, 1987). Liebig & Sheets (1998) stress that environmental interventions, while underused, are important strategies for maintaining the productivity and independence of our elderly population. As an example, a study of 30 community dwelling elderly women demonstrated the safety benefits and functional utility of a transfer pole in the home (Cooper & Stewart, 1997).

Adaptation

Using the environment as a modality forms the foundation for the second concept, adaptation. Corcoran & Gitlin (1997) propose that as the environment changes, the
client's ability to sustain an optimal level of fit with their environment expands—this constitutes the adaptive process (Ayres, Schultz & Schadke, Schkade & Schultz as cited in Corcoran & Gitlin, 1997). Furthermore, successfully adapting to a fluid environment is a prerequisite to successful occupational performance (Corcoran & Gitlin, 1997).

Occupational performance is influenced by both internal and external factors (Schkade & Schultz, 1997). Internal factors include abilities, skills, personality, values, and motivation. External factors consist of the built environment, social networks, cultural traditions, and societal rules and expectations. Schkade & Schultz (as cited in Christiansen & Baum, 1997) hypothesize that an individual is continually adapting the interplay between occupational expectations and the intrinsic and extrinsic factors described above. Occupational performance is the outcome of this process of integrating internal and external factors with our chosen roles. They further propose that if adaptation is the key to occupational performance, then poor adaptation is the primary cause of performance gaps rather than skill limitations or environmental demands. Using this line of reasoning, facilitating adaptation becomes the focal point of intervention for occupational therapists (Schkade & Schultz as cited in Corcoran & Gitlin, 1997).

Secondly, they propose that adaptation is primarily an internal rather than external process. Research by Csikszentmihalyi (as cited by Christiansen & Baum, 1997) supports this assertion. He proposes that people are motivated to engage in occupations that bring them pleasure for no other reason than “doing” the activity. This is congruent with Christiansen & Baum’s (1997) assertion that motivation, one of the seven factors influencing occupational performance, is primarily an internal process of reconciling drives and needs. It is also compatible with Law’s (1996) inclusion of self-identity and
the search for meaning as integral components of occupational performance. But, perhaps the most important postulate is that unless the therapist taps into a client’s internal adaptation process, adaptation may only begin in the therapist’s absence or upon termination of therapy (Schkade & Schultz 1997).

King (as cited in Schkade & Schultz, 1997) in her 1978 Eleanor Clarke Slagle Lecture supports the idea of adaptation as the focal point of therapy. She stated that the concept of adaptation had the potential to synthesize and unify the profession. To that end, King identified four normative characteristics of the adaptive process. The first assertion was that adaptation was dependent upon the client’s active participation in the treatment process. Secondly the demands embedded within the context of the activity initiate the adaptive process. Third, personal adaptation is not achieved at the conscious or cognitive level. In fact, King urges therapists to avoid focusing the client’s attention on the adaptive process as it is felt that this actually interferes with the motivation to adapt. Instead, they are encouraged to provide experiences that naturally motivate a client’s inherent urge to adapt. The fourth characteristic of eliciting an adaptive response is that it is self-reinforcing. This is congruent to the self-perpetuating cycle illustrated by the two underlying principles in Christiansen & Baum’s (1997) Person-Environment-Occupational Performance model: internal motivation and self-efficacy—as a person experiences successful adaptation, their occupational success motivates them to accept greater challenges. Adapting to these increasingly complex challenges encourages further motivation. In summary, it is the demands of the environment and a person’s inherent motivation to survive and succeed that both begin and sustain adaptation and occupational performance.
Environmental Press

The third concept, environmental press, was first identified by personality theorists Murray, Barrett, and Hamburger (as cited in Christiansen & Baum, 1997). They realized that characteristics of the environment influenced behavior by creating demands or expectations for behavior that could be either objective or perceived. Environmental press is also defined as the degree to which environment influences behavior, existing on a continuum of high to low and representing a force that motivates human actions (Corcoran & Gitlin, 1997). These theorists emphasized that a person's abilities, experience, and level of competence directly influence the relationship between press and adaptation. Corcoran and Gitlin (1997) state that adaptation is threatened when there is an inequity between environmental press and a person's abilities. Czaja (as cited in Corcoran & Gitlin, 1997) found that environmental press was an important factor in determining the degree to which elderly clients were capable of living independently. The normal aging process can reduce a person's level of occupational competence. When this happens, there is an imbalance between an elderly person's ability to interact with the environment and the press created by the attributes of their home surroundings.

Arousal

Arousal, the fourth concept important to understanding environment, is the process by which environments influence our inclination to interact with or explore our surroundings (Christiansen & Baum, 1997). It has both physical characteristics related to alertness and the central nervous system and psychological aspects associated with emotions such as boredom or anxiety. Three groups of environmental variables are associated with arousal (Christiansen & Baum, 1997): psychophysical characteristics
such as noise; ecological events related to one's well being such as storms; and novel situations including surprising or ambiguous situations. A level of arousal congruent with the demands of the environment is imperative to optimal occupational function (Christiansen & Baum, etc). Corcoran & Barrett (as cited in Christiansen & Baum, 1997) proposed that if arousal is too low relative to a person's competence, sensory deprivation can result. They define sensory deprivation as a decreased ability to respond to the environment in the absence of adequate stimuli. As an example, Christiansen & Baum (1997) point out that sensory deprivation in the elderly can cause competence to deteriorate, making them less able to be aroused by the environment. A study of sixteen residents residing in a long-term care facility supported this hypothesis (Corcoran & Barrett as cited in Christiansen & Baum, 1997). All sixteen clients were totally dependent in self-care and were divided into two control groups. One group participated in a sensory stimulation program two times per week for sixteen weeks, and the other received occupational therapy intervention focusing on basic self-care skills. At the end of sixteen weeks, only the sensory stimulation group showed significant gains in basic task skills. This suggested that creating a tailored fit between individual capabilities and environmental demands could facilitate occupational performance.
CHAPTER 3

METHODOLOGY

Study Design

This study will use a qualitative research design to investigate the phenomena of a.) consumer satisfaction with and b.) consumer experience of environmental modifications in the home as it relates to people with disabilities. First, the primary criteria differentiating qualitative from quantitative research will be delineated. Next, these criteria will be applied to this study specifically.

Denzin and Lincoln (1994) maintain that qualitative research is accomplished in a natural setting where researchers attempt to analyze and interpret phenomena through the meanings that people bring to them. Additionally, they emphasize three aspects of research: the socially constructed nature of reality, the intimate relationship between the researcher and the participant, and the contextual constraints that help shape the inquiry (Denzin & Lincoln, 1994). Schmid (as cited in Krefting, 1991) identifies two primary principles of qualitative research. The first principle and the foundation for naturalistic inquiry are that the physical, sociocultural, and psychological environment influences behavior. Secondly, subjective meanings and perceptions of the participant are vital in qualitative research, and it is critical that the researcher uncovers these. Finally, Morse (1991) identifies four characteristics of a qualitative research problem: 1.) the concept is immature due to a lack of theory or previous research; 2.) it is possible that the existing theory may be inaccurate; 3.) there may be a need to explore phenomena and develop theory; and/or 4.) the nature of the phenomenon may not be suited to quantitative methods.
Using Morse’s criteria, this study is suited to qualitative methodology on two counts: 1.) there is a conspicuous lack of theory pertaining to consumer-based criteria for home environmental modifications, and 2.) there is a corresponding need to investigate the experience of people with disabilities in modifying their home environments. There is a profusion of professional opinion and research describing the advantages of home environmental modifications, particularly the application of universal design (Mueller, 1990; Cannava, 1994; Ahmadi & Arch, 1997). Still, the research is more prescriptive rather than evaluative. There are some studies that survey consumer opinion in regards to modifying the environment. However, they primarily assess the use of technology [e.g., environmental control units] (Dickey & Shealey, 1987) and assistive devices (Batavia & Hammer, 1990; Cooper & Stewart, 1997). There are few, if any studies investigating the experience of consumers in modifying their home environment.

Part of the challenge in studying the home environments of people who are disabled is the inherent variability of the environment due to gender, culture, socioeconomic factors, nature of the disability, and other contingencies. This variability makes the research question more conducive to qualitative study as described by Denzin and Lincoln (1994). It is important to understand and accurately describe the experience of participants in their natural setting—their home environments—and to identify the environmental constraints and cultural paradigms that may influence a participant’s choice of environmental strategies. This choice of strategy as applied to the research question is also congruent with Schmid’s underlying principles of qualitative research. There is an assumption that 1.) a participant’s strategy selection is influenced by their
environment; and 2.) there are subjective meanings inherent within their choice of strategies.

In summary, this study will use naturalistic inquiry, specifically in-depth interviewing, to understand the experience of consumer satisfaction with and criteria for environmental modifications in the home as it relates to people with disabilities.

Role of the Researcher

Qualitative research differs markedly from quantitative research. One primary difference is that of internal validity. In quantitative studies the measurement and analysis of causal relationships is designed to be within a value-free environment (Denzin & Lincoln, 1994). More specifically, the objectivity of the researcher is paramount and all biases and individual perspectives must be identified and removed to prevent contamination by confounding variables (Hasselkus, 1997).

However, in qualitative research, the researcher and the participant are interdependent and interact to influence one another (Lincoln & Guba, 1985). The concept of interactivity between researcher and participant is assumed to be an inherent and even desirable aspect of qualitative research. This phenomenon can be analogous to the Heisenberg principle in which Heisenberg states “What we observe is not nature itself, but nature exposed to our method of questioning” (Lincoln & Guba, 1985). Tranel (Lincoln & Guba, 1985) elucidates on this principle by proposing that if observation changes the observed in physics, it is all the more likely that this occurs when the observed and observer are human. He emphasizes that what is important is not the elimination of the distortion (which is assumed to be inherently impossible), but rather an awareness of it.
Guba & Lincoln (as cited in Denzin & Lincoln, 1994) describe several advantages to active observation. First, the nature of quantitative research focuses on the pre-selection of specific variables for testing while working to actively eliminate others. Qualitative research, on the other hand, emphasizes the importance of contextual information. It is important to recognize and include this contextual information as this study specifically focuses on the participant’s home environment as an open system.

Secondly, Guba & Lincoln (as cited in Denzin & Lincoln, 1994) theorize that human behavior cannot be fully understood without referencing the meanings and purposes that people attach to their activities. The role of the researcher is vital to the discovery of the meaning and purpose that may be an important part of a person’s environmental strategy.

Thirdly, Lincoln and Guba (1985) emphasize that naturalistic inquiry relies upon purposive rather than representational sampling, also referred to as interactional sampling. If the purpose is to obtain information about how people with disabilities cope with their home environments, then investigator interaction is necessary to find those critical cases that match the purpose (Lincoln & Guba, 1985).

**Apriori Assumptions of the Researcher**

Although researcher interaction is vital to the goals of qualitative research, researcher bias, if left unidentified, can thwart the trustworthiness of the data. The issue of trustworthiness will be dealt with in detail in section four. In addition to trustworthiness, it is also important to identify researcher paradigm.

This researcher is a thirty-eight year old female, the oldest member in a class of twelve occupational therapy students. This is a second career; consequently the researcher's perceptions are a product of her past experiences which include working as a
commercial/consumer banker, and as a retail manager. In addition, the researcher's spouse is an ergonomics engineer, predisposing the research to some ideas and beliefs concerning human/environment interaction.

Based on previous experience, the researcher embraces the Person-Environment-Occupation model of human occupation. It is believed that each of these three facets is interdependent and is inseparable in practice. The researcher's education and personal experience also influence her belief that many people with disabilities could live more independently if their environments were altered to fit their unique needs. In other words, disability is more a function of the environment than of a person's physical capacity. Additionally, it this researcher's opinion that most people eschew environmental modifications due to the prohibitive cost and the lack of coverage under Medicare and Medicaid.

Finally, the researcher's opinion of the environment is also heavily influenced by a familiarity with psychoanalytic theory and object relations. This significantly influences the belief that the environment is often symbolic of and even co-exists with our most deeply held values, beliefs, and experiences. In other words, we as human beings ascribe to our environment personal meaning beyond the mere presence or absence of physical items. In fact, it may be that the meaning behind a person's choice of environmental set-up is inherent within their criteria, strategies, and satisfaction with home modifications.

Bounding the Study and Data Collection

The setting for the interview will preferably be in the participant's home. This will provide more reliable data concerning the participant's environment and choice of
strategies, if any. The participants will consist of between four and six individuals. The criteria for participation are: 1.) The participants must use a wheelchair for mobility at least part of the time; 2.) they must be living in a home-like environment (i.e., this excludes clinical environments such as skilled nursing facilities or residential units in which they cannot alter the environment without permission); 3.) they must be able to participate verbally in a 60-75 minute (approximately) interview; they must be at least eighteen years of age or older.

A convenience sample will be obtained through clinic contacts, practicing occupational therapists, referrals from the Center for Independent Living, and other appropriate sources. Participants will first be contacted by phone to secure interest. A personal meeting will be scheduled to provide information on the study and to distribute the consent form (appendix A). Participants will then have an opportunity to consider whether or not they want to take part in the study and to contact the researcher after the form is signed. An in-depth 60 – 75 minute individual interview will be scheduled with each participant. Each interview will be audiotaped with participant permission and the interviewer will take hand-written notes as a safeguard against mechanical failure. If a participant withdraws, the study will proceed using the remaining participants. All interviews, notes, and audiotapes will be kept strictly confidential using a coding system to ensure privacy. This coding system will entail assigning a letter of the alphabet to each transcribed interview known only to the researcher. No potential hazards are anticipated as there are no invasive procedures and the participants will not engage in any form of physical activity.
Data Collection Instruments

The primary data collection tool is a semi-structured interview and is similar to Lincoln & Guba's (1985) description of an unstructured interview. As they described it, an unstructured interview is distinguished by a non-standardized format in which the interviewer does not solicit normative responses. Instead, the problem in question is expected to arise from the participant’s response to the broad issue raised by the interviewer. Dexter (as cited in Lincoln & Guba, 1985) describes three distinct attributes of unstructured interviews: 1.) the interviewee's definition of the problem is emphasized; 2.) the participant is encouraged to structure the account of the situation and 3.) the participant largely introduces their opinions of what is considered relevant to the situation. Unlike a structured interview, this type of interview is interested in each participant’s unique and individual viewpoint (Lincoln & Guba, 1985).

The interviews will take place between June and December 1999. Appendix B describes the interview guidelines and areas that may be potentially addressed during the interview.

Trustworthiness

Krefting (1991) notes that it is erroneous to apply standard quantitative criteria of worthiness and merit to qualitative studies. As an example, she observes that in quantitative studies the concept of external validity is applied to test the ability to generalize from the research sample to the population. The ability to do so is indicative of trustworthy quantitative research. However, many qualitative studies including this particular study have as their major purpose the generation of hypotheses for further investigation rather than testing (Sandelowski as cited in Krefting, 1991). This study also
uses a phenomenological approach to investigate the unique experience of individuals with disabilities in altering their home environment to fit their occupational needs. The investigation of individual experience renders the quantitative criteria of internal validity inadequate to test the merits of qualitative research. Therefore, this study will use Guba & Lincoln’s (1985) model of trustworthiness for qualitative research.

Credibility

This term is parallel to the quantitative criteria of internal validity. Credibility is established when the qualitative study presents accurate interpretations or descriptions of human experience in such a way that others who share that experience immediately recognize the descriptions (Krefting, 1991). In other words, the researcher establishes confidence in the truth of the findings for the participants and in the context in which the study was conducted (Lincoln & Guba, 1985). The following measures will be employed to ensure credibility:

Reflexivity—This refers to assessing the influence of the researcher’s background, perceptions, and interests on the research process. The researcher bias section of the methodology specifically addresses the perceived biases of the researcher within the context of this research.

Member checking—This technique consists of continuously verifying with the participants the researcher’s data, analysis, categories, interpretations, and conclusions. This is accomplished through the hermeneutic process of data analysis that is described in the data analysis section.
Peer examination—Based on the same principle as member checks, the researcher will periodically discuss the research process and findings with impartial colleagues who have qualitative research experience.

The interview process—Krefting (1991) maintains that the interview process itself can also enhance credibility. The constant re-framing, repetition, and expansion of questions will facilitate the truth-value of the research. Credibility will also be supported by maintaining a logical rationale on the same topic in each interview (Krefting, 1991).

Transferability

The parallel quantitative criterion is external validity. According to Lincoln & Guba (1985), qualitative research meets this criteria when the findings fit into contexts outside the study environment that are determined by the similarity or goodness of fit between the two contexts. It is important to note that transferability is primarily the responsibility of the person desiring to transfer the findings to his or her situation. The responsibility of the original researcher is to provide sufficient descriptive data to facilitate this transfer (Krefting, 1991). This study will employ the use of descriptive data about the participants and the research context to allow others to more easily assess the congruency of the findings to other contexts.

 Dependability

Quantitative research uses the term reliability to test the consistency of the findings and determine whether it is possible to obtain the same results by replicating the inquiry with similar subjects and contexts. However, qualitative research highlights the uniqueness of human behavior and variability is inherent in the research process, making replication in the quantitative tradition irrelevant (Krefting, 1991). The qualitative
criteria is dependability, which tests the ability to track variations in data to their original sources. Dependability will be accounted for in two ways. First, the researcher will maintain a detailed account of the research process, methods, data gathering, and interpretation (Krefting, 1991). Second, the data will be systematically coded to ensure privacy and trackability to the original source.

**Confirmability**

Objectivity is the ancillary term to confirmability in quantitative research. This implies that the proper distance is maintained between the researcher and the subjects to minimize bias. Qualitative research attempts to decrease the distance between the researcher and informant to generate the descriptive data necessary for accurate and trustworthy results. Therefore, Lincoln & Guba (1985) suggest shifting the emphasis on neutrality from the researcher to the data. Confirmability is accomplished in two ways (Krefting, 1991). First, the thesis committee in addition to impartial colleagues will periodically evaluate the research process and rationale by examining raw data, data analysis, process notes, and thematic categories. Second, the researcher will review and explicitly state any personal bias or influence on the data.

**Ethical Considerations**

Traditional ethical concerns include informed consent, right to privacy, and protection from harm (Fontana & Frey as cited in Denzin & Lincoln, 1994). This study mitigates each of these by requiring each participant to sign a consent form and by keeping all identities confidential through data coding. The study does not require any physical activity or invasive procedures, thus negating any potential physical harm.
However, Fontana & Frey (as cited in Denzin & Lincoln, 1994) list three other ethical issues specifically applicable to interviewing. These issues involve dilemmas concerning overt/covert fieldwork, degree of researcher involvement, and the veracity of reports made by researchers. First, all participants will be informed of the study purpose and methods before the consent form is signed. These issues will also be explained as part of the consent form. Second, the researcher’s involvement is limited to one 60 – 75 minute interview with each participant, including the possibility of several brief (less than thirty minutes total) follow-up meetings and/or telephone conversations. There is no long-term immersion or involvement in the subject’s life. Finally, the researcher promotes veracity of reporting through member checks, peer review, and frequent review of the data and methods by the thesis committee.

Data Analysis

A hermeneutic process was the original technique chosen for analyzing and coding the research data. The hermeneutic process involves multiple respondents interacting with the researcher to arrive at a mutually agreeable explanation of the research question (Lincoln & Guba, 1985). It is both interpretive and dialectic as it illuminates divergent views to arrive at a greater understanding and synthesis of those views. The information obtained from each separate analysis is used to guide each subsequent interview and also to compare and contrast the divergent views of all participants. This ensures that an integrated final construct is formed that reflects a synthesis of all participants’ views. This final construct is then presented to all participants, providing each with an opportunity to react to the construct designed from their responses and to give additional feedback regarding this final construct.
This process was initiated in this study by conducting a detailed literature review of the topic to develop a basic understanding of the question. This information was used to create the first set of interview questions. The first participant was interviewed using the semi-structured interview format described in the data collection section. The questions listed in Appendix B were used as a starting point for the interview. After the initial interview, the first construction of consumer satisfaction with and experience of home environmental modifications was complete. The researcher conducted the second interview asking questions similar to the first. Additionally, the researcher provided the second informant with information from the first interview to begin the comparison and contrast of divergent views concerning consumer use of environmental modifications in the home. This process was continued until all participant interviews were completed.

However, time constraints necessitated using a modified hermeneutic process for data analysis. This entailed the researcher reviewing rather than transcribing each interview shortly after its completion. The researcher listened to the tapes, analyzed the handwritten interview notes and recorded the major themes or impressions for inclusion in the next interview. This analysis enabled the formation of an integrated construct after each interview to use as a framework for comparing and contrasting divergent views arising in subsequent interviews.

The audiotapes were transcribed after all interviews were completed and the transcriptions were analyzed and coded for emerging themes (Guba & Lincoln, 1989). This analytical process was repeated approximately three times for each interview over a period of two weeks to ensure that the themes accurately reflected the data and to enhance dependability. During that period, the thesis committee chair was also contacted
regularly for advice regarding analysis techniques and thematic progression. When the analysis was completed, the data was organized in outline format and formation of the final construct was initiated.

Time constraints also precluded the presentation of a final construct to all participants. However, in spite of the absence of a final construct, the trustworthiness of the study was maintained by adhering to other recognized qualitative strategies widely used to establish credibility, transferability, dependability and confirmability (Krefting, 1991).

Credibility was maintained by utilizing six specific procedures: a.) ensuring an adequate interview time of sixty to seventy-five minutes (prolonged engagement), b.) observation of the home environment, c.) specifically addressing the issue of researcher bias in Chapter 3 (reflexivity), d.) interviewing other family members familiar with the participants history and home modification process (triangulation), e.) including peer analysis of the data (peer examination) and f.) by expanding research questions to accommodate emerging themes (interview technique).

Krefting (1991) maintains that transferability is enhanced by the provision of sufficient descriptive data to allow comparisons. The interview format included questions that addressed each participant’s background and history both apart from and including the home modification process. This resulted in extensive descriptive data for all participants. Dependability, or trackable variability (Krefting, 1991), was augmented through the use of the thesis committee to check the research plan and it’s implementation (peer review).
Finally, confirmability, or accuracy of the data, was enhanced by specifically addressing researcher bias and by maintaining an adequate audit trail. The audit trail included hand-written interview notes, audio-tapes of the interviews, transcriptions of the audio-taped interviews, outlines of the analysis and organization of emerging themes and a record of interpretations and advice given by the committee members.

In summary, the semi-structured interview format in combination with the modified hermeneutic process allowed each informant to contribute to a potential theoretical base of consumer criteria for and satisfaction with home environmental modifications.

Limitations to the Study

There are several potential limitations to this study. First, the number of respondents is limited to a maximum of six, all from a common demographic area. This may limit the diversity of the construct both culturally and numerically. Secondly, although each subject is required to use a wheelchair as their primary method of ambulation, this criterion inherently includes a wide variety of disabilities, each with their own idiosyncratic symptoms and outcomes. Finally, there is the possibility that some of the informants will have no knowledge of or ability to incorporate environmental modifications into their homes.
CHAPTER 4

RESULTS/DATA ANALYSIS

Overview

The purpose of this study was to a.) investigate consumer experience in choosing home modifications to accommodate or compensate for a chronic disability and b.) explore the satisfaction with existing modifications. The results of the study are organized here in seven sections. Section one, Participant History and Characteristics uses a narrative format to describe each participant as well as a table for summary and easy reference. Section two, Specific Modifications, outlines the types of modifications made and includes definitions and criteria that are also critical for categorizing and identifying emerging themes.

The third section introduces the first theme from the interview data: *The importance of an adviser in the home modification process.* An adviser is characterized as a person who attempted to assist the participants in creating a new home environment that was congruent to their new abilities. Three types of advisers are described and the experiences and characteristics of each type of advisor are explored. The concept of self-advisement or self-agency is also examined as two participants acted as their own advisers during the modification process.

The fourth section, Client Perceptions of Occupational Therapy’s Role describes the second and third themes from the interview data: *The participants’ perception of occupational therapists as absent or not distinguishable from other professionals, and the participants’ perceptions of occupational therapy as members of a uni-disciplinary team in the execution and planning of their home modifications.*
The fifth section, Participant Criticisms includes three themes that highlight the gap between what the participants felt they needed from occupational therapists and others involved in the process compared to what they received in the way of guidance and expertise. These themes include: a.) ineffective execution of intervention strategies; b.) inadequate knowledge of applicable laws, standards, and codes; and c.) a disability versus client-centered perspective. The sixth section, Participant Advice, details suggestions for closing the gap between client need and occupational therapy intervention. The concept of client-centered practice forms the framework for these suggestions.

The final section, Environmental Meaning and the Home Environment, explores the seventh and final theme—the concept of environmental meaning as a driving force in the choice of and satisfaction with home modifications. This theme is divided into four sub-categories that will be explored by using specific vignettes taken from the participant’s narratives of their experiences during the modification process.

Participant History and Characteristics

Six participants were interviewed over a three-months beginning in October 1999. A brief narrative of each participant’s history sets the context for his or her experience with the home modification process [all participant’s names have been changed to maintain confidentiality]. Additionally, demographic data and participant characteristics applicable to the research questions are presented in Table 1 for easy reference.
## Table 1

### Participant Characteristics

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Subject</th>
<th>Donna</th>
<th>Dan</th>
<th>Dave</th>
<th>Steve</th>
<th>Tom</th>
<th>John</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td>Female</td>
<td>Male</td>
<td>Male</td>
<td>Male</td>
<td>Male</td>
<td>Male</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td>31</td>
<td>43</td>
<td>51</td>
<td>40</td>
<td>31</td>
<td>45</td>
</tr>
<tr>
<td><strong>Disability</strong></td>
<td></td>
<td>C-7 SCI Paraplegia</td>
<td>C-4/5 SCI Tetraplegia</td>
<td>C-4/5 SCI Tetraplegia</td>
<td>Tetraplegia</td>
<td>Hemiparesis &amp; TBI</td>
<td>T-8 SCI Paraplegia</td>
</tr>
<tr>
<td><strong>Etiology</strong></td>
<td></td>
<td>MVA</td>
<td>Diving Accident</td>
<td>MVA</td>
<td>Muscular Disease</td>
<td>MVA</td>
<td>MVA</td>
</tr>
<tr>
<td><strong>Years Post-Condition</strong></td>
<td></td>
<td>5 years</td>
<td>7 years</td>
<td>7 years</td>
<td>10 years</td>
<td>11 years</td>
<td>3 years</td>
</tr>
<tr>
<td><strong>Modification</strong></td>
<td></td>
<td>Retrofit</td>
<td>Retrofit</td>
<td>New Construction</td>
<td>New Construction</td>
<td>New Construction</td>
<td>Custom Modular</td>
</tr>
<tr>
<td><strong>Construction Time</strong></td>
<td></td>
<td>5 Weeks</td>
<td>3 Years</td>
<td>3 Months</td>
<td>3 Months</td>
<td>6 Months</td>
<td>2 Months</td>
</tr>
<tr>
<td><strong>Financing</strong></td>
<td></td>
<td>Michigan No Fault</td>
<td>Private Pay</td>
<td>Michigan No Fault</td>
<td>Private Pay</td>
<td>Private Pay</td>
<td>Michigan No Fault</td>
</tr>
<tr>
<td><strong>Personal Care Asst.?</strong></td>
<td></td>
<td>Spouse</td>
<td>Yes</td>
<td>Yes</td>
<td>Spouse</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td>Vocational degree</td>
<td>Vocational degree</td>
<td>Vocational degree</td>
<td>B.S.</td>
<td>H.S.</td>
<td>Vocational degree</td>
</tr>
<tr>
<td><strong>Employment Status</strong></td>
<td></td>
<td>Employed</td>
<td>Self-Employed</td>
<td>Unemployed</td>
<td>Self-Employed</td>
<td>Unemployed</td>
<td>Self-Employed</td>
</tr>
</tbody>
</table>

### Donna and Craig

Donna was twenty-six years old when a driver suffering from a diabetic reaction lost control of her car and struck Donna, leaving her with a serious spinal cord injury that left her paralyzed from the waist down. After the accident, Donna and Craig met while receiving inpatient therapy at the same rehabilitation facility and eventually married.

Craig had suffered a spinal cord injury in a motorcycle accident that also left him paralyzed from the waist down. Because he wasn’t expected to walk again and wanted to live independently, the house he lived in prior to the accident was modified to accommodate his new abilities. However, in spite of the prognosis he received, Craig eventually regained his ability to walk.
The medical teams inaccuracy in predicting Craig’s outcome became Donna’s gain as she now had a ready-made accessible home to move into when she and Craig decided to get married. However, in spite of the home evaluation performed by the rehabilitation team and the remodeling done by a recommended contractor, Craig’s home remained inaccessible for Donna in many ways. The lack of accessibility was made more acute by Donna’s pregnancy. At the time of the interview, she was approximately six months pregnant and the thought of negotiating their existing home while caring for an infant was untenable. They were able to use Donna’s insurance coverage to begin construction on a new home that would accommodate Donna and their new family. At the time of the interview, the initial construction on their new home had begun and they anticipated moving in by spring of 2000.

Dan

Dan’s tetraplegia was the result of a diving accident he incurred seven years ago at the age of thirty-six while diving off of his own boat while swimming. According to Dan, the doctors were never able to adequately explain how Dan broke his neck during the dive. The depth was sufficient for diving and there weren’t any marks or wounds anywhere on Dan’s body that would’ve been indicative of hitting the boat or another object.

To make matters worse, as Dan so eloquently stated, “you can’t sue yourself”. This meant that while both his boat and his home were adequately insured liability coverage only includes injuries to others—not the owners themselves. If Dan had been injured on someone else’s boat or in a motor vehicle (automobile or truck), that person’s liability coverage or the state of Michigan’s No-Fault insurance system would have
covered all medical treatment, equipment, training, and environmental modifications to accommodate his disability. However, Michigan No-Fault insurance coverage only applies to injuries incurred while operating an automobile or truck. Consequently, Dan was left with only a minimal payout from his insurance company and a pervasive disability that required extensive resources to both treat and accommodate.

In the absence of insurance, he and his wife had a extensive network of family and friends who provided the physical, financial and emotional support that allowed Dan to overcome the barriers he faced during rehabilitation and in moving back home. Dan’s prior experience as a pipe fitter also enabled him to facilitate many of his own modifications. This expertise combined with his tenacity and determination to be as active and productive as possible resulted in a home environment well suited to his needs and lifestyle. Dan died several weeks after our initial interview from complications related to his spinal cord injury. His can-do attitude and positive outlook will be sadly missed—the world remains a lesser place without him.

Dave and Elaine

Dave and Elaine prove that just when you think life can’t get any more complicated—it does. At the age of 44, Dave lost control of his truck on the way home from work, going through a guardrail and hitting a brick wall before it was all over. At the time, they had four children, all teenagers in high school and with the busy lives expected of a family in that stage of life.

According to Elaine, that life came to an abrupt halt after the accident as they questioned Dave’s very survival during his time in ICU. Dave did survive, but with a spinal cord injury that left him paralyzed from the neck down. Like Dan, Dave and
Elaine had a supportive family that mentored them through the rehabilitation process as well as played an active role in creating an ideal home environment that accommodated their children as well as Dave's new abilities.

Elaine's four brothers—all building contractors—guided them through the research, planning and execution required to build a new house for their family after Dave's accident. One of her brother's in particular went to extraordinary lengths to help Dave and Elaine find the ideal house plan for his needs. This brother was also instrumental in convincing the insurance company and the rehabilitation team that it was structurally unfeasible to remodel Dave and Elaine's current home. The insurance company favored remodeling their existing home plan until Elaine's brother intervened by pointing out the structural impracticalities of that plan and the advantages to building a new home. Her brother's tenacity and Dave and Elaine's perseverance resulted in a home that is beautiful, accessible, and allows Dave to maintain his roles of father, husband and grandfather.

Steve

Steve faced many of the same financial and support barriers as Dan. His chronic muscle disease made him ineligible for the extensive insurance coverage needed to mitigate the significant expense often required to treat and accommodate such a pervasive disability. Steve was a very athletic person previous to manifesting symptoms, and he first began to notice some muscle weakness fifteen years ago while exercising. However, it was not until 1990 that his gradually worsening condition was diagnosed. He initially required a manual wheelchair for mobility and eventually transitioned to an electric wheelchair when he lost the use of both his arms in addition to his legs.
Now, at the age of forty, Steve has a wife and two children to support, and he takes his responsibility very seriously. So seriously, in fact, that he has developed an notable ability to advocate for his needs. As an example, he was determined to own a home that enhanced his ability to live independently with his family. He knew the geographic area and type of home he wanted, and was undaunted by the developer's initial reluctance to modify the standard home plan. After a lot of negotiating and perseverance, Steve now owns a home he designed and financed independently.

Steve also expresses a need to remain productive and to be seen as competent. This desire is exemplified in two ways. First, his desire to remain productive is demonstrated by managing his own business as well as working as a job counselor for people with disabilities. Secondly, he expresses his competency through his refusal to use any more adaptive equipment or technology than is absolutely necessary. For Steve, his ability to remain productive and independent is closely tied to keeping his need for adaptive technology, equipment and modifications to a minimum.

Tom and Denise

At the age of twenty-one, Tom had recently completed a specialty certification at a nearby university that would help him carry on his family's dairy farm operation. He was married and his wife had recently given birth to their first child. Unfortunately, he was injured while riding with a friend who lost control of the car. Tom ended up with a massive head injury and one of the other passengers was paralyzed from the neck down.

Tom's life was changed forever after the accident and any possibility of taking over the family farm quickly evaporated. His head injury initially left him totally disabled and completely dependent for all of his personal care. To make matters worse, his wife
left him two weeks after the accident. Devastated by their loss and eager to give their son every advantage, his parents initiated an extensive and costly remodel of their current home. Tom lived with his parents for several years after the accident and remained largely dependent on them and home health aides to maintain his function.

One of Tom's aides, Denise, was an old friend from high school. In the process of caring for him, Denise and Tom renewed their friendship and love for each other and they eventually married. While acting as his personal aide, Denise began to recognize that as Tom's condition improved so did his potential to regain some independence in his self-care.

After they married, Tom and Denise contracted to build a new home and were able to find a builder with experience in building homes for people with disabilities. Tom and Denise have one child, a little girl, from their marriage and regularly care for Tom's son from his first marriage. Fortunately, the builder's competency and expert mentoring allowed Tom and Diane to create a home environment that maximized Tom's growing independence while allowing them to accommodate their expanding family.

For Tom and Denise, creating an environment that was flexible enough to change with their needs was just as important as building a house that could accommodate his wheelchair. In fact, Denise credits the builder's focus on designing their home to meet Tom's specific needs with his increased independence in his personal care. In short, Tom's ability to successfully participate in his environment was directly correlated to the specific design features of their home.
John

Before his accident, John prided himself on his skills as an electrician and had recently begun work on a large project at a corporation some distance from his home. This required him to drive about an hour each way on a two-lane state highway. John was driving from work one day during the winter months and it was "snowing like crazy", as he describes it. In fact, occasional whiteout conditions made visibility almost negligible. One whiteout lasted just a little too long, and a vehicle coming in the opposite direction crossed the centerline, hitting John head on. John suffered a broken back, a cracked pelvis and ribs, and a broken leg and wrist. The bad weather precluded air lifting him to the nearest trauma unit, so the ambulance tried to get John to the hospital as fast as they could while coping with the poor driving conditions.

What the emergency medical technicians couldn’t have assessed was that John’s aorta was torn and he was bleeding internally. By the time they had driven him to the ER, the damage to his spinal cord from the internal hemorrhage was irreversible and he was paralyzed from the waist down.

In spite of this turn of fate, John managed to make the best of his remaining abilities and now lives independently in a custom designed modular home. He volunteers his electrical expertise at an organization that helps people facing economic hardships more easily afford home repairs. He has also designed his home to accommodate a photography studio that allows him to pursue his own business. John’s positive outlook on life and a home designed specifically to fit his needs enables him to live independently and to remain productive through his volunteer activities and his photography business.
Specific Modifications

The homes modified and the kind of modifications performed by each of the six participants were divided into three general types: a.) remodeling an existing wood frame home, b.) building a new wood frame home and c.) ordering a custom designed modular home. The type of modifications made and the process involved in executing the remodel or building plan was closely correlated to the three general types of homes listed above. Three participants constructed custom wood frame homes that were specifically designed to their abilities and two participants modified existing wood frame homes. One participant decided to purchase a new modular home that was customized at the factory to meet his specific needs. Half of the homes were financed through Michigan No-Fault Automobile Insurance. The others were financed privately by the participants.

Specific home modifications are detailed in Table 2 and categorized according to the area in which they are found in the home: the bathroom, living area, bedroom, kitchen, interior/other and exterior/other. A critique of each category is also included which outlines any specific problems identified by each participant for that particular area. The modifications chosen by the participants were a combination of suggestions made by others and weren’t always helpful. The criteria for including an item as a home modification includes both structural alterations to the home as well as any technology or assistive device specifically used in the home to accommodate the participant’s abilities.
## Table 2

### Specific Modifications

<table>
<thead>
<tr>
<th>Subject Area</th>
<th>Donna</th>
<th>Dan</th>
<th>Dave</th>
<th>Steve</th>
<th>Tom</th>
<th>John</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Critique</strong></td>
<td>Sink placement. medicine cabinet height.</td>
<td>None.</td>
<td>None.</td>
<td>None.</td>
<td>Too small.</td>
<td>Shower depth too shallow (leaks).</td>
</tr>
<tr>
<td><strong>Living Area</strong></td>
<td>Wood floors, wider door frames, flush-mounted hinges.</td>
<td>Open floor plan, wider hallways, widened doors.</td>
<td>Open floor plan, skylights, floor length windows, accessible deck, computer desk, wider hallway.</td>
<td>Open floor plan, wider door frames.</td>
<td>Open floor plan, plexiglass protector for TV, wider door frames.</td>
<td>Open floor plan, 36” door frames, remote control blinds, touch lamp.</td>
</tr>
<tr>
<td><strong>Critique</strong></td>
<td>None.</td>
<td>None.</td>
<td>None.</td>
<td>None.</td>
<td>None.</td>
<td>None.</td>
</tr>
<tr>
<td><strong>Bedroom</strong></td>
<td>Transfer board, removed closet doors.</td>
<td>Expanded bedroom area, hospital bed.</td>
<td>Hospital bed, sliding door to deck, wall-mounted TV, adjacent to bathroom</td>
<td>Not modified.</td>
<td>Door frame cut on a 45 degree angle w/ french doors, adjacent to bathroom.</td>
<td>Motorized hospital bed.</td>
</tr>
<tr>
<td><strong>Participant Critique</strong></td>
<td>None</td>
<td>None.</td>
<td>None.</td>
<td>N/A</td>
<td>None.</td>
<td>None.</td>
</tr>
<tr>
<td><strong>Critique</strong></td>
<td>Sink access, floor-space, refrigerator, oven access, cupboard height &amp; door-handles.</td>
<td>N/A</td>
<td>None.</td>
<td>N/A</td>
<td>None.</td>
<td>Oven access (conventional door).</td>
</tr>
</tbody>
</table>

(table continues)
<table>
<thead>
<tr>
<th>Subject Area</th>
<th>Donna</th>
<th>Dan</th>
<th>Dave</th>
<th>Steve</th>
<th>Tom</th>
<th>John</th>
</tr>
</thead>
<tbody>
<tr>
<td>Critique</td>
<td>Poor dryer &amp; control access.</td>
<td>None</td>
<td>No basement access.</td>
<td>None.</td>
<td>Need extra bedroom.</td>
<td>No basement access.</td>
</tr>
<tr>
<td>Ramped entrance inside garage, ramped deck</td>
<td>Ramped front entrance &amp; deck, ramped sidewalk.</td>
<td>Home built on a grade (no ramps), sidewalk ramped to backyard &amp; patio area w/ tool shed, ramped garage</td>
<td>Home built on a grade (no ramps).</td>
<td>All entrances ramped, garage ramped.</td>
<td>All doors &amp; deck ramped.</td>
<td></td>
</tr>
<tr>
<td>Critique</td>
<td>None.</td>
<td>No access to backyard.</td>
<td>No interior access to backyard (must go outside)</td>
<td>None.</td>
<td>None.</td>
<td>None.</td>
</tr>
</tbody>
</table>

Originally, I intended to include only modifications to the structure of the home itself, however, the rationale for this strategy became suspect during my interview with Dan. Specifically, when I asked Dan to prioritize structural modifications and equipment according to importance his reply suggested that the separation between the two categories was artificial.

"I can’t separate the two because…they’re so—such an integrated part of my lifestyle that…I depend on everything. If one thing goes down…if this button that raises my feet up and down goes down, the rest of the chair works—but I sit so low to the ground I can’t get out the door because I run into the sidewalk at the bottom of the ramp…you can’t hardly separate…one thing from another."
This all-inclusive definition of home modifications was both directly and indirectly implied in the other five interviews as well. Therefore, my original definition of home modifications was modified to fit the participant’s paradigm of a modified home environment—one that included both structural changes and equipment.

As the interviews and data analysis progressed, it became apparent that the participant’s criteria for choosing and using home modifications and their satisfaction with them encompassed far more than just categories of rooms and their physical attributes. Just as important was the process involved in creating a new environment and each participant’s perception of the level of involvement of rehabilitation professionals and contractors in that process. The next section explores the themes related to the planning and execution of home modifications.

Theme 1: The Importance of an Adviser in the Modification Process

Simply describing the modifications made by each of the participants may give the impression that creating an accessible living environment is simply a matter of making a list of what you want and then buying or building it. However, according to the participants, creating an accessible home often involves weeks and even months of planning, decisions, research and frustration. This section details the problems and issues that the participants encountered in the planning and execution involved in designing a home that facilitated their specific needs and abilities.

One significant theme to emerge when the participants were asked to describe how their home environments were actualized was the concept of an adviser—most participants identified someone who served as an advisor to them in the process of designing a new home environment. I chose the term advisor because it has a neutral
connotation. Webster’s Encyclopedic Unabridged Dictionary (1996) defines an adviser as “one who gives advice”—good or bad.

Each participant had distinct and significant experiences, both positive and negative, with the builders and contractors responsible for constructing their chosen modifications. However, separating the adviser and the construction issues was artificial, as the adviser and the builder were often the same. Therefore, issues involving the development of the advisor and contractor relationship will be explored simultaneously in the following section.

Three categories of advisors emerged when the participants talked about their experiences while modifying, building or, in one case, ordering their homes. The first type of advisor was a *mentor*. The term mentor is usually perceived as a positive relationship between two people—Webster’s Dictionary (1996) defines a mentor as a “wise and trusted counselor or teacher”.

Those participants whose advisors fit into this category described them as helpful, effective, knowledgeable and self-directed. Mentors were most often friends, family members and in one case, even the builder himself. These mentors were indispensable in assisting the participants and their families in designing a home environment that matched their individual abilities. The mentor often facilitated this process by giving design advise, helping the person and their families research ideas and available resources, predicting and overcoming barriers to execution and even constructing the final product. In short, an effective mentor expressed a genuine concern and commitment to creating an environment that maximized the participant’s remaining abilities.
However, several participants described their advisors as ineffective, lacking knowledge, and even as incompetent. This type of advisor is designated as ineffectual. A lack of knowledge, giving poor or incorrect advice, being ineffective and sometimes even an impediment to the planning and execution of the home modification process characterized an ineffectual type of advisor.

Several participants acted as their own advisors. And, while self-advising isn’t necessarily congruent to the Webster’s definition, these participants did demonstrate an ability to advocate for themselves as self-agents in the home modification process. Webster’s defines agency as “the state of being in action or of exerting power”, and two participants were able to successfully assess their needs, amass the necessary resources, and execute their plan for an optimal home environment. In short, each acted on their own behalf by exerting power over their situation and their environment. All three categories—mentor, ineffectual adviser, and self-agency—are explored more fully in the following sections by using vignettes from each participant’s story of how they pursued a home environment best suited their individual needs.

Mentors

The positive mentoring experiences of Dave and Elaine, Tom and Denise, and John illustrate how an advisor who is a mentor can make the difference between an accessible home and a negotiable home. In terms of the environment, accessible implies the ability to approach or gain entry to a location or space (Webster’s 1996). A home with a ramped entranced is an example of an accessible environment.

A negotiable environment enables a person to both access a feature of the environment and to use that feature for it’s intended purpose. Accessing and using the
environment is done with a person’s usual adaptive equipment in a way that’s acceptable to that person (Bates as cited in Christiansen, 1994). The ability of a person to use the kitchen sink to wash dishes while in a wheel chair is an example of a negotiable environment. In other words, negotiable signifies not only access to the desired environment but the ability of the user to successfully interact with that environment in an acceptable manner to perform their chosen activities, tasks and roles.

Dave and Elaine: The family project. For Dave and Elaine, their family was the primary source of assistance when creating a new environment for Dave. Elaine’s brothers, all building contractors, took primary responsibility for researching, designing and contracting the construction of their new home. As Elaine relates “…I was basically at the hospital fifteen hours a day at that time period. I have four brothers and they’re all builders and they just kind of stepped in and figured it out for me.”

One brother and sister-in-law in particular were especially helpful in researching and evaluating design criteria for their new home. As Dave relates,

“…her [Elaine’s] brother is a building contractor. [He] went around to different homes and talked to different people and asked them questions…if there were any changes they would make…if they would build again or you know, what they like. They found the one house and the lady said that there was nothing that they would change, that everything worked out well for them. We cut it down a little bit, but we used their floor plan and everything works out pretty well.”

They also took pictures of the homes to show Dave for his input and opinion before making a decision.
For Dave and Elaine, the devotion and dedication of their family made the difference between a daunting task and a manageable goal: a house constructed to Dave's unique abilities. In fact, he and Elaine credit her brother’s tenacity with the relatively short construction time (three months) and their complete satisfaction with the home. When asked what she would have done without her brother, Elaine was at a loss. “...it’s kind of a scary question, really. *I hadn't thought about that—what would I have done?...I would have hired a total stranger.*”

Tom and Denise: The flower box. For Tom and Denise, choosing a “total stranger” to build their new home had some unexpectedly positive results. Not the least of which was the builder’s creativity and commitment to building a home that was customized to Tom’s needs. Denise relates that a friend of theirs had contracted with this particular builder to complete some remodeling work on their home. Denise was so impressed by the contractor’s craftsmanship she asked him for an estimate on the house that she and Tom were planning to build. “...he gave us a bid and he was such a down to earth, nice honest guy that you know, he went over everything and my Lord, the price was right.” Fortunately for Tom and Denise, the contractor was not only an expert craftsman, he also had experience designing and building accessible homes—he had recently built a home for his mother who was also disabled and used a wheelchair.

This experience enhanced his ability to make recommendations and guide the design process by anticipating Tom’s needs. According to Denise, “…he really kind of steered us. We had the plan and he sort of steered us the way that he wanted to. He kind of *did things without even asking*...I mean there were so many common sense issues that came up that *he was able to just deal with it*, not call up at every turn.”
For example, Tom's upper extremity spasticity on his right side made it difficult for him to stabilize while using the bathroom during toileting. The builder's creativity and sensitivity to Tom's needs resulted in his idea for a recessed area on top of a half wall adjacent to the toilet. This "flower box", as Tom and Denise called it, enabled Tom to independently stabilize by positioning his affected arm in the recessed area while completing his personal hygiene and clothing management with his left arm. This type of attention to detail resulted in an environment that supported his independence.

The builder was also sensitive to Tom and Denise's desire for a "normal" looking home. According to Denise, she appreciated the builder's commitment to accessibility but was worried that the house would look like a "modified home". When she confronted the builder with her concern, he assured her that by enhancing the aesthetics of the home, they could mitigate the "modified" look. As Denise relates, "...he added little special touches...he really took into account all the things...and even the ramps—the ramps, they don't really look like ramps."

When Tom's parents remodeled their home to accommodate him just after his rehabilitation, they were not as fortunate. Tom lived with them for several years after he left the inpatient rehabilitation unit and before he and his wife were married. In the absence of family expertise or a friend's recommendations, Tom's parents were forced to independently locate a builder to remodel their home. The absence of a competent and committed advisor had several negative consequences.

First, several of the modifications were unnecessary—they weren't built with Tom's needs in mind and some of the modifications weren't even accessible to him. These included a basement under the new addition, an additional garage, a mud-room and
a breezeway. According to Denise, the total cost of the modifications exceeded the cost of the new home that she and Tom had built. Furthermore, Tom lived with his parents for only two years after discharge, rendering much of the remodel superfluous as well as costly.

**John: One stop shopping.** Unlike Dave and Elaine or Tom and Denise, John decide to purchase a modular home. His decision was based on several factors. First, a modular home was $8,000 – $12,000 less than wood frame construction, and his insurance company seemed to favor a modular home. Secondly, if John had decided to build a wood frame home, he felt that he would have been on his own, and finding a compatible home plan, modifying it and locating a builder to construct it would have been a daunting task. Finally, John believed that he had a larger number of design options with a modular home. However, the real advantage turned out to be a ready-made mentor—the mobile home dealer.

According to John “They were pretty well versed in dealing with para’s [i.e., people who are paraplegic] like myself...they took me around to various homes they had sold and set up for para’s.” So like Dave’s family, the mobile home dealer facilitated a first-hand tour of design options to assist John in his choice of home environments. The dealer also familiarized himself with John’s lifestyle and preferences apart from his disability. “…the reason they opened up this [living] area was because…I wanted a lot of space for photography and for the sound [from the audio system] to open up.” A bay window in the front room was also recommend by the dealer to enhance his television and stereo system.
Floor plan flexibility was also a strong selling point and the dealer offered John “a ton” of floor plans to choose from. After deciding on a general floor plan, John was still able to adjust it to meet his remaining abilities. In short, he could have had “virtually anything” in the way of home design.

His experience with the mobile home dealership while better than most, was not perfect. Both the mobile home dealership and the insurance company were slow to respond to some minor design flaws and several additional needs that John discovered after the modular home was installed. For example, the dealership has been slow to repair stress cracks in the walls due to settling and the insurance company has not responded to his requests for a generator. In spite of these shortcomings, John still felt that the over-all experience was positive.

Ineffectual Advisers

Donna and Craig’s experience illustrates what can happen when the advisers and the builder don’t establish a close working relationship with the final user or with each other. Their home was originally modified to accommodate her husband, Craig who had also been injured in an unrelated accident before they were married. Initially, Craig was not expected to regain his ability to walk again, prompting the rehabilitation team to recommend modifications for a person who was paraplegic. Craig was unable to make any decisions at the time the home evaluation was done, so his parents coordinated the remodeling effort and chose a contractor based on the insurance company’s recommendation. Unfortunately, making sure a home evaluation was done and hiring an experienced contractor didn’t guarantee a negotiable home environment. Many areas of the home remained inaccessible in spite of this.
Donna and Craig: “I’d never seen the backyard”. An OT, PT, and a RN jointly performed a complete home evaluation prior to the remodeling process. This team communicated their recommendations to the builder, who then integrated these suggestions into the final project. However, it is unclear how well they consulted with the family before or after the home evaluation. Ironically, in spite of the home evaluation and the contractor’s experience, the final outcome was sub-optimal in many ways. Craig commented that

“...a lot of it is what should be done and actually what is...a professional company came in and did [remodeled] the house but yet they still made mistakes and didn’t do things they could have done...there’s still a lot of limitations right here still for wheelchair users.”

Table 2 lists the most glaring omissions including an inaccessible kitchen sink and a refrigerator with a top freezer compartment. A stacking washer/dryer unit specifically ordered for Craig had a top dryer and a washer with controls located on the back of the machine—this would have been inaccessible to anyone in a wheelchair.

Exterior modifications were problematic as well. The contractor wanted to build the wheelchair ramp outside the house—Craig had to convince them to build it inside the garage so he wouldn’t have to navigate the ice and snow during the winter months. Other contractors were no better. After Donna and Craig were married, Craig realized that Donna had never been in the backyard, so he immediately contracted to have a ramped deck built on the back of their home. However, when he asked the builder to ramp the sliding door tracks to accommodate Donna’s wheelchair, the builder told him it couldn’t be done. Skeptical of the builder’s expertise, Craig and his dad finally modified the
sliding door tracks on their own and in his words, "...it's not a big deal". Craig succinctly summed up their experience when he said, "It's tough to find a good...builder. For them to understand what you really want...Good builders are real important to find."

**Self-Agency**

Dan and Steve didn't rely on anyone for guidance and suggestions—instead, they advised themselves. They were also the only participants who were not covered by Michigan No-Fault Insurance. This correlation is significant because, in the state of Michigan, if you are injured in a motor vehicle accident [automobile or truck], it doesn't matter who is at fault. As long as the vehicle is insured, all personal injuries and any medical care or equipment related to that injury are fully covered. This coverage can include hospitalization, rehabilitation, durable medical equipment, home modifications, a new home and a personal care attendant among other things.

However, Dan was injured on his own boat [Michigan No-Fault Insurance doesn't apply to boats] and Steve's disability is the result of a degenerative muscle disease. In spite of their lack of financial resources, they were vigilant in advocating for their needs. They turned their *self-agency* into an asset that resulted in homes that met both their physical needs and their lifestyle preferences.

**Dan: Tenacity and $5,000.** Dan had everything in place before the accident that left him paralyzed from the neck down—extensive insurance coverage on his boat and a large umbrella policy on the house. Unfortunately, as he put it "...you can't sue yourself...so I ended up with $5,000 and that is it." What this means is that although Dan had sufficient liability coverage extending to his personal property, this coverage is activated only if someone else—not the homeowner—is injured on the property insured.
Fortunately, his experience as a pipe fitter before the accident enabled him to act as his own home modification consultant—“I [built] and fabricated stuff for twenty years—If we [came] up against something…we would try to figure it out”.

Like Dave and Elaine, Dan’s family and friends turned out to be his biggest asset aside from his own expertise. This was especially important financially as he was now permanently disabled and without any insurance coverage to lessen the financial burden. “We went from a two income family and I was the major breadwinner and to going down to one income and the bills ran up…so, [it was] very worrisome, extremely tough”. Fortunately, friends and family assisted them financially by holding a benefit to raise money for some of the needed home modifications. In addition, his wife’s employer also provided some financial support.

However, financial support was only one part of the equation. Designing and building the modifications can be an intimidating task, especially for someone like Dan who faces physical challenges that impede his ability to both design and fabricate the necessary changes. Fortunately his building experience in addition to an adapted computer allowed him to plan and design several of the modifications to his home.

In addition to the modifications, it became apparent that Dan would require assistance with his personal care. His wife worked full-time and because of the lack of insurance coverage, there was very little money to devote to a personal care attendant. So, Dan and his wife created a resourceful solution to a potentially serious problem.

“…it became obvious that…with just me and my wife here…she’s not going to be able to do my care. And this is a long-term deal, so what we did, we didn’t have the cash…at the time to pay out for all these aides and everything and the
insurance will only cover so much... [so] I took the basement and turned it into a two-bedroom apartment".

Dan and his wife made arrangements with a young couple that included the semi-furnished two-bedroom apartment they created in the basement along with free utilities each month in exchange for a pre-set amount of aide care per week in addition to performing other household responsibilities.

Dan’s ingenuity and drive resulted in other creative solutions to accommodate his disability as well. He had retained some shoulder flexion and tenodesis on his left side, which enabled him to use a pointer to type and control switches. His remaining physical ability and the pointer made it feasible for him to install an environmental control unit (ECU) to enhance his independence. However, these units are very expensive, and without insurance to mitigate the cost, they are financially out reach for most people. Dan’s solution was simple but effective.

"...there were times when I was seriously looking at it [a commercially made ECU] and I’m thinking, do I need to spend three, four, five, six thousand dollars or whatever for all this stuff when I can find a TV with a remote control in it? Do I need—I mean my stereo’s got a remote control on it”.

For Dan the obvious solution was to run as many household appliances as possible by remote. The outcome was similar to an ECU at a fraction of the cost. In addition, he connected everything through his computer, so one click by his wife or his personal aide activates the system and he is “...set for the day".
Actually executing the modifications to the home required some outside expertise. A nearby rehabilitation hospital provided Dan with some recommendations for builders, but they were either *too busy or too expensive*.

"...those people tended to be busy or you know, their time that they could get to us was pushed out so far...in some cases they realized they've got a captive audience and the prices are a little bit out of line where I know that I can go someplace else and get them better. Because most of the time they think they're dealing with insurance money”.

This forced Dan to look 'outside' the health care system to find competent builders to execute the plans he had developed to modify his home. For Dan, the obvious obstacle was money, because—"...you can build anything, it’s getting the financing to do it”.

Steve:  *Money talks*. Steve’s condition, a progressive muscle disease, also limited his insurance options. Fortunately, his full-time position as a vocational counselor and as the owner/manager of his own business enabled him to privately finance construction on a new home. When asked if he had any assistance with the design of his home, his answer reflected the same type of independence and determination displayed by Dan.

"I basically knew what I wanted. I looked at the model and just eliminated one of the bedrooms to make my hallways bigger and the bathroom bigger—you know, I basically designed it myself”.

Unfortunately, realizing his goal of owning a home that both he and his family could live in was often frustrating. The builder in particular was initially reluctant to understand or assist a customer who required any deviation from the conventional home plan. First, it was extremely important to Steve for his house to look like any other
house in the neighborhood—in other words, without a ramp. The only way to build an accessible home without a ramp [i.e., ‘threshold-free’] is to build the house on a grade. The builder was initially unwilling to accommodate Steve’s request and tried to use his inexperience in working with wheelchair users as a justification for his inability to construct a threshold-free home.

However, Steve’s insistence and his fervent determination to be valued like any other potential customer eventually won out.

“...I faced objections from the builder on how it’s going to be, you know and how [they] can’t make the house look like [it’s] without a ramp...My answer was if I’m paying for it and I’m telling you how to do it, you do it. If you don’t want to do it, somebody else will. And you know, it was done to my satisfaction and I’m very happy with it”.

The builder’s inaccessible model home/office, while more of an inconvenience than an obstacle, was another indication of his reluctance to accommodate customers with disabilities.

“You know, they build a house and then they just use that house as an office...I basically did the $150,000 loan on the sidewalk. That’s where I negotiated my deal, and you know that didn’t sit very well with me”.

Steve also points out that accommodating customers with special needs doesn’t have to be inconvenient or expensive.

“...they could afford to get a ramp...just maybe a temporary one, portable one...You know, it’s not expensive. I have one in my van right now you can buy
for five, six hundred dollars... you [can go] anywhere you want... They don’t take that into consideration”.

Bottom line for Steve, in his words was “…the only way that they understood is when they saw that I was able to pay for what I want”.

So why tolerate a builder that wasn’t motivated to understand his needs? Simply put, Steve liked the neighborhood and the basic home model was congruent to his family’s needs. He was unwilling to settle for anything less just because his needs were different and the dealer was reluctant to cooperate. Steve’s self-agency—his ability to advocate for his own needs—made the builder’s attitude more of an outrage than a show-stopper.

**Client Perceptions of Occupational Therapy’s Role**

This next section explores another important theme to emerge: the participants’ perceptions of occupational therapy’s role in the home modification process. Christiansen and Baum (1997) state that the goal of occupational therapy intervention is to use a collection of strategies that encourages each person to develop or use the resources available to him or her to enhance their ability to successfully perform the meaningful and necessary occupations in their lives. They emphasized occupational therapy’s partnership with clients—“...occupational therapy almost never does things to people; it more frequently does things with people…”(p. 49).

Christiansen and Baum also emphasized that occupational performance is always influenced by the characteristics of the environment in which it occurs. Therefore, the environment is an intrinsic part of occupational performance and hence, a vital part of occupational therapy’s scope of practice.
How did the six participant’s experience occupational therapy’s role in the home modification process? The next section details two themes that emerged from exploring this question. These themes are: occupational therapy as absent, and occupational therapy as uni-disciplinary in the home modification process.

Theme 2: Occupational Therapy as Absent

Several participants specifically stated that occupational therapists didn’t play an active advisory role during the modification or building process. Steve independently financed the construction of his new home and consequently acted as his own advisor during the process of negotiation, choosing, and designing his new home.

When Tom and Denise built their new home, the occupational therapist was very helpful with activities of daily living (ADL) retraining, but didn’t consult on the home design or any specific structural modifications conducive to accessibility. Like Steve, Tom and Denise also independently financed their home without any assistance from insurance. As mentioned in the mentoring section, they identified their builder as the person whom they consulted on all design elements and who customized their home according to Tom’s specific needs.

For John, the mobile home salesman was the expert that guided his selection of an optimal living environment. This conversation between John and myself clearly articulates his perception of the occupational therapist as environmental expert.

Researcher: “...did they [the occupational therapist] do any kind of home evaluation or consultation with you...?

John: “...not at [the hospital]. It was at [the rehabilitation center]...the occupational therapist I was seeing... She talked to me about setting up a home
and what I needed. She found out quickly I was seeing a guy [the mobile home salesman]...at [the mobile home dealership] and [he] pretty much had the whole situation covered”.

Researcher: “So you already had started handling it before [the occupational therapist] had even talked to you?”

John: “Yes.”

Researcher: “So if she hadn’t of talked to you it wouldn’t have made any difference?”

John: “...not really. Because [the mobile home salesman] educated me just as much as what she did.”

Researcher: “Maybe more?”

John: “Yeah, I’d say more.”

It is interesting to note that in these first two situations—Steve’s and Tom and Elaine’s—Michigan No-Fault Automobile Insurance was not involved. Each of these participants had to finance their homes on their own and both went through the process without any help from the health care community. Dan also falls into this category. The other participants had the opportunity to finance their homes and/or modifications through the insurance coverage mandated by Michigan No-Fault coverage. This suggests a possible correlation between cases involving and the presence of an occupational therapist as well as other members of the rehabilitation team. In other words, the absence of Michigan No-Fault coverage seems to remove occupational therapists from the home.

This potential correlation between third party reimbursement and occupational therapy services begs the question has occupational therapy become overly dependent on
the health care system and insurance reimbursement to provide opportunities to intervene
at the environmental level. And, as evidenced by Steve, Dan, and Tom and Elaine's
situations, there may be a number of people who would benefit from modifications to
their home that instead are caught between the need for occupational therapy services and
their available financial resources.

Theme 3: Occupational Therapy as Uni-Disciplinary

The participants identified the rehabilitation team in general but not occupational
therapists specifically as fulfilling four major roles during the process of modifying or
building a new home environment. Those roles included home evaluator (performing
home evaluations), acting as a community referral source (providing participants with
names of community organizations and builders who could possibly assist them in
modifying their home), home modification advisor (making design suggestions and
recommending specific structural modifications), and claims administrator (acting as the
liaison between the participants and the insurance company/case manager).

More significant than the specific roles that emerged was the participant's
experience of the rehabilitation team as uni-disciplinary. When integrated into the larger
theme of the client's perception of occupational therapy's role in the home modification
process, this theme does provide a plausible rationale for occupational therapy's lack of
influence.

The perception of the rehabilitation team as uni-disciplinary wasn't directly stated
by any of the interviewees. However, during data analysis, it became apparent that when
the participants were asked questions about which member of the team performed a
certain service (home evaluations, for example) they often didn't identify that person by
profession. Instead, if the participant was asked ‘who did your home evaluation?’ they often replied by saying, ‘XYZ [hospital, rehabilitation facility] came out and did the evaluation’.

In other words, the nature of their responses suggested that the participants had difficulty distinguishing between the various health care professionals that were involved in facilitating their transition from the health care facility to their homes. The exception to this phenomenon was their view of the case manager. Most of the participants were readily able to both identify the case manager by his or her profession and to describe the role he or she performed in the modification process. In fact, the case manager was described by nearly all of the participants as actively involved in this process.

Because this uni-disciplinary theme was ubiquitous throughout the participant narratives, I will address it in each of the following sections on identified roles rather than attempt to represent it as a distinct and unrelated phenomenon. Integrating this theme into each of the perceived roles is justified because it was only when the participants began to talk about the rehabilitation team and their roles that the blending of professional responsibilities became apparent.

**Home evaluator.** The role of home evaluator was probably the most common role identified when the participants were asked about occupational therapy’s involvement. This role typically involved the occupational therapist and occasionally the physical therapist and a case manager (often a registered nurse or social worker), visiting the home in person and evaluating it for accessibility. In my clinical and educational experience, the format for a home evaluation is typically developed from a textbook and then altered by the health care facility to meet their guidelines for evaluating the home environment.
The goal of this evaluation is to make recommendations on the structural changes (although in my experience, the evaluation seldom requires a structural analysis), assistive technology, and equipment necessary for the participant to function safely in the home environment. This goal is usually achieved by using several criteria. The most common criteria included measuring various physical aspects of the home (e.g., doorframe widths, the distance between the bed and the floor, threshold height), assessing the need for two accessible exits from the home, and evaluating bathroom accessibility. In fact, the two most common recommendations reported by the participants were the need for a second exit for emergencies and modifications to enhance bathroom accessibility.

In most cases, this evaluation had to be completed and the changes in place before the facility approved the participant's discharge home. Three participants—Donna and Craig, Dave and Elaine, and Tom and Denise—reported that a home evaluation was performed before they were allowed to go home (In Tom's case, it was required before he was allowed to live in his parent's home).

As stated above, there were also similarities between participants in the type of recommendations made. Both the home evaluation 'team' (an OT, PT, and RN) involved with Donna and Craig and the 'advisers' assisting Dave and Elaine recommended a second exit out of their respective homes. In addition, Dave and Elaine's 'advisors' also made suggestions for altering the structure of their home to accommodate Dave's wheelchair. However, in Dave and Elaine's case, it was unclear who was responsible for either the exit or the structural suggestions. Elaine referred most frequently to the case manager when discussing their experience with home evaluations. She also implied that
an OT might have evaluated the home, although OT involvement in the process was not clearly stated.

Two of the families also indicated that each of their respective therapists/rehab-team/advisers were instrumental in recommending adaptive equipment and assistive technology additions to enhance home accessibility. Donna indicated that her 'therapy team' recommended bathroom equipment in addition to a stacking washer/dryer. While Donna and Craig were able to identify the three distinct professions involved in evaluating their home, it was unclear whom, if anyone was most instrumental in the process.

Dan indicated that “…they headed me in the right direction to get the door opener and they helped me get the voice activation for the computer”. In Dan’s case, ‘they’ indicated someone from the outpatient rehabilitation facility—presumably an OT. However, the professional identity of this person isn’t conclusive, as Dan didn’t specifically distinguish this person by profession. Tom’s wife was the only participant to specifically report that an occupational therapist performed the home evaluation and advised his parents to add on an additional bathroom and bedroom to accommodate his need for a wheelchair.

Two conclusions can be drawn from the participant’s perception of OT’s role as a home evaluator. First, occupational therapy’s professional role isn’t clearly apparent—the participants are often unable to distinctly identify occupational therapists by profession when asked to describe who from the health care field was involved in evaluating their home for accessibility. Secondly, when occupational therapists are
identified, their role appears primarily technical—they are characterized as experts in measurement, emergency exits, bathrooms and assistive technology.

**Community referral source.** Three participants reported referrals to two types of outside resources as part of the advising process. The outside resources most commonly listed were community agencies and/or builders. Initially, I assumed that occupational therapists had made these referrals. My assumption was based upon the premise that as indicated previously, OT's are expected to intervene at any or all of the three levels of occupational performance (Law, et.al., 1997; Christiansen & Baum, 1997) and that referrals to outside agencies are one facet of the community environment. However, upon closer analysis of the interviews, I discovered that these referrals were either made by other members of the rehabilitation team or that the source of the referrals was unclear.

In spite of OT’s absence from this process, I decided to include this particular role category for two reasons. First, it is important to understand who and what participants’ experience as community versus health-care related resources. Secondly, if we as occupational therapists aren’t filling participant’s expressed need for competent home modification expertise, it is vital that we understand who is filling that gap.

Both Dave and Elaine and Dan reported that they were informed of outside agencies that offered financial assistance and/or design advice. In Dan’s situation, his case manager told him about a state-sponsored rehabilitation organization that Dan identified as the most financially helpful community agency.

“...as far as government and organizations, [this agency] has been more that fair with me...they will help you with adaptations to your home, they will help you with retraining yourself, going back to school [and] they’ll help you with
transportation or modifications to [your] vehicle so that you can drive... I found
that they normally are not going to go in and pick up the whole tab, but they’re
going to require you to make an effort because they have limited funds and try to
spread them around, but if you work with them... they’re a pretty good
organization”.

Dave’s wife, Elaine indicated that a recreation therapist discussed community
resources with both of them. However, Elaine reported that she didn’t use any of the
recommended community agencies. She felt that their combination of family expertise
and Michigan No-Fault funding made outside resources unnecessary.

In addition to community referrals, Dan indicated that the outpatient rehabilitation
facility he utilized also recommended several contractors qualified to complete the
necessary home modifications. It is interesting to note that Dan didn’t identify any
particular professional when discussing this referral—he simply reported that ‘XYZ’
[rehab facility] gave him the names of a few contractors.

Aside from the lack of an identifiable source for the referrals, none of the
recommended contractors were able to assist Dan in modifying his home anyway.
“...those people tended to be busy or you know, their time that they could get to us was
pushed out so far... in some cases they realized they’ve got a captive audience and the
prices are a little bit out of line where I know that I can go someplace else and get them
better. Because most of the time they think they’re dealing with insurance money”.

As mentioned in the section on participant characteristics, Craig wasn’t able to
actively participate in finding a builder to modify his home. Consequently, his parents
decided to use a builder recommended through their insurance company. According to
Craig, the insurance company frequently referred this builder to clients due to their experience in building for accessibility. Again, it is unclear whether the specific person making the recommendation was a case manager or agent, however what is clear is that it was not an occupational therapist.

**Home modification advisor.** Both Donna and Craig and Dave and Elaine indicated that they were advised about the specific structural modifications needed to make their house wheelchair accessible. In Donna and Craig’s case, the OT, PT, and the case manager evaluated their home as a team before making recommendations to the insurance company and the builder. In is not clear whom, if anyone from this team acted as the primary contact for either the family or the builder.

Dave’s case manager was also involved in making remodeling recommendations for their original home. According to Elaine,

“...the person from our insurance company that was in charge of our case [case manager] came to our other house and wanted to walk through and said she was going to draw up an occupation plan—you know, to go ahead and rip that one [their house] apart and redo it. So basically she got the ball rolling…”

Afterwards, the insurance company and rehabilitation hospital therapy team created several floor plans before her brother became involved. In addition, a home evaluation was also performed—presumably by an occupational therapist who also made suggestions for interior modifications.

Again, it is not at all clear from listening to the interviews exactly which professional was instrumental in making suggestions for structurally modifying their existing homes. In Donna and Craig’s case, it appears that three members of Craig’s
rehabilitation team collaborated on the recommendations, however how this was done is uncertain. With Dave and Elaine, it seems that the case manager was the person that initiated the structural modification process. However, Elaine was not certain which member of the team performed the home evaluation or how the OT was involved in drawing up plans or making suggestions to remodel their existing home.

Claims adviser. One participant specifically stated that the rehabilitation hospital was instrumental in guiding them through the paperwork and building specifications required for discharge to his new home. Again, this may not be a traditional OT role; however, this role was specifically mentioned when Dave and Elaine were asked about how the health care team (as opposed to builders or family members) assisted them in the home modification process.

The role of claims adviser typically involves managing the financial aspects of the case in addition to ensuring that the appropriate criteria is met for justification of services and coverage by the insurance company. Dave and Elaine indicated that the rehabilitation facility played an active role in this process. Elaine relates that “...they’re [the rehabilitation hospital] the ones that gave me all the paperwork...told [me] what all the specifications were that were required and then they sat with us and went through it all”.

Dave and Elaine’s response to this query continues the theme of perceiving OT’s as a general and obscure part of a larger, hospital-focused uni-disciplinary bureaucracy.

The next section will describe what the participants felt they needed from those involved in the process compared to what they received in the way of guidance and expertise.
"They Didn’t Understand What Was Needed": Participant Criticisms

At the beginning of the section on Client Perceptions of Occupational Therapy’s Role, I made the case for the inclusion of occupational therapy as an integral part of the home modification process. In addition, Law (1996) and Christiansen and Baum (1997) both justify occupational therapy’s use of the environment as an intervention tool.

However, most of the participants had specific criticisms and suggestions in regards to the rehabilitation team’s role (and occupational therapy’s role by association) in the home modification process. These complaints comprise three emerging themes:

a.) ineffective execution of environmental interventions, b.) inadequate knowledge of applicable laws, standards and codes and c.) a disability-focused versus client-centered perspective. After discussing the participant’s specific criticisms, I will detail the specific advice offered by the participants when they were asked what could be done to help OT’s and others improve their execution of services in the home modification process.

Theme 4: Ineffective Execution of Environmental Interventions

When Donna and Craig’s home was modified, the rehabilitation team (an OT, PT, and case manager) focused on Craig who was recovering from a motorcycle accident. At the time, Craig’s condition was nearly identical to Donna’s—he was paraplegic, used a manual wheelchair and was not expected to walk again. After the remodeling was completed however, Craig regained his ability to walk. The remodeling effort was not wasted, however—Donna’s condition was so similar to Craig’s previous abilities, that the home should have been ideal for her needs.

However, in spite of the similarities of their conditions and the compatible focus on the modifications, several important household areas and tasks remained inaccessible
to Donna. First, the stacking washer/dryer recommended by the home evaluation team had a back control panel that Donna was unable to reach. In addition, the top loading feature of the washer necessitated that dryer being elevated five inches, making it impossible for Donna to retrieve the clothes from the dryer without Craig’s help.

Secondly, the cupboard and the baseboard from beneath the kitchen sink hadn’t been removed, making it completely inaccessible for a wheelchair user. The oven was no better as it had a conventional door with a bottom hinge, making it not only awkward but also dangerous to try to lift something out of it from a wheelchair. Finally, the refrigerator had a top freezer compartment that Donna wasn’t able to reach and the kitchen cupboards were also too high for her to navigate.

These omissions may initially seem justified, as the home was not specifically modified for Donna’s needs. However, at the time of the remodel, Craig’s condition was nearly identical to Donna’s and he was going to live in the home alone. As Donna explains,

“...[by] the same token they didn’t take into consideration that at the same time they thought he was going to be in a wheelchair. You know, when they came in to make those modifications, probably he was going to be in a wheelchair also.”

When Craig’s condition and independence are considered, these oversights are less understandable.

Tom also had problems with getting around in his parent’s home after it was remodeled. He initially lived with his parents for approximately two years before marrying and building a new accessible home with his wife Denise. According to Denise, an occupational therapist did perform an evaluation of his parent’s home and
made two recommendations: the addition of an extra bath and a bedroom for Tom. However, even after the additions, accessibility remained a problem. His wife recounts that poor traffic flow and furniture placement in the bedroom limited his ability to safely navigate to both his bed and the bathroom—neither traffic flow nor an accessible floor plan was addressed by the OT.

The problem, as Denise saw it was follow-up.

"She [the OT] came out to their house initially, but no one came in afterwards. No one did a follow-up visit... that was something they [his parents] could really have used help with because when it was blank... when there was no furniture in there he could have gotten through really easy... I think his parents didn’t understand. I think they had never had anyone in their family in a wheelchair, so I don’t think that they completely understood what was needed."

Denise’s response suggests that occupational therapy’s job was not finished after the home evaluation and/or modifications were complete. Clients continue to require assistance with environmental factors such as furniture placement, traffic flow, and equipment needs—problems and needs that may only appear after a person has settled into their new environment.

Theme 5: Inadequate Knowledge of Applicable Laws, Standards, and Codes

Donna and Craig and Dave and Elaine described modification recommendations that were both structurally unfeasible and aesthetically unattractive. When a member of the home evaluation team suggested tearing out a kitchen wall to install a second exit, Craig didn’t take the recommendation seriously. He ignored the recommendation because the placement would have been inconvenient and it wasn’t compatible with the
existing floor plan. Instead, he chose to build a deck and a ramp off of an existing sliding glass door. This was more practical as it not only provided a second exit out of the home but also allowed access to the backyard and didn’t necessitate tearing out a wall.

Elaine, Dave’s wife, recalls the efforts of the therapists, case manager and insurance company to create an ‘occupation plan’ for their first home to accommodate his remaining abilities. The suggested plan was similar to Donna and Craig’s situation as the results would also have been unworkable and unattractive.

“I’m not so sure that the therapists at [the hospital] were that knowledgeable...because if you’re not a builder, and you don’t know what walls you can take out and what walls you can’t...it gets a little silly. And you know there were a few floor plans drawn up between the insurance company and [the hospital] that were just, silly. You know, looked nice on paper and everything, but wasn’t going to work, and made our house look really stupid both inside and outside.”

Both experiences suggest that the therapists, case managers, and insurance companies focused on creating an environment to accommodate a wheelchair to the exclusion of appearance and workability. Unfortunately, this approach was made worse by their ignorance of building codes and basic construction standards.

**Theme 6: Disability-Focused Versus Client-Centered Perspective**

In addition to coping with unfeasible floor plans, Dave’s wife Elaine was also faced with both a case manager and a therapist who addressed Dave’s disability in a manner that seemed to separate his condition from his family and their lifestyle, as well as from his roles and values. Elaine related to me her frustration with a case manager
who began to “bug” her about modifying their home before Dave was even discharged from intensive care. His medical status at that time remained guarded and Elaine was at the hospital fifteen hours a day. At that point, Elaine recalls that she didn’t know if he was even going to “make it”. This experience was so negative that she requested a new case manager.

Her experience with the person who performed the initial home evaluation (presumably an occupational therapists) was also negative. During the walk-through of their original home, the therapist told her that they had to “knock out” walls and that all of the furniture that she had recently purchased “had to go” to accommodate Dave’s disability. Their home, it’s style and their possessions were a source of significant meaning for Elaine, and she recalls being “insulted and hurt” by the therapist’s insensitivity.

“It’s Not the Wheelchair”: Participant Advice to Occupational Therapists

When participants were asked about the advice they would give to occupational therapists and other rehabilitation professionals, they again emphasized the importance of a client-centered approach. This involved treating each client as an individual instead of applying the same strategy and techniques to each situation. In other words, the participants discouraged the occupational therapists from using a template or cookie cutter approach when recommending modifications to the home environment.

When Dan was asked for suggestions his response clearly articulated the problem with a template approach.

“...that’s a tough question. I really don’t know off the top of my head. With all the people that I’ve been through rehab with and the hospital and I’ve met you
know, in school, and the different functions and stuff, every case is so unique that it's really hard to tell. You almost have to look at it case by case.”

Steve’s response also supported a more individualized approach.

“...I've only been in a wheelchair for a few years and my thinking process is it matters to them [the user]... You know, I don't need a lot of different things to make my life easier. Even though it does exist, it's all on the person who wants to use it.”

When asked how occupational therapists could support this type of approach, Steve strongly advocated for including the user in the design process.

“...depending on the environment you would like to create, get the people that...are going to use it. You know if you are trying to push the push-button doors, try to get somebody in a wheelchair....Don't put yourself [an able-bodied person] in a wheelchair because, when you put yourself in a wheelchair, you might be able to reach farther than I can. Or you might be able to...[support] yourself more than somebody in a wheelchair. It's not the wheelchair that's the problem...you need the individual who's going to use it [the modification]...”

Steve’s last statement—"it's not the wheelchair that's the problem"—clearly expresses that it is the individual and not the disability that is the most important focus for occupational therapists using environmental interventions.

So, what happens when an occupational therapist uses a standardized approach when recommending environmental modifications or equipment to individual clients?

Steve offers a humbling and perhaps, predictable response.
“When I first became disabled in a wheelchair, they showed me a lot of stuff that is still in my closet as it is… I used it for a while, but at the time they said ‘Oh you will need this… you have to have this.’ Because in my situation [for example] they give you something to put your socks on…. Those things can’t pull more than four ounces. And you know and I know that it takes more than four ounces to put your socks on.”

This statement suggests that a template approach may not only perpetuate equipment abandonment, but it also places an occupational therapist’s professional credibility at risk as well.

For Tom, the hazardous floor plan and overall poor accessibility in his parent’s home was also a result of ignoring his unique needs and abilities and recommending ‘standard’ modifications. His wife emphasizes that

“... you really have to take into consideration their needs more. And that was the thing we found with his parents. In a lot of ways, it was their desire to have the additional rooms—it wasn’t for Tom.”

When building their new home, Tom and his wife were insistent about designing the interior and exterior specifically to meet Tom’s needs, preferences, and abilities.

Dave and Elaine’s recommendation to occupational therapists was prompted by their perception of the team as inexperienced in the areas of environmental design and construction planning.

“... I would say to be knowledgeable and up to date with all of the information dealing with home modifications and things that would make it better and more accessible and a better quality of life for the person.”
This last phrase—*a better quality of life for the person*—suggests that the clients themselves have a different perception of what constitutes an accessible living environment. Again, the participant’s perception focuses more on their ability to *participate* in the environment and less on their *disability* and the resulting limitations.

For Steve, however, high technology is neither necessary nor sufficient to creating an environment that is conducive to participation. In fact, in his opinion, it can become a barrier to achieving functional independence.

“Sometimes, all you need is a stick to push a door knob...I’m not against technology, technology is wonderful. It’s just there’s sometimes something a lot easier—do it!

Finally, Tom’s wife suggests a subtle, but important facet of that occupational therapists need to include in their paradigm of an accessible environment—that people with disabilities are dynamic and constantly changing just like able-bodied individuals.

“I think from the beginning they [occupational therapists] would have to—it’s sort of hard to look into the future, [but] if they could look into the future and whether that person wants to be independent, because spending a lot of money to modify a home that’s not their own, and then they want to be out on their own—[a friend of Tom’s] was in the accident with Tom and he’s a quadraplegic. Now, they did all the home modifications to [his friend’s] parents’ home as well, and [now] he’s living in an apartment [by himself].”

Like his friend, Tom’s functional abilities and life situation also changed over time and he eventually moved out of his parent’s completely remodeled home. When he
and his wife built their new home, they designed it to accommodate Tom’s increasing independence.

"...for example...using the bathroom by himself—If [the builder] hadn’t put that [flower] box in there, he wouldn’t have been able to do it [use the toilet] with just the hand rail. So looking down the road at things they may be able to do in the future so that you’re not cutting yourself off because you don’t know. And I know that doctors don’t like to give any hope, but you really do have to have some thought that the person’s going to do some things.”

Theme 7: Environmental Meaning and the Home Environment

The final theme of environmental meaning may be the key to integrating the other five themes while at the same time bridging the gap between professional expectations and the client’s lived experience of occupational therapy’s involvement in the home modification process.

Participant responses suggested that the meaning a person ascribes to their environment was a subtle but significant factor in their choice of and satisfaction with home modifications. This section explores the theme of environmental meaning and investigates how this aspect of the built environment affects personal identity and thus influences a participant’s choice, opinion of, and satisfaction with their home modifications.

Several issues emerging from the interviews suggested that the environment and the meaning ascribed to it by individuals may be an inherent part of self-identity. As such, each participant’s self identity and the meaning they attached to their environment significantly influenced the home modification process. There were four primary issues
that emerged under this theme: a.) the interplay between the outside environment and self-identity, b.) the concept of a ‘normal’ environment as an expression of ‘self-normalcy’, c.) the connection between self-competency and the built environment, and the d.) environment as an inherent aspect of chosen roles and/or occupations.

The Outside Environment

Most of the occupational therapists involved in the home modification process focused on the interior home environment during home evaluations and when recommending changes. The only exception to this was the evaluation of exits out of the home for emergencies. However, several participants expressed the importance of accessing their immediate outdoor environment for reasons other than emergency situations.

When asked about a second exit for emergencies, Donna and Craig “...hadn’t really thought about it at all.” However, the need for an additional exit became important when Craig realized she had never seen the backyard. “[Craig] took care of it right away once he realized I’d never seen the backyard because we’ve only got one way to get out.” For Donna and Craig, accessing their immediate outdoor environment was more a quality of life issue than a safety issue.

When Dan was asked if there were any activities that remained limited to him due to his environment, he also expressed the desire to access the outdoors.

“I’d like to be able to get down by the river and enjoy the river more but my wheelchair isn’t—won’t handle it... it won’t handle the area and the inclines.”

In spite of this limitation, Dan found other ways to maintain his connection with the outdoors. One alternative to physically accessing the backyard and the river is his ability
to view both via a large deck that was built on to the back of the house and the extension that provides access from his bedroom. In addition, a wall of large, floor-length windows provides a full view of the backyard from the inside of the house.

Dave and Elaine specifically designed their house so Dave would "...feel like he was outside even though he was inside...” The living area is large and open with a vaulted ceiling, and the ceiling includes several skylights so Dave can look up at the sky when reclining his wheelchair for pressure relief. They also ensured that he had ready access to the backyard by ramping a sidewalk from the front to the backyard and including a large cement courtyard so he could feel involved in backyard activities.

An environmental control unit (ECU) also provides additional independence for accessing the outside. Elaine relates that

"...[Dave] uses it more—in the summer...for going in and out of the house. He'll just come and go in the summer and then, you know if I'm outside, he'll come out by me and if he gets cold, he comes back in by himself...”

Again, accessing the outside was expressed more as a preference for maintaining his outdoor life prior to his accident than as a safety measure for emergencies.

Steve also identified accessing his backyard as a priority. In fact, the only change he would make to his home is the addition of a walkout basement. When asked if accessing the outside was important to him, his answer was unambiguous—"...sure, I don't stay in the house.” Yet, the primary focus of home evaluations is the interior of the house.
The ‘Normal’ Environment

The concept of normalcy was also a recurring theme when describing the appearance and design of the home environment. To Dave’s wife Elaine, designing the outside of their house so it looked ‘normal’ was inherent in identifying their house as a home. Several design features of the home were symbolic of normalcy. First, their home was built without a threshold. This was accomplished by building their home on a grade rather than using ramps for inside access. When I commented on the home’s attractive outside appearance, Elaine’s reply that “…everything is ramped but unseen…” indicated the importance of concealing any culturally unconventional feature, such as wheelchair ramps.

The interior layout was also important in maintaining a ‘normal’ look. This meant that the house was designed so that all of Dave’s equipment and special needs would be confined to one side of the house. “…I didn’t want my house to look like an institution, I wanted it to look like a home…” Privacy was another symbol of normalcy for Dave and Elaine. Dave requires maximum assistance with his personal hygiene, necessitating a visit from a home health aide two times per day. The meaning they ascribed to a normal home did not include a stranger walking through their entire house twice a day. Locating Dave’s work room, bathroom, equipment and bedroom on one side of the house limited the aide’s access thus preserving the privacy that was an inherent part of living a ‘normal’ life in a ‘normal’ home environment.

When Steve designed his home, a ‘normal’ looking exterior was a top priority. This meant the absence of traditional ramps.
"...I have designed it in such a way that we don't have ramps—or anything. If you look at the house from the outside, you would not know what's going on."
The last phrase *you would not know what's going on* suggests a desire to avoid the stigma that many people with disabilities face—the stigma of being *different*.

When Steve continues the description of his home, the meaning he ascribes to the concept of a 'normal' looking exterior becomes apparent.

"...there's no steps. What I did is I arranged the whole front yard...The reason I did that is I didn't want my house to look different than any other in the neighborhood. Usually people tend to...if there's a seller...if there's a buyer coming into a neighborhood they might see a wooden ramp or whatever it is around the outside and they might have...people are kind of funny about this kind of stuff. So I don't want to...it's not that it's offending anybody, it's just that I didn't want to look different. That's all."

But perhaps ramps do offend us. Or as Steve implies, perhaps our culture is offended by what looks different or *abnormal*. If it is only the external appearance of an inanimate object that is offensive, then what does that have to do with us as alive, animated people who are separate from our environment? That is, unless our environment really is a part of who we are—an inseparable part of our unique self. If that is the case, then an abnormal environment may imply that we too are abnormal and thus offensive as well.

For Tom and Denise, living in a 'normal' home meant building an accessible home without the accessible look.
Denise: "...he [the builder] made everything very accessible for Tom and I was worried about it looking too...too...

Interviewer: "...looking like you lived in a modified home?"

Denise: "...exactly. And he said 'nope, nope, we can get around it'. So he added little special touches...and even the ramps...they don't really look...like ramps."

Interviewer: "...like a porch..."

Denise: "...yeah."

When asked for specifics, Denise elaborated on what it meant to live in a normal home.

Researcher: "...so aesthetics were important to you."

Denise: "It was, and I think it was important to Tom too—that he didn’t want to be told that he’d have, you know, whatever—things hanging out over, or you know, grab bars everywhere. You knew that [he] didn’t want that. And we also considered if we ever wanted to sell it."

Researcher: "Resale was important to you?"

Denise: "Resale—yeah. We didn’t want it to be just one type of buyer. We didn’t want that. This house—I think anyone could come in and buy and have kids or whatever."

For Tom and his family, the meaning of normalcy was tied to both identity and practicality. Tom wanted to live in an environment that looked and therefore ‘felt’ normal while also preserving their option to change environments in the future.

However, Denise later made a comment that suggested a normal looking environment was also a part of their identity. She indicated that Tom "...really wanted normalcy..."
[so] he could bring people in and be proud of his house.” Be proud of his house. This statement implies that a house that looks like a “modified home” is not normal and therefore isn’t something to be proud of. Like Steve, this suggests that a home environment that contains obvious built objects to accommodate a disability is different and therefore not a source of pride for the owner but a source of shame. And that shame becomes a part of that person’s identity.

**Competency and the Built Environment**

Closely related to the concept of normalcy was the idea that the nature of the built environment was also an indication of competency. Webster’s Encyclopedic Unabridged Dictionary (1996) defines competency as “having suitable or sufficient skill, knowledge, or experience for some purpose.” In the case of this study, competency relates to a person’s ability or ‘skill’ to successfully interact with an environment designed for able-bodied individuals. Steve clearly expresses this cultural connection between environment and competency.

In spite of the pervasiveness of his disability, Steve is determined to do as much as possible without relying on special equipment or modifications. When asked about the equipment he used that enabled him to maintain his chosen activities, his answer revealed his determination to remain competent without a lot of special help.

“…There’s no modification [on my computer]…I still drive my car with modifications. I still function my business because of, I guess, my desire to do it if nothing else. But I guess I wanted to do it—I guess it was my desire to lead a productive life and that’s what’s pushing me.”
Steve is also proud of the fact that in spite of his loss of muscle function, he doesn’t require an aide or a lot of special equipment when taking a shower. In fact, his adamant refusal to use equipment prompted this researcher to pose a question suggested by Gitlin, Luborsky, Schemm, & Burgh (as cited in Corcoran & Gitlin, 1997): Do therapists create disabling environments? His answer: “Absolutely.” He elaborated by adding that

“...there’s a lot of things I could sacrifice. I could use a voice-activated keyboard. I don’t want to do that. I type slow, but that’s the only way I type, whether I’m able or disabled. I could use it but I don’t want to use it. I have my hands and fingers, I should be able to use them and I will use them.”

In the final part of the interview, Steve succinctly expressed his desire to maintain his identity as a strong, able and competent person by maintaining a modification-free environment.

Researcher: “...sounds like you’re really frustrated at some of the experts when you refuse to act like a disabled person.”

Steve: “You’re right, you’re right”

Researcher: “...and I say good for you.”

Steve: “...you’re right, you’re right. I guess that’s the bottom line.”

Researcher: “...and that’s probably what’s kept you as independent as you are.”

Steve: “I would like to think so. I would like to think my attitude is what’s keeping me going. I do not present myself as a weak individual, which I’m not. I’m not a weak individual at all.”
Environment and Occupational Roles

Five of the six participants talked about specific objects or characteristics in their environment when describing their participation in their chosen occupations or roles. Dan used an adapted personal computer as an integral part of his drafting and design business. When asked if he could rank home modifications and adaptive equipment in order of importance, he was reluctant to choose either category.

“Well, I mean like my computer—I guess I could get by without it, you know, I could get by without the TV...[but] I’d be bored to death...they’re a part of my everyday life now.”

This reluctance suggests that while neither the computer nor his audiovisual system is vital to his physical health, they are important to his quality of life and his role as a draftsman and a business-owner.

In Dave’s case, the role of father remains an important part of his life. So much so, that the dining area was designed specifically so he could eat with his family during the evening meal. “This counter here was specially built around his wheelchair and to the right height so he can pull up there to eat meals or...read the newspaper.” They also ensured that the dining room table would accommodate Dave’s wheelchair. His wife, Elaine describes a typical evening—

Researcher: “You mentioned that the eating area was important.”

Elaine: “Yeah, we spend a lot of time there...”

Researcher: “…So you have a lot of family get-togethers or dinners?”
Elaine: “Oh we sure do...our daughter cuts hair downstairs, so they just kind of show up. Almost, I would say, five nights out of seven we...one of our kids is home.”

Researcher: “You just can’t get rid of those kids!”

Dave: “We’ve got two grandkids, so we get to see them.”

The role of competency and the environment so clearly depicted by Steve is also closely tied to his occupational identity. He implies that his desire to lead a productive life is what pushes him to run a business—a business that is not handicapped accessible. This apparent irony is actually congruent to his paradigm of himself as a person who limits his use of equipment and modifications because he is strong and competent.

Tom’s wife Denise pointed out that a person’s occupational roles change over time and that the environment must follow suit. As an example, when they first moved into their new home, Tom was showing progress, but continued to require maximum assistance during toileting. However, as his condition improved, he was able to increase his independence in this area with some environmental changes. Denise points out that “...if [the builder] hadn’t of put that [flower] box there, Tom wouldn’t have been able to do it with just the hand rail…” The addition of a modification suited to Tom’s changing abilities allowed him to transition from the role of disabled patient to a person who was able to participate in his own self-care.

When John was looking at mobile homes, an open floor plan and a bay window were extremely important features due to his chosen roles and occupation. When asked what he considered the most important room in the house, the open living room was his obvious choice.
“...I had to fit this [audio/visual system] stuff in here. To me, I had to fit it all in... 'cause I consider myself to be an audiophile. I wanted the perfect surroundings for it and I wanted it to sound real good. So... this floor plan worked out real good along with that bay window helped in the imaging.”

He also used the open living area as a studio to accommodate his home photography business.

In Chapter 5, I will continue to discuss the concept of environmental meaning and the home environment by using Csikszentmihalyi and Rochberg-Halton’s (1998) theory of domestic symbols and self-identity. Then, using this theory as a framework, I will expand the premise of environment as an inherent part of self-identity to explore possible connections and barriers that may influence the nature of occupational therapy’s use of the environment as a treatment modality.

Next, I will use this analysis of environment, meaning, and self-identity as a starting point for examining the implications for future occupational therapy practice and to offer several suggestions to enhance our performance in this area. Limitations inherent in this study as well as areas for further research will be also be discussed. Finally, I will conclude my exploration of consumer choice and satisfaction with home modifications with a discussion of self-agency as the common ground between occupational therapy intervention and a more client-centered approach.
CHAPTER 5
DISCUSSION AND IMPLICATIONS

Introduction

As stated in Chapter 1, the purpose of this study was to a.) Investigate consumer criteria for choosing home modifications to accommodate or compensate for a chronic disability and b.) Explore the satisfaction with existing modifications. However, it became apparent during the participant interviews that the criteria for choosing, using, and being satisfied with the home environment encompassed more than just the specific modifications, physical abilities of the participants or even the tangible physical environment itself. When the participants talked about their homes, they emphasized concepts such as normalcy, competency, their families, and even aesthetic features such as audio systems, decks, family dinners, and their ability to go outside.

These responses suggested that meaning might have been a subtle but significant aspect of the environment that significantly influenced choice and design. However, meaning is an abstract concept made more complex because it is intangible, unique to each individual, often ambiguous and even paradoxical. These qualities warrant further examination of how meaning is related to self-identity, environmental choice and satisfaction with the environment.

Environmental Meaning and Self-Identity

A home is perceived as a home because of the objects or possessions associated with it, both interior and exterior, and because it is itself an object. Csikszentimihalyi & Rochberg-Halton (1981) define objects as "...any bit of information that has a recognizable identity in consciousness, a pattern that has enough coherence, or internal
order, to evoke a consistent image or label. Such a unit of information might be called a sign. Using this perspective a symbol is a kind of sign—a sign defined as the representation of some object (a quality, physical thing, or idea) to some other interpreting sign.” (p. 14).

When a person interprets the objects or possessions associated with their home and even the home itself by evoking images, labels or other symbols, this suggests that the home and its possessions are imbued with symbolism or meaning beyond their tangible physical attributes. Many of the participants implied that the meaning they ascribed to their home environment significantly influenced their choice of modifications and their satisfaction with those modifications. In this study, objects included but were not limited to furniture, gardens, lawns, equipment, interior décor, audio/visual equipment, computers, and the rooms within the home as well as the home itself.

Corcoran & Gitlin (1997) emphasize that people everywhere design their environments to make a statement about themselves as individuals and as members of a distinct culture. However, it is evident from the participant responses in this study that occupational therapists and other members of the rehabilitation team addressed the home environment, the objects within it, and their clients as separate and distinct concepts and/or entities. If objects are so critical to our identities as unique individuals, then what is the consequence of treating objects and the people who choose and/or create them as separate and distinct? Georg Simmel (as cited in Csikszentimihalyi & Rochberb-Halton) as early as 1908 sensed a growing “dissonance” caused by the separation of the objective world (believed to be governed solely by mechanistic forces) from the individual. He
believed that as a result, “life becomes increasingly a technique rather than a process of cultivation” (p. 12).

Webster’s Encyclopedic Unabridged Dictionary (1996) defines cultivate as “…[promoting]…growth or development”; technique is defined as “…the body of specialized procedures and methods used in any specific field…technical skill; [the] ability to apply procedures or methods so as to effect a desired result.”

Using these definitions, when the participant’s expressed needs are analyzed against their perception of occupational therapy’s role in the home modification process, occupational therapists seem more like technicians than cultivators. In other words, occupational therapists and other health care professionals were focused on applying standard techniques, procedures and methods in the form of home evaluations, ‘occupation plans’, and measurements. They gave priority to these technical skills to the exclusion of recognizing the client as a unique person who was intimately connected with their environment. The result, as eloquently described by the six individuals interviewed, was a view of the rehabilitation team in general and occupational therapists by association as often superfluous and sometimes detrimental to the entire home modification process.

Treating the client as separate and distinct from their environment suggests a considerable gap between client need and professional service. What are the barriers that prevent occupational therapists from being cultivators of human ability and to instead act as technicians of prescribed methods and results? The next section analyzes this gap between client need and occupational therapy service in the area of environmental interventions.
Analyzing the Gap: Occupational Therapy Intervention vs. Client Need

The previous analyses of participant perceptions and occupational therapy's role in the home modification point to three general perspectives in occupational therapy that may impede a therapist's capacity to cultivate human ability through environmental intervention. These perspectives are: a.) therapists' view of time, b.) therapists' view of the environment and c.) therapists' view of the client.

Therapists' View of Time: Static vs. Dynamic

Participants in this study described therapists as working within a static view of time. This perspective was clearly articulated by Tom and Denise. When Tom was first discharged from rehabilitation to home, his parents were eager to provide him with the best environment to fit his needs. Unfortunately, they lacked guidance and instead created an environment more suited to the needs of a completely dependent and disabled individual. Tom's abilities subsequently improved and he expressed a desire to be independent and pursue a life apart from his parents. His parents were left with a large, modified home that didn't meet the needs of anyone in particular.

Donna also exemplified the dilemma of a changing person stuck inside an inflexible environment. At the time of the interview, she was six months pregnant. When the house was modified for Craig, neither the builder nor the therapy team considered that he might marry and start a family, let alone regain the ability to walk. In short, the team didn't consider that like able-bodied individuals, people with disabilities also experience the normal ebb and flow of life. This often includes buying a starter home and eventually moving to a larger home that can accommodate a growing family.
Likewise, Donna and Craig finally decided to sell their home and build a new one more congruent to both Donna’s needs and the needs of their growing family.

**Therapists’ View of the Environment: Material vs. Symbolic**

Participants in this study viewed their environment as more than simply a house and its personal effects. Instead, a home was seen as synonymous with their identities. Unfortunately, several of them indicated that the occupational therapists viewed their home as a structure primarily for personal care and emergencies. Most of the participants indicated that the therapists were vigilant about recommending bathroom modifications and a second exit. However, when it came to addressing the aesthetics, roles, and meaning synonymous with a home, the results were often inadequate at best and insulting at worst.

Dave and Elaine’s experience demonstrated how far the occupational therapist was from seeing their home as a source of meaning and identity. Elaine described her feelings of anger and hurt when she was told to “get rid” of all her new furniture to accommodate Dave’s disability. The floor plans created by the therapy team and the insurance company were another indication that their home was seen as nothing more than a structure to accommodate a disability. Elaine describes them as “silly”—they “looked nice on paper…but made our house look stupid, both inside and outside.”

The meaning that Elaine ascribed to their environment was evident when she described how she decorated the interior of the house. The wallpaper and molding were color coordinated and the furniture was also chosen to match the interior design. The outside of the house was professionally landscaped with flowers and bushes that were
expressly chosen to disguise the absence of steps as well as give the appearance of a “normal” home.

**Therapist’s View of the Client: Disabled Patient vs. Participating Adult**

The World Health Organization (WHO) recently revised its 1980 classification of impairments, disabilities, and handicaps to a classification of impairments, activities, and participation (WHO, 1980, 1997). Key to this change is the concept of participation rather than handicap. **Participation** refers to the transaction between the person and their environment as they perform an activity in daily life situations. It includes the context of performance as an inherent and essential part of a person’s ability to successfully engage in chosen activities within the environment. In other words, participation implies successfully bridging the gap between abilities and environment in order to engage in chosen activities.

Unfortunately, occupational therapy practice as it applies to environmental interventions continues to operate under a disability model. Using this model, the focus is on the client’s lack of ability—disability, as it were—rather than on maximizing their remaining abilities. This type of focus was prevalent in the participant’s description of occupational therapy’s role and their misunderstanding of their client’s desires and needs. The concepts of normalcy and competency as they related to environmental intervention also illustrate this conflict.

Steve’s acknowledgement that therapists often create disabling environments by recommending unnecessary equipment is an example of a disability perspective. His perception of himself as a “productive” person and “not weak” are related to his ability to participate successfully in his environment as a “normal” person. So, for Steve
participation, competency and normalcy mean acquiring only the minimum environmental modifications needed to successfully participate in his environment.

However, participation means something very different for Dave and Elaine. When asked if he would suffer a significant loss if he gave up his ECU, both Dave and his wife immediately pointed out a loss of independence. The ECU enables him to come in and out of the house independently and to stay at home alone if necessary. In other words, the ECU bridges the gap between an environment that requires him to be dependent and an environment that maximizes his ability to open the door, answer the telephone, and turn on the television and stereo.

Like Dave, Dan's ability to engage in his environment is also enhanced by environmental modifications. His previous construction and design expertise enabled him to build a central control unit utilizing remotes that is very similar to a commercially manufactured ECU. This system allows Dan to pursue his goal of becoming a self-employed draftsman and CAD operator as well as independently negotiating other aspects of his environment. Both Dan and Dave demonstrate that using a participation perspective allows occupational therapists to focus on a client's remaining abilities. This makes bridging the gap between dependence and independence feasible instead of hopeless.

Implications for Future Occupational Therapy Practice

These three perspectives involving clients and disability provide a template for creating important recommendations that can enhance future occupational therapy practice in the area of environmental interventions in general and home modifications in particular.
First, it is essential for OT’s to change their temporal view of their clients from one that is static to a view that is dynamic or changing over time. An individual’s developmental history does not end when he or she becomes disabled. On the contrary, each of the participants demonstrated a dynamic, changing life that included new experiences, events, and people—each of them was in continuous relationship and conversation with their environment.

To this end, it is imperative for OT’s to learn a client’s history, both past and present and to gain an understanding of a client’s self-perception and their goals. We need to build a partnership with our clients and their families by helping them to envision their future and to integrate that into our designs and modifications. The Occupational Therapy Guidelines for Client-Centered Practice in addition to Law et.al.’s Person-Environment-Occupation Model of Occupational Performance (Law et.al., 1996) provide an excellent framework for including the environment as a treatment modality.

Both of these frameworks can also be used to enrich and expand the approach of occupational therapy as a whole (Law, et.al., 1996). Including all three elements of occupational performance—person, environment and occupation—increases occupational therapy’s treatment repertoire and scope of enabling interventions that can be evoked to assist clients. When we understand that a person with a disability is a changing, growing entity, we can improve our ability to assist people in creating dynamic environments.

Secondly, if OT’s are to create not only dynamic but also meaningful environments, then an understanding of the environment as an inherently meaningful and identity-laden realm is also required. Csikszentimihalyi and Rochberg-Halton (1998) submit that man is to a large extent a reflection of the things with which he interacts.
This idea suggests that creating accessible environments encompass more than an extra bathroom and a second exit. It is essential for occupational therapists to work towards "normalizing" the design of our modifications as well as making them functional. This involves understanding a person’s life and how that life is expressed in his or her surroundings.

For example, John described himself as an "audiophile" or sound system expert, and a photographer. Accommodating these hobbies required that his environment be designed to optimally house a “state of the art” sound system and a photography studio. Neither one of these hobbies nor the modifications associated with them were necessary to his physical well being or the negotiability of his environment. However, they were so important to him and his self-perception, that he specifically designed his modular home around them. Occupational therapists must possess an understanding of how meaning influences individuality if we are to help create environments that affirm identity and motivate engagement.

Thirdly, it is imperative for OT’s to understand the potential paradox we create when we encourage environmental modifications, equipment, or adaptive technology to reduce the burden of disability. Twentieth century theologian Reinhold Neibuhr cautioned that within every act of good is the seed of evil that will undo it. “High-tech” may not facilitate independence as much as either “low-tech” or even “no-tech” at all. When applied to occupational therapy, this admonition reveals that the very thing we intend to mitigate—disability—can in fact be exacerbated by our good intentions.

Steve made this very clear when he agreed that OT’s can create disabling environments by recommending unnecessary equipment or modifications. Dave’s
experience indicated that the rehabilitation team’s exclusive focus on his disability resulted in both structurally and aesthetically unfeasible recommendations. Therefore, as occupational therapists we must be mindful that a person is more than their disability. Ignoring these facts risks both our professional credibility and our effectiveness as environmental experts.

Finally, the issue of technical expertise was a recurrent theme for all the participants. If occupational therapists are to include environmental interventions in their repertoire of treatment, then it is essential that we maintain a working knowledge of environmental design principles as well as remain up to date on the latest technology, equipment, laws, standards and codes related to accessible design.

Enhancing our technical expertise can be accomplished in a number of ways. Law, et al. (1996) suggests that the shift of health care into a community forum provides occupational therapists with the opportunity to link with and learn from other professional groups with person-environment interests. These groups can include builders, architects, psychologists, anthropologists, ergonomists and interior designers as well as other health care professionals. Secondly, there are numerous continuing education opportunities provided both by our professional organization as well as others. These opportunities include certification as a professional ergonomist, builders licensing classes, as well as materials for self-directed learning in assistive technology, home adaptation, and aging in place.

However, it is of primary importance to continually work towards and maintain a client-centered approach that encompasses the three levels of occupational performance while at the same time acquiring these needed technical skills. This client-centered
framework plays a crucial role in occupational therapy’s metamorphosis from technicians of prescribed methods and results to cultivators of human ability.

Finding the resources is easy. What is more difficult is to create an awareness of and excitement for the exceptional opportunity that occupational therapists have to fill in the currently unmet need for environmental design expertise. And with the increasing convergence of the aging and disabled populations combined with the desire to age in place (Liebig & Sheets, 1998), that need is only going to become greater. If we as occupational therapists don’t begin now to assert our presence in this growing industry, we risk losing it to other, equally qualified professions.

Study Limitations

Most of the study limitations were related to sample size, sample diversity and the geographic area. Only six participants were interviewed and females were under-represented—only one woman was interviewed. In addition, all participants were between the ages of 31 and 45. This excludes the experience of both children and older adults with modifying their home environments. The sample was also made up of predominantly white, middle class mid-western Americans. Only one minority was represented, and all participants expressed highly similar cultural backgrounds and preferences.

Finally, as stated in the techniques of data analysis section, time constraints prevented the development of a seventh and final construct. Although five of the six interviews were influenced by the previous interviews, participants weren’t given the opportunity to provide feedback after analysis of all interviews was completed. This
doesn’t necessarily negate the existing themes, but it may have impacted the depth of analysis and the development of other, related themes.

Suggestions for Further Research

I chose to use a qualitative format for this study for two of the four reasons outlined by Morse (1991). First, the concept of consumer criteria and satisfaction in regards to home modifications was immature due to a lack of theory or previous research. Secondly, due to the first reason, there was a need to further explore the phenomena and possibly develop theory related to consumer experiences with home modifications because of the absence of literature on the subject.

This study suggests that there are significant differences between the participant’s expressed needs in the area of environmental modifications and occupational therapy’s current approach to intervention in this area. With this in mind some possible areas for further research include:

- Repeating the study using a larger and more demographically diverse participant group.
- Surveying occupational therapists’ perceptions of their role in the home modification process.
- Conducting a separate study of builders, contractors, and/or architects on their perceptions of clients needing to modify their home environments due to a disability.
- Conducting a quantitative study by surveying consumers with existing modifications on their opinion of the most important modifications.
- Interviewing consumers without insurance about their experience modifying their homes.
- Investigating the relationship between environmental meaning, self-identity and choice of modifications.
- Investigate what and how occupational therapy students are being taught on the environment, accessibility and functional design/modifications.
Yerxa (1998) offers two views of occupational therapy's future—one sobering in its familiarity and the other a model for a thriving, sought-after professional service. The first describes occupational therapists as rehabilitation generalists who treat patients in large corporate-owned centers using technology-based interventions driven by reimbursement and diagnostic categories. The other scenario envisions occupational therapists as autonomous professionals offering a wide range of services uniquely tailored to enable persons, regardless of their physical abilities, to achieve self-organization and mastery of their environments through their own actions (p. 365).

The first scenario sounds more like the present than some distant health care future. In fact, the six participants in this study confirmed the existence of Yerxa's pessimistic prediction by offering a view of occupational therapists as both generalists (rehabilitation as uni-disciplinary) and technicians (applying standard methods and procedures via home evaluations).

However, Yerxa's second scenario was also represented in the participant interviews. Each person, regardless of their injury or financial resources demonstrated self-agency—the ability to achieve self-organization and mastery of their environments through their own actions. In spite of poor advice from builders, a lack of insurance money, or the complete absence of occupational therapy or other health-care expertise—each of these people and their families demonstrated a desire to re-organize their environments in a way that allowed them to participate in their chosen occupations. Their greatest challenge was coping with the absence of professional expertise or
financial resources that often impeded their ability to achieve an environmental that allowed them to optimally participate in their desired occupations.

One facet of Yerxa’s second scenario is already present and indicative of a gap between current service and expressed need—people with impairments who are eager to engage in their chosen occupations by developing the skills and resources necessary to achieve self-organization and mastery of their environments. The missing link is occupational therapy’s ability and willingness to respond to that need under current practice paradigms.

Yerxa (1998) eloquently characterizes the choice occupational therapy faces as a profession: we can continue to emphasize technique over ideas and risk the fragmentation or obsolescence of our profession; or we can nurture an integrated and strong profession that serves the important human need for self-agency. Fortunately, the need is great and shows no signs of abatement in the near future as evidenced by Liebig and Sheets (1998). Occupational therapists can begin to fulfill this need by forming partnerships with clients and other professionals, acquiring the necessary skills, and by using a client-centered practice model that facilitates helping people discover and utilize their own unique strengths and resources.

Occupational therapists also have the opportunity to be instrumental in initiating and orchestrating a cultural transformation that may change society’s paradigm of the elderly and disabled. Where these individuals were once viewed as expendable ‘tragedies’, they can now be recognized as healthy, efficacious and having the right to equality of capability (Bickenbach as cited in Yerxa, 1998). The environment is a
powerful tool for facilitating self-agency. It's time for occupational therapists to reclaim the environment as a legitimate and effective practice intervention.
References


Appendix A

Consent Form

I understand that this is a study investigating consumer criteria for and satisfaction with environmental modifications in the home. The information gained is expected to assist therapists, architects, builders, and other interested professionals to provide more pertinent advice and direction for people who require a more accessible living environment. It is also meant to help consumers with disabilities more knowledgeably choose and execute environmental modifications in their home. The principal outcome is to begin building a foundation of knowledge that will facilitate maximum independence in daily living skills in the home through the use of environmental modifications. I also understand that:

1. participation in this study will involve one 60–75 minute interview and a 15–20 minute discussion of the results regarding each participants criteria for and satisfaction with home environmental modifications.
2. I have been selected because I am an adult with a chronic disability that requires at least part-time use of a wheelchair.
3. it is not anticipated that this study will lead to any physical or emotional risk to myself.
4. the information I provide will be kept strictly confidential and the data will be coded so that identification of the individual participants will not be possible.
5. a summary of the results will be made available to me upon my request.

I acknowledge that:
1. I have been given an opportunity to ask questions regarding this research study and that these questions have been answered to my satisfaction.”
2. “In giving my consent, I understand that my participation in this study is voluntary and that I may withdraw at any time.”
3. “I hereby authorize the researcher to release the information obtained in this study to scientific literature. I understand that I will not be identified by name or location.”
4. “I have been given Linda Mohney’s phone number so that I may contact her at any time if I have any questions.”
5. “I acknowledge that I have read and understand the above information, and that I agree to participate in this study.”

Witness

Participant Signature

Date

Date

I am interested in receiving a summary of the results.

Linda L. Mohney, researcher - Home (616)837-9466
Barb Hooper, Committee Chair - GVSU (616)895-3356
Paul Huizenga, Human Subjects Research Review Board - GVSU (616)895-2472
Appendix B

Interview Guidelines

1. What is your age, level of education achieved, and occupation?
2. What type of disability do you have and how/when did you acquire it?
3. Do you use a manual or a power wheelchair?
4. Do you employ a personal assistant to help you with any tasks or activities?
5. What specific physical limitations led you to identify a need for home modifications?
6. What activities are limited to you due to your home environment?
7. What modifications have you made to your home?
8. If so, why did you choose these particular modifications?
9. What is the most important modification(s) you have made to your home? Please explain why.
10. Did anyone consult with you on making modifications to your home? If so, describe the consultation.
11. Who was responsible for constructing the modifications?
12. Please detail any obstacle you encountered in making modifications to your home environment.
13. Are you satisfied with the existing modifications? Please explain why or why not.
14. What other modifications would be helpful?
15. How did you finance the modifications?
16. What was the time-line for your modifications? All at once or over a period of time?
17. What advice do you have for a person with a similar disability regarding modifications to their home?
18. What advice do you have for therapists, builders, or other professionals who make recommendations for home modifications or construct the modifications?
19. Are you familiar with universal design? Have you used any UD features in your home?
20. What other issues do you feel are important to understanding home modifications from a consumer's point of view?
Appendix C

Initial Telephone Contact Script

Hello, my name is Linda Mohney and I’m an occupational therapy student at Grand Valley State University. Paula Guy, the occupational therapist from the Center For Independent Living, suggested I call you to ask for your help in a research project I’m doing. My project deals with finding ways to help people with disabilities improve their home environment. And I’m calling you because I’m interested in learning about any physical changes you’ve made to your home and how satisfied you are with those changes.

All I need is one hour of your time for a personal interview in your home. I will be recording our interview on tape, but I will keep your identity and where you live strictly confidential.

Would you be willing to participate?

When is a good time for us to meet?

I’ll provide you with more specific information about the study when we meet and I’ll answer any questions you may have. For your benefit, the university also requires me to have you review and sign a consent form. This form explains the study in detail, outlines your rights as a participant, and highlights your right to confidentiality.
Appendix D

Letter of Introduction

5701 Garfield St.
Coopersville, MI 49404
November 25, 1999

Mr. John Doe
1234 Main St.
Grand Rapids, MI 49999-0123

Dear Mr. Doe,

It was a pleasure talking to you last week. As I told you on the phone, I am a
Masters degree student in my final year of study in the occupational therapy program at
Grand Valley State University. Conducting an independent research project is part of
fulfilling my requirements for graduation, and I have chosen to interview approximately
six people who have made modifications to their homes or built new homes to
accommodate a long-term disability. My primary goal is to find out how and why people
choose to make home modifications and if they are satisfied with the results. I have
chosen this area of study because there is a great deal of information from architects,
builters, therapists, and other disability “experts” concerning home modifications and
what they view as an “accessible” environment. However, I have found very little
information detailing what home modifications the actual consumer finds most useful.
Consequently, I’m very interested in hearing from people like you who have made the
changes or built homes to create a more accessible environment.

I have also enclosed a consent form. This form is required by the Human
Subjects Review Board at GVSU to ensure that 1.) you’re fully informed of the purpose
of the study, 2.) you’ve willingly given your consent to participate, and 3.) your identity
is kept strictly confidential. If you have any questions concerning my study or your
participation, please call me, my thesis advisor (Professor Barbara Hooper) or Dr. Paul
Fluizenga of the GVSU Human Subjects Review Board—our phone numbers are listed at
the bottom of the consent form. Thanks again for your help—I look forward to meeting
with you on December 1st.

Sincerely,

Linda L. Mohney
Occupational Therapy Student
Grand Valley State University