User Initiated Design Proposed by People Who Have Had a Stroke:
Adapting Unaccessible Environments

BY

MARTHA PATRICIA SARMIENTO
D.I., Universidad Nacional de Colombia 1987
Esp., Universidad del Bosque 2002
M.Sc., Universidad Nacional de Colombia, 2007

DISSERTATION

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Defense Committee:

Joy Hammel, Chair and Advisor
Carol Gill
Carrie Sandahl
Sarah Parker Harris
Deana McDonagh, University of Illinois, Urbana–Champaign

To Gabriela:
We inhabit our lives; we assume there is a starting point and an ending one,
but the reality is that we live in a continuum of journeys that make our inhabitation.

This journey began with you; it is a journey of humanness.

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Porque sin ser mi piel, te amo como a ella,

Porque sin ser tus ojos los míos, ves a través de ellos,

Porque he reído a carcajadas,

porque has visto mi futuro.

Thank you.

MPS

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

LIST OF ABBREVIATIONS

AT   Assistive Technology

IRB   Institutional Review Board

MOHO   Model of Human Occupation

OT   Occupational Therapy

PAR   Participatory Action Research

PEOP   Person–Environment–Occupation–Performance Model

PWD   People With Disabilities

PWS   People Who Have Had a stroke

UCD   User–Centered Design

UD   Universal Design

UIC   University of Illinois at Chicago

UID   User–Initiated Design

NIH   National Institute of Health

SUMMARY

Ideation is a common human mental process used to create and recreate our environments. People with stroke often ideate solutions for the challenges they face navigating their home environment after a stroke, and they implement them when possible. Yet, this process is largely un-researched in the field of design, even though contemporary design approaches involve people with disabilities as co–designers. There has not been a systematic examination of why and how people who have had a stroke (PWS) engage in actions, activities and processes to transform their environments. This qualitative–participatory study seeks to address this gap by offering insights on why and how PWS undertake these actions.

This dissertation is presented in a three–article format. The first article is a critical review that highlights the need to understand user–initiated design (UID) and the importance of engaging in design processes as an empowerment tool for PWS. The second article explores how participatory research methods can help reveal the way in which PWS design, how they create their home environment following a stroke and which barriers and supports they find in this process. The third article demonstrates the results of the study and outlines the design process model that PWS implemented to transform their home environment.

Participatory methodologies were used to meaningfully engage PWS in research and to reveal how they designed; including how they conceived changes to the environment and the role lived experience had on this process. A comparative case study using participatory methods describes this design process as directly experienced by people with stroke, and the facilitators and barriers to it. Finally, this research study proposes an analytical framework to understand this user-centered and controlled design phenomenon and implications for professional designers and rehabilitation professionals.

I.   **INTRODUCTION**

Disability scholars, occupational therapists (OT) and designers have long acknowledged and studied the importance of the built environment as key factor in the lives of people with disabilities and their everyday participation. The social model equates disability aspects of the environment that disable or oppress equitable participation, rather than factors within the individual (Oliver, 1990; Shakespeare, 2006). Ecological theory bases, such as the Competence Environmental Press model (Lawton & Nahemow, 1973), explain how the ability to actively adapt and modify the environment is critical to support continued performance and participation in life.

Designers have faced many challenges in the understanding of the needs, desires, and experiences of people with disabilities (PWD). Evidence of these challenges lies in the existence of theories (Hamraie, 2013; Sanders & Stappers, 2008; Sanoff, 2008), concepts (Clarkson & Coleman, 2015; Gleeson, 1999; Hansen & Philo, 2007; Imrie, 2004; Luck, 2003; Von Hippel, 1986), and methodologies (Binder, Brandt, & Gregory, 2008; Lee, 2007; Sanders, 2002) associated with the study of the environmental design with disability and participation despite this research, PWD frequently experience exclusion given lack of access to and accessibility within the built environment. People who have had a stroke (PWS) are no exception.

Stroke is among the top 18 diseases contributing to years lived with a disability and leading cause of long-term disability (Go et al., 2014). The American Heart Association estimates that about 795,000 people experience a new or recurrent stroke every year (Mozaffarian, et al., 2015). Over the next 30 years, the number of incident strokes is expected to more than double, with increase among the elderly and minority groups who have less access to physician care and lack of health insurance (Go et al., 2014). Projections to 2030 expect total direct medical stroke related cost to triple.

In 2014 over 4.5 million people 65 and over were below the poverty level (Mozaffarian et al., 2015). Considering that about one in every seven Americans is 65 years or older, that three-quarters of strokes are on people over 65 and that after 55 the risk of having a stroke doubles, and that additionally by 2060 there will be about 98 million older persons (Mozaffarian et al., 2015) research in stroke and stroke related issues gains enormous importance.

Two thirds of the people who have had a stroke survive and most of them live with mild to moderate impairments (Wolf, 2009). Recovery from a stroke poses physical and psychological challenges that evolve with time as stroke represents a long-term disabling condition. In post stroke adjustment, acceptance of changes, engagement in new roles and activities and the presence of social support seen to be important factors (Ch'ng, French, & Mclean, 2008). The physical environment plays an important role in adapting after the stroke (Lawton, & Nahemow, 1973) and can be a challenge for PWS as disabilities related to stroke such as hemiparesis, cognitive deficits, depressive symptoms, aphasia, visual impairment (Go et al., 2014) demand a new way of interaction person-environment.

Discharge to home and cessation of rehabilitation are milestones for PWS as adjusting to a new normal self and dealing with discrepancies between rehabilitation outcomes and recovery expectations are critical issues on returning home after the stroke (Ch'ng et al., 2008)

PWS actively respond to the stroke by amongst other things creating new ways of doing things through imaginative and ingenious actions in order to maintain independence (Pound, Gompertz, & Ebrahin, 1999). In the field of OT these actions are understood in terms of coping with and strategizing the context to respond to stroke (Pound et al., 1999).

Pound et al., (1999) identified that after the stroke people mobilized informal social support, created new ways of doing things, took things slower, began the process of relearning exercised and attempted to conceal the disability. None of these was related to physical interventions over the environment or actions towards changing an existing situation into a desired one (Simon, 1996) even though they were recognized as imaginative and ingenious ways of maintaining independence and equilibrium after the stroke.

In the field of design actions and activities non-professional designers engage in have been researched before (Briedes, Chow, & Joost, 2010; Candi, 2010; Gorb & Dumas, 1987; Nelson, Buisine, & Aoussat, 2009; Von Hippel, 1986) but there is no research on actions undertaken by PWS as non designers or on actions undertaken by them to transform the physical environment. The way PWS actively respond to their condition has had little interest in the field of design despite the fact that many of these strategies can be denoted as design actions and activities PWS engage in to problem solve the environment.

In the field of OT in the area of stroke research focuses on the impact of stroke framed in terms of coping and adjusting (Sarre et al., 2014) but there is a lack of research examining how people with stroke actively design and redesign their environment post stroke and the impact that the design process has on their overall life participation.

To date, there has not been a systematic examination of why and how people who have had a stroke (PWS) engage in actions, activities and processes to self-design, adapt and transform their environments to fit their changing needs despite the importance and applicability this type of research has for design and OT in a time when there is a growing population in high risk of stroke (U.S. Department of Health and Human Services, 2014), stroke rehabilitation requires a considerable amount of resources and is an expensive Health condition (Go et al., 2014; Sarre et al., 2014) and the importance of the environment in adapting after a stroke (Lawton & Nahemow, 1973) is well recognized. Additionally, finding of this type of research can be generalized to other groups of people with disabilities for the role of the environment in the disablement process is true for all people with disability and PWS can have different types of disabilities after the stroke.

This qualitative–participatory study seeks to address this gap by offering insights into why and how PWS undertake these actions. This study is an important step towards the identification of design processes initiated by PWS and will also serve as an analytical framework to understand the nature and structure of this user-controlled design phenomenon.

The study includes three phases that seek to: 1) identify important issues in the relation between the home environment and PWS, including their lived experiences, perspectives, and views on how they relate to the space and objects in it; 2) gain basic understanding of how PWS engage in these self-led design processes; and 3) elicit information about participants' individual and collective experiences with home modification and provide recommendations for designers and OTs on how to integrate user-centered and controlled design within their services and research about the built environment. Refer to Table I for a model of the research process and products.

TABLE I
RESEARCH MODEL

INPUT		

-People who have had a stroke -Home environment features -User experiences with the environment	Knowledge about: -Approaches and theories on design and disability -Design, ergonomics -Disability studies	Knowledge about: -Participatory research -Qualitative research -Research space

METHOD		

Issue Identification	**Understanding: User Initiated Design**	**Active engagement in User Initiated Design**
-Participant observation -Observing the home environment -Semi-structured interviews	-Participant observation -Photovoice -Follow-up interview	-Focus group

OUTPUT		

TABLE I (continued)

RESERCH MODEL

-Identification of environmental requirements that act as constraints on PWS's daily activities -Transformations made to home environment by PWS -Making user-initiated design visible for PWS during the research process and as a research outcome	-Identification of the design process PWS engage in to transform the home environment as a way of exerting control over the environment -Identification of forces that drive PWS to user-initiated design -Identification of the impact of engaging in design processes to transform the home environment	Recommendations for designers and OTs

SHORT TERMS / OUTCOMES

-Descriptive definition of User Initiated Design -Analytical framework to understand User Initiated Design	-Identification of factors that can help PWS, actively engage in UID as a form of empowerment	-Knowledge Dissemination International Conferences - 2015 Design principles and practices Chicago (Paper and lecture) - 2013 DSI Amsterdam (Paper and lecture) - 2013 DSI Orlando (Poster)

TABLE I (continued)

RESERCH MODEL

LONG TERMS / OUTCOMES

For PWD-PWS	**For Disability Studies**	**For Design Studies**	**For Occupational Therapy**
-UID is an empowerment tool as empowerment comes from controlling access to space. From our control over this space and our power to change it. Empowerment is also related to our power to propose routines and identify through our environment.	-UID is purposive and intentional. -Design is both shaped and explanatory of notions of standard, membership and desirability. -Purposive Design has the potential of profound change -UID has the potential of re-signifying environments to represent user wanted experiences	-UID is design done by non-designers, it expands our understanding of how, by whom and where design is done. UID could help create new paths of collaboration among different views of design to support meaningful social change focusing in emergent ways of collaboration and cooperation.	-If recognized, UID can be used by OTs as empowerment tool for PWS, to advance in the process of adaptation

A.   **The Dissertation**

As an Industrial Designer and master in Disability Studies working in the academic field, I have had the

opportunity to teach small groups of industrial design students and occupational therapy students in undergraduate

courses. What I learned from those experiences is that PWD are constantly problem-solving the environment yet

these actions are not considered design. As I got involved in disability studies, I realized that despite all theories and

methods used in design to understand the intersection of design and disability access to the environment requires

more than normative approaches conforming to standards through recommendations or norms or the involvement

of PWD to inform the design process. Their embodied experience is irreplaceable in the design process and their

involvement in the design of the built environment an ethical stance.

At University of Illinois at Chicago (UIC), through my advisor Dr. Joy Hammel and one of her research

studies I had the opportunity to approach community–based participatory research related to community living and

participation choice, control and societal opportunity and disparities experienced by people who are aging with dis-

abilities, including people who have had a stroke and seek to return to full community living and participation post

rehabilitation This study seeks to identify key environmental barriers and supports to this least restrictive commu-

nity living and full societal participation of people with stroke. The dissertation research explores if PWS engage

in design processes to transform the environment, how this process unfolds and how it impacts the person and their

overall participation.

B.   **The Three-Article Format**

This dissertation is presented in a three–article format. The first article is a critical review that highlights

user–initiated design (UID) and the importance of engaging in design processes as an empowerment tool for PWS.

This article synthesizes the literature to inform the UID phenomenon and calls for a conceptualization of it based on

lived experiences of people with disabilities, including stroke. The second article explores how participatory research

methods were used to reveal the way in which PWS design, including: how they create and recreate their home

environment following a stroke, how this UID process unfolds, how it impacts them and their social worlds, how they

designed social spaces in which to participate and engage, and which environmental factors were facilitators or barriers to this consumer–directed design. The third article demonstrates the results of this participatory study, summarizing and conceptualizing the design process model that PWS implemented to transform their home environment.

C.   **<u>Aims</u>**

The aims of this study were to:

1) Identify the relation between the home environment and PWS, including their lived experiences, perspectives, and views on how they relate to the space and objects in it;

2) Gain basic understanding of how PWS engage in self-led design processes, and how this design ideation influences their overall participation; and.

3) To provide recommendations for OT's and designers on how to integrate user-initiated design within their services and research about the interactions PWS have with the built environment and its impact on participation.

II.   BACKGROUND

A.   **The Environment**

The built environment has a profound effect on the way we live our lives. The cause–effect perspective or environmental determinism paradigm states the environment causes users to behave in certain ways (Hardin, 2009). Environmental determinism is favored as a theory by the design professions because of its immediate applicability to practice (Vischer, 2008). However, thinking only the environment determines our behavior is simplistic. In a given situation the social environment as well as the physical environment influence our behavior and body, feeling and expectations determine our experience of use of that environment (Hansen & Philo, 2007). For Pallasmaa (2012) we constantly interact with the environment, we do so through our body. The interaction self-word has the capacity of redefining and informing the environment as well as the self (Pallasmaa, 2012) thus built environment can be challenging when conceived disregarding human experience and bodily variability.

For PWD, the built environment presents a multitude of challenges and can be oppressive (Gleeson, 1999). Issues of exclusion through the built environment can be explained if we understand that the environment is shaped by struggles among conflicting forces such as economic benefits and social interests (Margolin & Margolin, 2002). And even though many products for the market meet social needs the market is not always responsive to all social needs, especially those experienced by people with low incomes or people with needs due to aging, health, or disability (Margolin & Margolin, 2002). These social groups are often ignored or invisible in market design creating social inequities reflected in the design of the built environment. Additionally, only until recently have the professions in charge of the creation of the environment had social justice approaches to address large social scale issues, such as environmental justice and social justice oriented design.

Environmental justice emerged as a concept in the 1980's. For Noonan (2008) environmental justice it is the fair treatment of all people in environmental laws, regulations, and policies. Social justice design approaches highlight design strategies that target the goal of social justice along six dimensions (Dombrowski, Harmon, & Fox, 2016), transformation, recognition, reciprocity, enablement, distribution, and accountability.

To attain a just society we need respect of social differences and the creation of environments that satisfy material and cultural needs (Gleeson, 1999). From the viewpoint of PWD, justice requires the creation of enabling environments to liberate their social capacities and guarantee their material needs. For Gleeson (1999) demanding an inclusive social and built environment that guaranties material welfare and cultural recognitions is the way by which Enabling Justice can defend the emancipatory need of PWD.

B.   **Built Environment–Disability Relationship**

The social model of disability asserts that people with disabilities are discriminated and excluded from participating in contemporary society and emphasizes the role that attitudinal, physical and institutional barriers have in this process (Lang, 2009; Smith, 2009). In the social model, disability is an experience that is dependent upon how society is politically and socially organized and structured in relation to medical conditions. Thus, the built environment plays an important role in the exclusion of certain bodies by constructing barriers.

Theoretical frameworks link the person, the disability and the environment; for example, the environmental press model conceptualizes the individual as having a set of competencies, and the environment as presenting *press* or demands and expectations upon that individual (Lawton & Nahemow, 1973). The relationship between individual competence and environmental press is conceptualized in terms of adaptation. The importance of the person–environment interaction, as well as the importance of the environment in influencing and mediating the individuals' competence and the participation, is described in the Person–Environment–Occupation–Performance Model (PEOP) as developed by Baum and Christiansen (2005). The PEOP describes an interaction of personal and environmental factors that either supports or restricts the performance of activities. The relationship between occupational performance and participation is significant when understanding that participation in occupation is dynamic and context dependent, as well as that occupation is essential to self–organization (Kielhofner, 1995).

The environment can affect the challenge experienced by the person to the point of eroding their sense of competence and creating a sense of learned helplessness (environmental docility); thus, when there is too much environmental press, people give up trying to adapt and consequently give up the use of that environment (Lawton

& Nahemow, 1973). The press can also be positive, resulting in adaptability and resilience in responding to future demands (environmental proactivity), so the person's sense of competence is maintained and may in fact even grow and spread to problem solving other environments. The direct relationship between press and adaptation can play an important role in understanding why PWS engage in design processes to transform the environment to support life participation, and whether changing the press by adapting the environment has a positive influence on them.

PWS are often forced to adapt themselves to fit the existing environment or, via trial and error, to find other creative ways to make the environment work for them. They do so in isolation, as they are often unaware of other PWD struggling with similar environmental issues. But the most important issue is not only being able to elucidate how to problem solve the environment through design but how to transform it. Design is more than a way of redefining space, objects and actions; it is a way of redefining the self.

C.   **People Who Have Had a Stroke**

PWS are often referred to in negative ways that imply a burden to their families and communities (Pound et al., 1999). But PWS actively respond to the stroke by amongst other things creating new ways of doing things through imaginative and ingenious actions in order to maintain independence (Pound et al., 1999). The physical environment plays an important role in adapting after the stroke (Lawton & Nahemow, 1973) and can be a challenge for PWS as disabilities related to stroke such as hemiparesis, cognitive deficits, depressive symptoms, aphasia, visual impairment (Go et al., 2014) demand a new ways of interaction between person and environment. Pound et al. (1999) identified that after the stroke people mobilized informal social support, created new ways of doing things, took things more slow, began the process of relearning exercised and attempted to conceal the disability.

Although stroke has an impact in people's life, PWS play an active role in managing their life after the stroke reacting imaginatively and ingeniously to maintain equilibrium (Pound et al., 1999). The home plays an important role for PWS to engage in valuable activities.

D.   **<u>The Home Environment and People Who Have Had a Stroke</u>**

The home gives form and significance to people's lives (Imrie, 2004). Ideally, domestic habitation provides security and privacy. Nevertheless, these provisions can be challenged when impairment appears (Imrie, 2004). This is due in part to design conceptions not conceiving impairment as part of the domestic habitation (Imrie, 2004). As such, the experiences of PWS are at conflict with the ideal conception of the home, where the impaired body is rarely a subject of analysis.

Research about the home environment in the field of occupational therapy (OT) has addressed the impact of home modifications in respect to falls in older adults (Cumming et al., 1999) to increase independence, safety, and usability, as well as to understand the relation of modifications to the environment in the adaptation process (Fange & Iwarsson, 2005). In architectural housing studies, modifications to the home environment have also been studied to determine accessibility issues for PWS. However, a person's feelings and experience about the home cannot be dissociated from their corporeality (Imrie, 2004). The body is our basic mean to relate to the context; hence, embodiment represents a value of human knowledge (Ueda, Takenaka, Vancza, & Monostori, 2009). Knowledge placed within a context where situated points of view are rich in content information (Haraway, 1988).

E.   **Design and Disability**

The increasing complexity of economic and technological modernization during the 20th century required collective solutions for environmental human needs. Collective solutions required a qualified specialist the designer to standardize both needs and solutions. Design then became an integral component in production and was consolidated as a profession. But standardized conceptions in the built environment were oriented by the dynamics of the market (Margolin & Margolin, 2002). Defining the built environment by standards disregards the specific needs of populations that are not in the interests of the market economies. This is the case of minorities such as PWD (Margolin & Margolin, 2002).

In the mid 60s of the 20th century, the impact of humanities and social sciences on design produced a change in approach towards the participation of the user in the processes of design. The term *participative* is used widely in various fields to imply a way of creating environments, objects, services and experiences that are more considerate and adequate to the cultural, emotional, spiritual and practical needs of people. Participative approaches to design depict it as a social process, showing that the scope of the activity of design extends beyond designers or the individual designer (Sanders & Stappers, 2008).

The tenet of collaborative design approaches is collaboration between designer and non designers (Binder et al., 2008). The first advances towards reaching the user are called *user centered design* (UCD) approaches. UCD represents a philosophy of design, which draws users or consumers towards the process of design (Mao, Vredenburg, Smith, & Carey, 2005). It is a multidisciplinary approach to improve the understanding of the needs of the user and the requirements of the task, as well as the iteration and assessment of design (Mao et al., 2005).

Currently, UCD has become a common practice for designers and has had crucial aspects to represent users and to anticipate their understanding of new artifacts. In UCD, the ways in which users participate can vary. In some models, its role is that of participants in the assessment of usability (Lindgaard, 2009); in other models, user inclusion may be all throughout the process of design and with a participative approach.

These two approaches are well differentiated. The first is known as the *user as subject approach*, where the researcher acts as the interpreter, the information generated enters the process of design in the form of design criteria (Sanders, 2002) and the importance lies in the object designed (Sarmiento, 2015). In this approach of UCD, deviation in use is considered undesirable, thus unfamiliar design proposals are more likely to be ruled out instead of being considered an opportunity for new design (Bredies, 2015). UCD under a participative perspective is an approach where users provide their expertise and participate in creation, ideation and conceptualization. In a participative approach, the individual roles of designer and user become indistinguishable, and the user becomes a critical component in the process of design (Sanders, 2002).

In the field of disability design processes, which involve users' participation, deal with how they are been represented in said process, if represented in the stage when needs and desires are detected is desired or in the last stage to confirm design decisions (Luck, 2003). A key step in the policies to accommodate PWD is a change in the emphasis from aiding them to do things in a normal way to simply doing things their way (Hansen & Philo, 2007).

F. **Researching Design Processes People Who Have Had a Stroke Engage In**

Design done by non–designers has been studied in the field of design to explain innovative changes to products, design changes during production and adaptation to designed products done by users (Brides, 2010; Candi, 2010; Gorb & Dumas, 1987; Hara et al., 2013; Nelson et al., 2009; Von Hippel, 1986). The phenomenon has expanded our understanding of how, by whom and where the design is done (Botero, Kommonen, & Martilla, 2010). But there is no reference in the literature to design done by PWD, specifically by PWS. Possible explanations for the current lack of understanding of the phenomenon of PWS engaging in design processes include: 1) the phenomenon is silent, thus, has not been denoted or denominated; 2) it is mostly practiced in solitude; or 3) it has no recognition as a valid action taken over the environment.

PWS are constantly modifying the home environment to respond to their needs. Their involvement in research to understand how the phenomenon develops is fundamental. It is the responsibility of the researcher to develop innovative and accessible ways to make this design process visible. Subjective methods allow for an under-

standing of the experience (Fulton, 2003), experience as knowledge and lived experience (Garland-Thomson, 2011).

Interviews, participant observation, Photovoice and focus groups are all-subjective techniques used to investigate

experience and can be proposed to understand design processes undertaken by PWS whose perception of the con-

formability of the environment changes rapidly after the stroke.

III.   PEOPLE WITH STROKE ENGAGING IN DESIGN PROCESSES AS A WAY OF EMPOWERMENT: A CRITICAL LITERATURE REVIEW

A.   **<u>Abstract</u>**

People with disabilities (PWD), particularly people who have had a stroke (PWS), frequently experience exclusion through the built environment. In response to this exclusion, they constantly ideate changes to the environment, and when possible, implement them. However, this phenomenon has been poorly researched in the field of design and has been understood as an adaptation strategy in the field of occupational therapy (OT).

Contemporary design approaches involve PWD as co–designers, and with the use of collaborative and participatory methodologies, develop design solutions to respond to their accessibility needs. Participation of PWD can be at different stages of the design process, with participation at the ideation stage being the most contemporary of the approaches. In the field of OT, several ecological–base theories explain how critical active adaptation and modification of the environment is to support continued performance and participation in life after a stroke. OT emphasizes the role OT professionals have in the adaptation process of PWD and in the process of modification to their environment. However, there are issues that still need to be addressed, including critical reflection about the actions and activities PWS autonomously engage in to transform the home environment after the stroke. This article highlights the need to understand this phenomenon and the importance that engaging in design processes has as an empowerment tool for PWS. The article synthesizes the literature to inform the phenomenon and calls for a definition to describe it.

Keywords: Design process, Design space, People who have had a stroke, User–initiated design

B.   **<u>Introduction</u>**

Many fields of knowledge study how the environment is created. Our capability to transform the environment and the way in which we interact with it are studied in, for example, architecture, engineering and design. Fields such as economics and politics have studied the environment to establish how it determines us. In disability studies and OT, the relationship person–environment is essential to understand disability. In the field of design,

designers have faced many challenges in the understanding of the needs, desires, and experiences of PWD. Evidence of these challenges lies in the existence of theories, concepts, and methodologies associated to the study of the design–disability intersection found throughout the recent history of design as it is reflected in the literature.

User–centered design has studied the participation of PWD at different stages of the design process. Collaborative and participatory methodologies are frequently used when designing for PWD (Binder, Brand, & Gregory, 2008; Lee, 2007; Sanders, 2002). Designers have proposed numerous approaches to better understand the experiences of PWD, such as participatory (Luck, 2003) and empathic design (McDonagh et al., 2010; McDonagh & Formosa, 2011).

Furthermore, universal design (Story, Mueller, & Mace, 1998) and inclusive design (Clarkson & Coleman, 2015; Clarkson, Coleman, Keates, & Lebbon, 2013) promote the inclusion and participation of PWD by maximizing accessibility to the built environment, while barrier–free design (Preiser & Ostroff, 2001) relies upon technical accessibility standards to attain accessibility for PWD. However, PWS frequently experience exclusion through the built environment. In response to this fact, they constantly ideate changes to the environment, and when possible, implement them.

The capacity for or the act of forming ideas or concepts (Ideation, 2016) about modifications to the environment can be considered a common human mental activity. Interventions to the environment proposed by PWS are prone to happen at the home environment because it is their place of authority. This activity has been studied by occupational therapists as one of many *strategies* developed by PWS during the adaptation process (Lawton & Nahemow, 1973). However, it has not been recognized as a design process aimed at changing an existing situation into a desired one (Simon, 1996).

On the other hand, in the field of design, changes to the environment proposed by non–designers have often been studied as: 1) evidence of the need for a professional design intervention (Candi, 2010); 2) an activity that only very few innovative users can achieve (Von Hippel, 1986); and 3) a reaction experienced by the user as a response to unexpected changes in the environment (Brides, 2010). Changes to the environment ideated and enacted by PWS have been poorly studied and the process is ill–defined.

C.   **People Who Have Had a Stroke Transforming Their Home Environment**

"The role of the home environment for maintaining and improving functioning of PWD is widely rec-

ognized in research" (Wahls & Fange, 2009 p. 355). Building on the disablement press model and the concept of

person–environment is fundamental (Lawton & Nahemow, 1973). Occupational therapists emphasize the home

environment as a critical factor in supporting or undermining individual functioning (Iwarsson, Wahl, & Nygren

2004). To enable performance of activities, an important intervention in community–based OT is the adaptation

of physical environments (Fange & Iwarsson, 2005). The environmental press model explains how critical active

adaptation of the environment is in supporting continued performance (Lawton & Nahemow, 1973). The person–en-

vironment–occupation–performance model (PEOP) describes an interaction of person and environmental factors that

either support or restrict the performance of activities (Baum & Christiansen, 2005). The model of human occupa-

tion (MOHO) emphasizes that participation in occupation is dynamic and context dependent, and that occupation is

essential to self–organization (Kielhofner, 1995).

1.   **The home environment**

The home give form and significance to people's lives (Imrie, 2004). Ideally, domestic habitation

provides security and privacy. Nevertheless, these provisions can be challenged when impairment appears is (Imrie,

2004). This is due in part to design conceptions and not to conceiving impairments as part of the domestic habita-

tion (Imrie, 2004). As such, the experiences of PWS are at conflict with the ideal conception of the home, where the

impaired body is rarely a subject of analysis. Research about the home environment in the field of OT has addressed

the impact of home modifications regarding falls in older adults (Cumming et al., 1999) to increase independence,

safety, and usability, as well as to understand the relation of modifications to the environment in the adaptation pro-

cess (Fange & Iwarsson, 2005). In architectural housing studies, modifications to the home environment have also

been studied to determine accessibility issues for PWS and in design studies to address usability issues.

2.   **<u>People who have had a stroke and their embodied knowledge</u>**

The physical environment plays an important role in recovering from a stroke (Jacobs, Kelly, & Sobolewski, 2007; Northridge, Sclar, & Biswas, 2003). PWS face many types of challenges when returning to everyday life after the stroke, including return to their homes with a new bodily experience. A person's feelings and experience about the home cannot be dissociated from their corporeality (Imrie, 2004). The body is our basic means to relate to the context; hence embodiment represents a value of human knowledge (Ueda, Takenaka, Vancza, & Monostori, 2009). PWS have knowledge that is placed within their context knowledge which is in turn produced by actions and interaction that their body has with the context where situated points of view are rich in content information (Haraway, 1988). The body has inherence in the world, and bodily experiences press our reflective capacities. This is the core principle under which we intervene the world; we transform it to fit us, we transform it to fit us, we change it through interactions to interact with it.

Disability theorists have developed accounts of embodied aspects of disability and how the particularities of embodiment interact with the environment (Garland–Thomson, 2011), identifying disablement as a profoundly spatial experience and something that is lived (Gleeson, 1999). For PWS, the relationship between space, disability, and mobility dictate their experience (Gleeson, 1999) and construct their unique perspective of the environment. A critical reflection is necessary on "how much more could be accomplished if people with disabilities were better able to make their way in the world on their own terms" (Hansen & Philo, 2007 p. 501). PWD's unique perspective of the environment is basic to highlighting the need of research about modifications to the home ideated by PWD, the processes they undertake, and the way in which they engage in these processes.

D.   **People Who Have Had a Stroke Engaging in Built Environment Design**

The relationship between built environment and PWS encompasses a wide range of concerns. Some concentrate on physical accessibility and mobility, some focus on social acceptability and the ableism of human–environmental design, and others deal with the stigmatization of PWS in everyday spaces (Hansen & Philo, 2007). In response to the many challenges that this relation imposes, PWS frequently engage in actions to transform the environment. Herb Simon (1996), in The Sciences of the Artificial, that if you engage in design activities to change a present situation into a desired you are a designer.

Design is embedded in trail–error processes and is about what is not yet developed (Jonas, 2007). In design, the question is about how and why we design (Hugentobler, Jonas, & Rahe, 2004). In User centered theory knowledge accumulated at two scales is linked, the micro scale or users' experience and knowledge gained at the macro perspective of the production and delivery of the environment (Vischer, 2008).

At the macro scale, the access needs of PWD are articulated in public policies and practices towards the development and regulations of the physical environment (e.g., Americans with Disabilities Act, universal design, inclusive design and design for all). At the micro scale, housing studies have developed normative accessibility to accomplish legal requirements, but such provisions are conditional and can be challenged by the onset and develop-ment of bodily impairment (Imrie, 2004). The micro scale for PWS is dictated by the fact that recovering from a stroke is a lifelong process where the physical environment plays an important role (Jacobs, Kelly, & Sobolewski, 2007; Northridge, Sclar, & Biswas, 2003).

PWS, who participate in transformations to the environment to attain environmental support and remain healthy, stay in the home and the community, pursue life goals and engage in design (Lawton, Windley, & Byerts, 1982). Thus, for PWS, design is the way to contend being excluded from and by the home environment. Surprisingly, their ability to solve problems imposed by the context and to manage them across different environments (Lorig & Holman, 2003) has not been studied from a design perspective. Consequently, to establish the context of built environment modifications, enacted by PWS, we need to understand how the built environment is created initially for PWD, but most importantly by PWS.

1. <u>**Design for people who have had a stroke**</u>

Design approaches for PWS focus on the concepts of accessibility and usability. Universal Design (UD) encourages design of products and environments to be used by all users (Connell et al., 1997); as such, it is an environmental facet to the needs of the maximum possible number of users (Iwarson & Stahl, 2003). Besides disability studies, scholars often cite it as a proof of the validity of the social models of disability. However, critics of UD focus on universalism as a value and the assumption of design being truly universal. Additionally, the deficient use of tools from the disability studies field that consider cultural, material, and scientific understandings of embodiment has also been contended in the context of UD (Hamraie, 2013). On the other hand, assistive, adaptive, and rehabilitative devices, as well as the process used in the selection and use of these devices, promotes greater independence for PWD by enabling them to perform tasks, providing enhancements or changing methods of interaction with the technology needed to accomplish a task. In this scenario, design of assistive technology (AT) plays an important role in the independence of PWS (Lenker & Paquet, 2003). Therefore, the importance of UD and AT to provide necessary accommodations cannot be underestimated.

Inclusive design introduces the concept of design exclusion as a quantifiable aspect of products and services. This issue differentiates it from UD by assuming that no design will work perfectly for everyone (Clarkson & Coleman, 2015). In inclusive design, designers aim to create designs that are mainstream in nature, which can benefit the majority by including those who are naturally design–excluded. But a consequence of the mainstream nature of inclusive design is that some PWD feel "out of place" (Hansen & Philo, 2007). In these cases, accessible solutions offered by the market leave individuals with particular needs, capabilities, or expectations, facing the dilemma of accepting and adapting to these solutions, or giving up functional use to those products and environment altogether. Additionally, many designs for PWD aim at rehabilitation or normative appearance. But for PWD rehabilitation to normative practice or normative appearance is less important than the lived experience of disability (Shildrick, 2015). When PWS engage in design, they do so under their own rules from an insider perspective and achieve what is important to them. Consequently, understanding how this engagement impacts them is imperative.

2.   **<u>Design with people who have had a stroke</u>**

Involving PWS in design is the hallmark of participatory design. The term participative is used widely in various fields to imply a way of creating environments, objects, services, and experiences that are more considerate and adequate to the cultural, emotional, spiritual, and practical needs of people. Participative approaches to design depict it as a social process, showing that the scope of the activity of design extends beyond designers or the individual designer (Sanders & Stappers, 2008). Collaborative and participatory methodologies are frequently used in participative approaches to design (Binder et al., 2008; Lee, 2007; Sanders, 2002). User centered design has studied the participation of PWD at different stages of the design process and designers have proposed numerous approaches to better understand the experiences of PWD (Luck, 2003).

Participatory design has provided opportunities for PWD to become more engaged in the design process (Sarmiento, 2015). But processes that involve user participation deal knowing if PWD are been represented in said process, if represented in the stage when needs and desires are detected is desired of in the last stage to confirm design decisions (Luck, 2003). On these issues, Steen, Kuijt-Evers & Klok (2007) described six methods and practices of early user involvement in design. The focus of each method is based on whose knowledge is privileged, that of the researchers, designers, or end–users.

When researchers and designers move towards the end–user as in ethnographic fieldwork, contextual design, and empathic design, their knowledge is privileged. But something different happens when users engage in design processes because they bring their knowledge into the process this is true in co-design and other participatory approaches. Therefore, their knowledge is privileged (Steen et al., 2007).

Empathic strategies are used in the field of design when we want to better understand experiences that are rooted in social, emotional, and cultural desires. The use of empathic methods such as *real people, empathic exemplification,* and *shadowing* (silent observation) provide the designer with textual, visual, and verbal information regarding the interaction of expert users with their material contexts. Empathic exemplification places the designer in the role of the expert user and supports the processes of understanding their experiences; in this manner, it secures appropriate and relevant results (McDonagh et al., 2010). In the ground of disability, empathic methodologies

sensitize the designer to the experience of PWD; it has the potential to question designers' values and beliefs. Nevertheless, disability theorists have developed accounts of embodied aspects of disability, as well as how the particularities of embodiment interact with the environment (Garland–Thomson, 2011).

Creativity found in the processes of design, where designers and people without formal design training work collectively, is referred to as *co–design* (Sanders & Stappers, 2008). In co–design, designers become facilitators and users can be part of the design team, provided the appropriate tools for expressing themselves (Visser, Stappers, Van der Lugt, & Sanders, 2005). Co–design has been identified as collective creativity applied across the whole span of a design process (Sanders & Stappers, 2008); consequently, co–design is a central approach to the inclusion of PWD.

Beyond co–design approaches, PWS autonomously engage in design processes to transform their home environment. These intents are not recognized as legitimate design, mainly because the professionalization of design endorses modifications to the built environment, preferentially to designers. Yet, accepting the ideation stage of design process initiated by PWS is an ethical imperative for designers.

3. **<u>Design by people who have had a stroke</u>**

PWS are often forced to adapt themselves to fit the existing environment. When adapting to the type of interaction that the existing environment requires is not possible or desirable, they find creative ways to make the environment work for them. To achieve this, they engage in design processes even when they are not professional designers. The phenomenon of design practiced by non–professional designers has been studied, for example, in the field of industry, to understand the decision–making processes in the manufacturing of a product. There, it receives the name of *silent design* (Gorb & Dumas, 1987). In the field of innovation, people who have already explored innovative ways to get things done and who develop and modify products for their own use are called *lead users* (Von Hippel, 1986). These concepts have been analyzed by a significant number of researchers who confirmed that the phenomenon is not recognized or referred to as *design* (Candi, 2010). When discussing designs executed by non–professionals, design historian Phillip Pacey (1992) states that consumers very often envisage improved or alternative products, arguing that this means taking a first step into the design process.

Non–professional design has been related to: 1) non–intentional design; and 2) design–in–use. Non–intentional design results when an object is used in a different manner from the prescribed functional intention or when the prescribed application is not honored in the new use (Breides et al., 2010). A bottle used as a candleholder, a chair used as a shelf or any object used in ways that were not originally envisaged can be non–intentional design (Bredies et al., 2010). The ways in which users take over existing products according to their personal needs are referred to as *design–in–use* (Nelson et al., 2009). Use has been described as a process that involves compliance to prescription in use and definitions of constraints to personal and situational factors (Nelson et al., 2009). Design–in–use is an unpredictable response of the user to unexpected perturbations in the context (Brides, 2015). When the environment undergoes unexpected changes, emergent processes are involved. In such cases, a design act and design process is an emergent synthesis (Ueda et al., 2009). To understand design–in–use as design acts and processes, design theorists have developed the concept of design space.

i. **Design Space**

Westerlung (2009) defined design space in terms of a conceptual tool to design and understand design processes. He argued that explorations of design space are done from the point of view of solutions rather than problems. Thus design space is the potential that available circumstances have for the development of new design (Botero et al., 2010). This concept includes design–in–use activities developed by people. Here, space is not a place; rather, it is understood as all design relevant information in a design process such as stakeholders, tools, technologies, materials as well as social processes and agreements. This definition of design space recognizes the user as designer and situated perspectives on design activity.

Under the concept of design–in–use, the user engages in emergent synthesis when the environment undergoes unexpected changes. This is not the case of design enacted by PWS, even though what they do is an *emergent synthesis*. For PWS, the environment does not undergo an unexpected change, but the way in which people have to interact with it does, subsequently provoking a response that can be innovative, silent and that may require the modification of designed objects or the development of new designs. Regrettably, this phenomenon has not been

recognized as design previously; therefore, it has not been analyzed using a design framework. Design space in the case of design activities by PWS needs to be explored and the actions they undertake need to be defined.

E.   **How to Open Design Space for people who have had a stroke**

To understand processes initiated by PWS and truly acknowledge them, it is necessary to create the possibility of doing emergent design in order to show that they engage in design. There are several theory–based models in design that typify a design process. A well–recognized model is the one proposed by Hugentobler, Jonas, and Rahe, (2004). They redefined the linear process model *analysis–projection–synthesis* proposed by Jonas and made an operational interpretation that contains a pragmatic version of the three domains of knowledge —the true, the ideal and the real— connected to the process model of analysis–projection–synthesis. This model can be used to typify and analyze design processes PWS engage in. The actions they undertake to transform the environment can be recognized as legitimate design processes.

1.   **On typifying a design process**

Designing requires a compound form of inquiry in three domains of knowledge —including the real, the ideal and the true (Nelson & Stolterman, 2003)— in relation with the process model of analysis (what is the problem), projection (how do we want to live) and synthesis (what do we need for this). Figure 1 is a diagram of Jonas' linear model and Table II shows information on the three domains of knowledge.

Figure 1. Linear-design model, based in Jonas

TABLE II
DOMAINS OF KNOWLEDGE AS EXPLAINED BY NELSON AND STOLTERMAN (2003)

Domain	Refers to	Based on	
The true	Objective facts	Scientific inquiry	How it is today
The ideal	Norms and values	Higher orders, spiritual systems	How it could be
The real	Subjective particulars	Human intention	How it is tomorrow

A visual representation of the design process model proposed by Hugentobler et al. (2004) can be seen in Figure 2. In this model, the true, the ideal and the real are depicted as part of a process in a circular scheme. The sequential three–step model of analysis–projection–synthesis disappears to be replaced also by a circular scheme that relates to the three forms of inquiry in a concentric morphology. The central "C" component symbolizes the human centeredness of the design approach schematized in the model. The inner components of the scheme are proposed to represent the *reflection–in–action* and the outer components, the *reflection–on–action* principles of the design process.
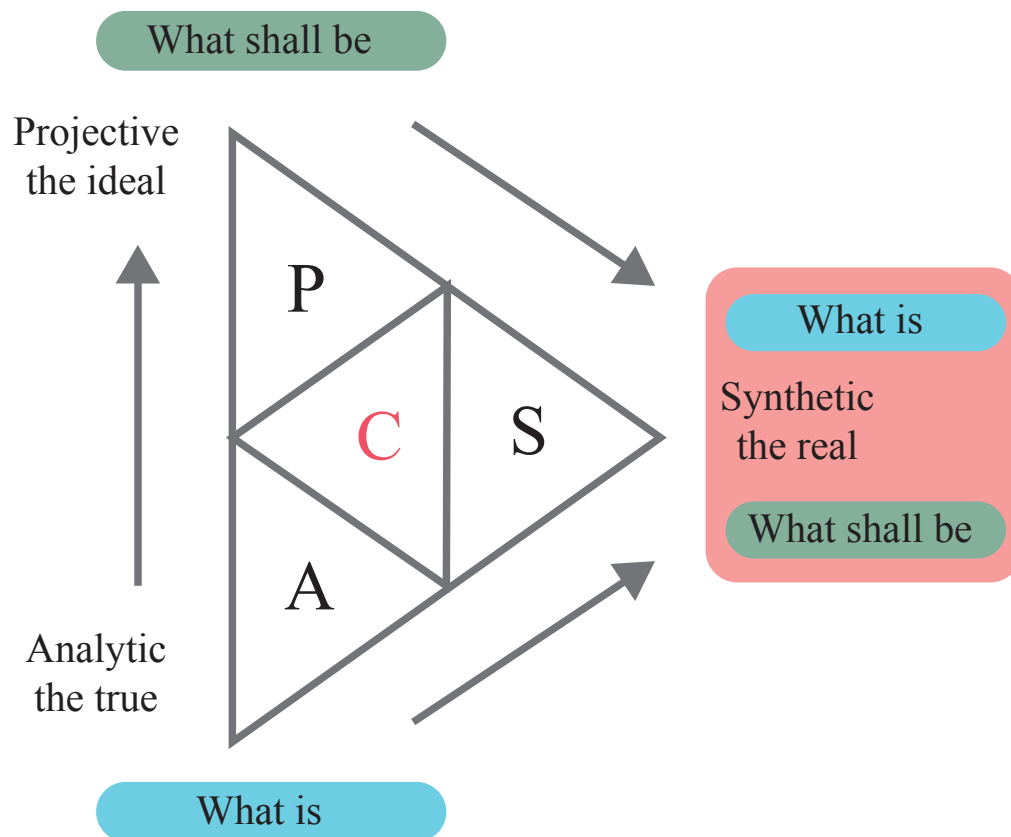
Figure 2. Operational interpretation of a design process.
(Hugentobler, et al., 2004 p. 7)

2.   <u>On reflexivity advance during design processes</u>

Design is embedded in trail–error processes and it is about what is not yet (Jonas, 2007). Reflection–in–action is related to how experience teaches us. It is described as reflecting on the incident whilst it can still benefit that situation rather than reflecting on how you would do things differently in the future (Schön, 1992).

In reflection–in–action, there is an innovative way of listening and resolving a surprising event during the design process. Designers reflecting decide what works best at a specific time, for that unique situation. Thus, this concept can be used to highlight the presence of reflexivity towards change. In design processes done by PWS it can reveal: 1) innovation in a design solution; and 2) change.

Reflection–on–action is understood as the deliberate review of one's action. It involves reflecting on how practice can be changed after the event (Schön, 1983). This concept can be used to reveal how PWS: 1) reflection on how their experience may lead to a solution; and 2) reflection on the solution they have reached to propose a new solution. Not all changes require transformation in the form or nature of objects, but all changes denote control over that which has been changed. In the environment, patterns of change reveal the laws it is subjected to.

F.   <u>How to Recognize Changes in the Environment</u>

To recognize change in the environment we first need to understand that it is human intervention that which causes change. By observing and recognizing change as human intervention we can also observe how the change game develops and how we act over the environment as well as the rules we use (Habraken & Teicher, 2000).

1.   <u>Perceiving configuration</u>

Studying the processes used to create inhabitations, Habraken and Teicher (2000) argue that to understand environmental structure, configurations need to be designated in ways that relate to the actions of agents as transformation results from agent action. Accordingly, the physical organization of the built environment can be described depending on one's focus of interest through conceptualizing the environment in terms of elements that are combined and grouped into configurations. Thus, a particular configuration can be defined by its elements named and then form more complex configurations (Habraken, 2000). This highlights how parts and configurations are under agent control.

2.   **<u>Defining control</u>**

Space and the objects inhabiting it are arranged to form configurations reflecting human preferences. Consequently, choice, relationship and placement of objects will depend on the inhabitant's action and reflective control. Habraken and Teicher (2000) refer to *live configurations* as configurations actively under unified control of a single agent. Observing live configurations and the way they behave reveal how the built environment is structured and who exerts control over it. It is necessary to differentiate ownership from control. Ownership does not imply transformation.

Habraken and Teicher (2000) proposed levels of organization of the environment, e.g., the room, the building, and the street network. Agents can vary and not every agent has control over every level. Each level connects to a domain of intervention, defining the way of acting and the expertise needed for transformation. Ideally, environment offers equilibrium understood as reduced situations where more than one agent exerts control. Levels also reveal dominance and dependence. The higher–level configuration dominates over the lower–level configuration; thus, the lower is dependent on the higher level. This can be understood if we think about the furniture in a room. Arranging and rearranging it occur normally in room usage; but if a room is rearranged, that will most certainly disturb furniture. For this study, the first levels of organization will be used to analyze control over the configuration of the environment, for example, furniture in a room, the room and the building. Figure 3 shows detailed information on layers, levels, and user control.
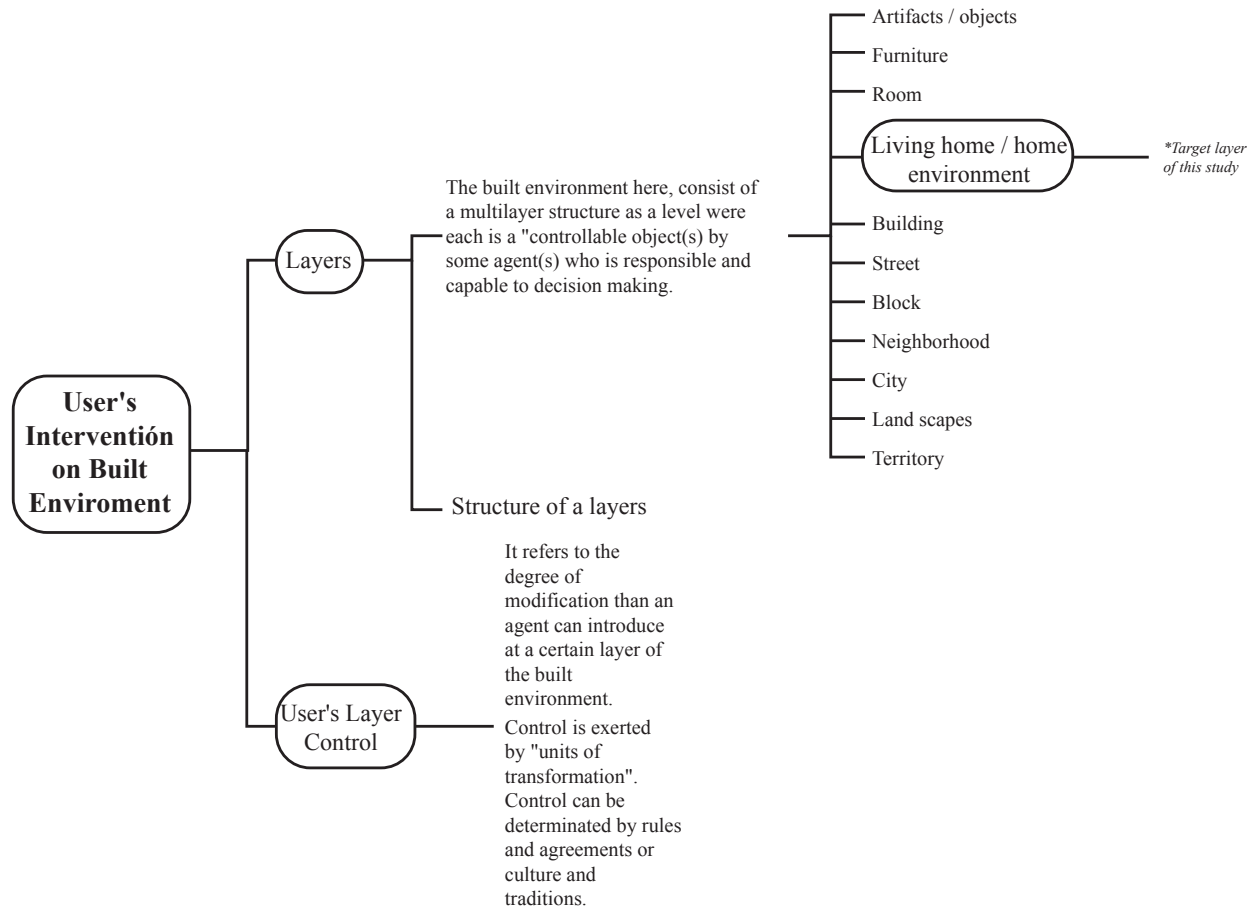
Figure 3. Layers and users control over them. Based on Habraken and Teacher (2000).

G.   **<u>Definition for Design Processes Initiated by People With Stroke</u>**

Buchanan (2001) remarked the importance of definitions for strategic and tactical purposes in inquiry. "A definition gathers what will be investigated and sets the relation of causes of subsequent inquiry" (Buchanan, 2001, p. 9). Most definitions of design have the clean simplicity and emotional force of descriptive definitions (Buchanan, 2001). A definition that describes this phenomenon needs to account for: 1) a process that is done in solitude, as PWS are often not aware that other PWS are struggling with similar environmental access issues; 2) the phenomenon occurring naturally in their environment, without the participation of professional designers; 3) invisibility

because no one refers to it as design; 4) PWS envisioning of improved or alternative products to satisfy their needs; 5) an embodied nature of such design; and 6) an empowerment of PWS to create and recreate their environment.

I suggest a descriptive definition of UID[1] as "the existence and recognition of alterations to the environment enacted by PWD, becoming a tool of empowerment for these individuals." UID is design ideation that accounts for the lived experience of disability, with its embodiments, displacements, and prosthetic additions. It generates possibilities that extend the performativity of the self. This definition challenges current ideas about the participation of PWD in design processes as well as the way in which modifications to the home environment have been understood and can support in developing a more efficient research in design from a disability–studies perspective. UID recognizes that PWS have an understanding based on the context of disability (Haraway, 1988). It also acknowledges that their experience is the product of daily practices in common places where their bodies interact with materiality, one which is designed to be inhabited by "able" bodies (Hansen & Philo, 2007). On the other hand, it claims that their design proposals respond to an existential experience (Pallasmaa, 2014). Furthermore, it places at the center of the design–disability intersection the definition of design proposed by Lucy Suchman: "System development is not the creation of intrinsically significant objects, but instead the cultural production of new forms of practice" (Suchman, 2002, p. 99).

To shed light on these issues, this study proposed a cross–case analysis of UID in a group of PWD as they strategize to adapt their home environments following a stroke. A participatory approach was used to involve PWD in the research process, to change how designers and rehabilitation professionals look at design of everyday living environments, and to encourage them to find ways to include disabled people more actively in this process. Six PWS were invited to participate in the study. Results show patterns among PWS who strategized to adapt their environment and those who did not. Similarities and differences on who and what influences this process and intergroup patterns appeared among PWS as active agents in environmental changes.

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1   User-initiated design as a verbal form to understand the phenomenon of design enacted by people with disabilities appeared in early discussions with Dr. Carol Gill at UIC.

H. **<u>Conclusions</u>**

Participatory design approaches are considered to reflect design as a social process (luck 2003). In doing so, they recognize we all have capabilities. Nevertheless, PWS constantly experience exclusion through the environment.

In the field of OT, the environmental press model emphasizes the importance of the environment in the adaptation process. The PEOP model describes the interaction of personal factors and the environmental factors that either support or restrict performance of activities. The MOHO argues occupation is dynamic and context–dependent. But modifications to the environment are viewed as strategies developed either by the professional therapist to improve the competence of clients or by PWD to overcome negative demands from the environment. Additionally the interactions disabled body-home spaces are seldom investigated in housing studies (Imrie, 2004).

In the field of disability, universalism has been criticized as a value. In UD, tools that consider embodiment have not been used (Hamraie, 2013). Consequently, many PWS feel out of place. Design theorists have argued the need to open "the space of potentials that the available circumstances afford for the emergence of new designs" (Botero et al., 2010, p. 1). They have acknowledged that the design space is co–constructed. Up to now, this opening has recognized design developed by users in the use stage, and defined it as an unpredictable response from the user to unexpected perturbations in the environment. However, this definition does not account for the design activity in which PWD engage when they modify their environment, specifically PWS.

The concept of "design processes initiated by users" seems to be a common concept in contemporary design literature, for example, changes to the environment proposed by non–designer are being studied in the innovation discourse but the experience of PWS doing design has been neglected from research in the field of design, even though they negotiate and adapt the environment and their interactions with it daily.

PWS are forced to adapt themselves to fit the existing environment, or to do so via trial and error, finding other creative ways to make the environment work for them and often doing this work in isolation, as they are often unaware that other PWD are struggling with similar environmental access issues. These active efforts to try to problem solve the environment can be viewed as *user–initiated design*.

UID recognizes that PWD have an understanding based on the context of disability (Haraway, 1988) and that their experience is the product of daily practices in common places where their bodies interact with materiality designed to be inhabited by "able" bodies (Hansen & Philo, 2007). On the other hand, it claims that their design proposals respond to a particular existential experience (Pallasmaa, 2014).

The UID concept has effects on the way in which we understand the process of design, the mechanism of ideation, and the experiences that these designs propose. User–initiated design needs to be recognized as a phenomenon. To do so, we need to understand how it develops and how PWD engage in it. Therefore, a research study is proposed to explore designs suggested by PWS in domestic environments.

IV.   MEANINGFULLY ENGAGING PEOPLE WITH STROKE

IN THE CREATION OF KNOWLEDGE ABOUT USER INITIATED

DESIGN: A PARTICIPATORY APPROACH

A.   **Abstract**

Design is a common human mental process used to create and recreate our environment. After a stroke, people often plan and design solutions for the challenges they face in their home environment. Yet, this user-initiated active design experience has been neglected in the research field of design, for is it fully understood as a strategy to overcome or adapt to environmental barriers disabled people themselves may face. Because design has been isolated to the realm of professional designers and rehabilitation professionals when disability enters the picture, the power of user-initiated design (UID) is often neglected. This paper explores the way in which participatory research methods can help reveal how people who have had a stroke (PWS) design, how they create their home environments following a stroke, how this process impacts PWS and their social world, how they create social spaces in which to participate and engage, and which environmental factors (social, cultural, economic, systemic, political) act as facilitators or barriers to this user initiated design. Participatory methods such as Photovoice can help illuminate this phenomenon by: 1) illuminating the active voice and experiences of PWS as active participants in this environmental design process; and 2) making the design process visible so PWS can confidently participate in and inform environmental design.

Keywords: participatory methods, stroke, knowledge creation, design, home environment.

B.   **Introduction**

Recovering from a stroke is a lifelong process in which the physical environment plays an important role (Jacobs, Kelly, & Sobolewski, 2007; Northridge, Sclar, & Biswas, 2003). Although the access needs of people with disabilities are addressed in public policies and practices that develop and regulate the physical environment (e.g., Americans with Disability Act, universal design, inclusive design and design for all), the ability of PWS to solve problems imposed by the context and to strategize on how to manage them in everyday life across different environments —social, physical and systemic (Lorig & Holman, 2003)— has not been studied from a design perspective. The

approach of this research implies that PWS are innovative users, who actively shape and personalize their environment, but whose experience and contributions in this process are not visible.

The active participation of PWS in the creation of accessible living environments can increase their sense of competence and enable their social participation. Consequently, it is necessary to understand how this process unfolds and which factors enhance PWS's active role in it. This paper will explore the way in which participatory research methods can help reveal how PWS design, how they create and recreate their home environment, how they interact with it after a stroke, and which factors enable them to take an active role in this process.

C.   **Literature Review**

The participation of people with disabilities (PWD) at different stages of the design process has been studied by user–centered design through collaborative and participatory methodologies (Binder et al., 2008; Lee, 2007; Sanders, 2002). To better understand the experiences of PWD, designers have proposed numerous approaches such as participatory design (McDonagh et al., 2010) and empathic design (McDonagh & Formosa, 2011). Participatory approaches are also used to involve PWD during design process in both Universal Design and Inclusive Design (Clarkson & Coleman, 2015; Clarkson, Coleman, Keates, & Lebbon, 2013; Story, Mueller, & Mace, 1998). Regardless of the acknowledgement of participatory design, user-initiated design processes developed by PWS have not been adequately studied.

The most common approach to design with PWD is *participatory design*, which is based on participatory methodology derived from participatory research. However, the act of designing with PWD raises a discussion regarding the stage of the design process in which they are invited to participate. If during the entire process including the ideation stage as in co-design or to by observed during task completion when given instructions as in user centered design under the perspective of the expert (Sanders & Stappers, 2008). Despite how early in the process they are involved, disability as a lived experience (Garland-Thomson, 2011) and a life-long process compels PWS to adapt the environment to their changing needs (Jacobs, Kelly, & Sobolewski, 2007; Northridge, Sclar, & Biswas, 2003). This change is attained through design activities that are not recognized by user-centered design or co-design because they are part of an autonomous design process.

User–initiated design (UID) is a phenomenon in which many PWS engage while daily navigating their less–than–accessible environments. However, it has been poorly researched and not recognized as design even though design itself is considered as a basic human activity, that is, every person who tries to transform an existing condition into a more desirable one is ultimately engaging in the process of design (Simon, 1996).

In the design process, the mechanism of ideation has two levels of imagination: one makes formal projections and the other simulates the emotional, mental, and sensory encounters with the imagined (Pallasmaa, 2014). The first imagines the object, and the second, the experience. Consequently, the qualities of what is designed are existential and stem from the encounter with the tangible (Pallasmaa, 2014). PWS who start design processes bring this complexity into consideration as they forge their experience with design and on the design solution its self insider design.

Then, the questions arise: how can we investigate this phenomenon, and how can we unveil this imagination? Participatory methods focus on a process of sequential reflection and action that has its own highly articulated methodological orientation, methods, and techniques (Spinnuzi, 2005). In participatory methodological frameworks, the interest is on who defines the research problems, generates analyses, owns and acts on the information, and on whether the results represent the participants' interests (Cornwall & Jewkes, 1995). Participatory methods, such as Photovoice, have proved to be effective in the production of knowledge, identification of concerns, and promotion of critical reflection (Wang & Burris, 1994). Photo elicitation uses visual images to obtain information. However, while photographic methods are commonly used in qualitative research to involve PWD in knowledge construction, it is less usual as a methodology to research design processes or user's perspectives on design.

Participant observations provide access to different types of information by gaining intimate familiarity with the participants, their environment, and their practices (Geertz, 2003). In participant observation, the researcher's interests determine which events are relevant as the researcher participates in ongoing activities and records observations (Patton, 2005). In this study, the researcher's design discipline–based interests guided observations to illuminate how the design process developed.

D.   **<u>Research Project Background</u>**

The concept of exclusion due to lack of access within the built environment (Pope & Brandt, 1997), added to an increasing aging population, has prompted the importance of design methods and solutions in the construction of more usable and universally designed environments. Hence, designers have been moving closer to the future users. Design for PWD incorporates approaches such as universal design, design for all, accessible design, barrier–free design and inclusive design. All these share the same ethical principles (Bieling, 2010) and are embedded in the struggles for equality.

Design by non–designers has been studied to explain innovative changes of products, design changes during production, and adaptation of products done by users (Brides, 2015; Candi, 2010; Gorb & Dumas, 1987; Hara et al., 2013; Nelson et al., 2009; Von Hippel, 1986). This phenomenon has expanded researchers' understanding of how, by whom, and where design is done (Botero et al., 2010). However, there are scant references in the literature for design done by PWD, specifically by PWS.

In the field of occupational therapy (OT), ecological theory bases explain how the critical active modification and adaptation of the environment supports continued performance and participation in life (Lawton & Nahemow, 1973). The environment–person interaction has been modeled to understand its role in supporting or restricting the performance of activities and full participation in society (Baum & Cristiansen, 2005). And it is argued that occupation is context–dependent and essential for self–organization (Kielhofner, 1995). Modifications to the environment are primary for OT professionals; however, modifications proposed by PWS are considered adaptive strategies that should be developed and taught to people by occupational therapists, rather than recognizing user design strengths and assets PWS bring to the process. Because OT, professionals are not trained as designers and knowledge production in their field is meant to improve occupation, modifications performed by them or by PWD are also not accepted as design by design professionals. Thus, in the OT field, the phenomenon of user-initiated design and its impact is not studied even though the importance of the environment is acknowledged as related to social participation.

User–initiated design is the process by which many PWD interact with and negotiate inaccessible environments (Sarmiento, 2014). For PWS, it is ideation that develops into design processes and design solutions to modify the environment, interactions with the environment based on PWS experience and the knowledge that this experience has given them. Despite the benefits of universal design, design for all and inclusive design in accessible design, according to the experiences and preferences of disabled users, these models are still inaccessible and do not reflect PWD's holistic user experience (Jacobson & Pirinen, 2007). PWD would like their environment to know and say something about them.

Having PWS participate in research and using participatory methods to do so provide insights on how people experience and transform complex situations into design solutions. A qualitative research approach was used to gather in–depth personal information from participants who have had a stroke and who seek to create and recreate their home environments to meet their needs and desires. This participatory approach drew the researcher's attention toward studying how disabled participants make meaning of their adaptations, actions, and activities to recreate and design their home environments. Because every person is unique, every stroke is different, and every home is distinct, this approach afforded several layers of data collection and analysis, encouraging the discovery of meanings and design strategies used by people living with stroke and long–term disability.

E.   **Methods**

1.   **Role of the researcher**

Contemporary qualitative research approaches consider that knowledge is constructed as the research process unfolds. My role as observer, interviewer, collector, and interpreter was constructed during this research as well. I realized that reflecting upon my position and experience related to the research topic was essential for the development of my role (Patton, 2005).

As an industrial designer, I know the world of objects and spaces that respond to human needs and desires. Human–centered design methodologies are part of the array of knowledge my studies have granted me. I am an ergonomist too, and consequently, I am interested in human occupation based on the concepts of social justice and equity. During the past decade, I have developed a genuine interest in Disability Studies. This mixture of events and

interests outline my skills to undertake this study: a solid theoretical stance, multidisciplinary methodological approaches, and a rich experience in analysis and transformation of human–environment interactions.

Qualitative research has developed different theories and methodologies to face the challenge of studying the user-initiated design phenomenon, such as creating participatory strategies, constructing rapport, and debriefing. These were implemented to address the issue of the researcher being an *outsider* as well as to address issues of PWS being outsiders to professional design.

2.   **Study design**

A qualitative research approach was used for this study. A comparative case study design (Merriam & Tisdell, 2015; Patton, 2005; Yin, 2009) allowed analysis and synthesis of the similarities, differences and patterns across cases; resulting in the identification of components supporting or hindering the active engagement of people with stroke in design. Likewise, a participatory methodology allowed for an in–depth exploration of adaptations to the home environment made by a group of people who had a stroke.

To address issues of trustworthiness and authenticity of the research strategies used in this study, triangulation, member checking, and thick description were implemented (Lincoln & Guba, 1990). Data was triangulated using several data sources and methods to reduce the effect of the researcher's bias (Lincoln & Guba, 1990; Miles & Huberman, 1994). Member checking during and after the data collection period was applied, and all the six participants provided feedback. Background data was gathered to establish the context of the study and a detailed description of the phenomenon in question. In this way, comparisons were made and transferability was addressed. Furthermore, the researcher's beliefs and assumptions, possible shortcomings in the study's methodology, and their potential effects were acknowledged and documented as part of the researcher's notes. This study design was evaluated and approved by the Institutional Review Board at the University of Illinois at Chicago (UIC).

This study was part of a larger federal grant project titled, *Evaluating Community Living and Work Participation Environments and Technologies for Use by People Who Have a Stroke: A Consumer–Directed, Dynamic Assessment Methodology.* An amendment to protocol #2005–0001 was submitted to the UIC Institutional Review

Board prior to data collection under this same title. *This research* project focused on environmental design and its influence on home, community and work participation of PWS. It involved consumer–directed participatory assessments of everyday living environments, on–the–fly problem solving of barriers, and strategizing solutions with peer mentors who also had a stroke and with access specialists including an occupational therapist.

3.   **Participants**

Six participants took part in this study. They were selected from a group of individuals attending the Stroke Rehabilitation Group at UIC. The target sample included people who had had a recent stroke, who were in or had completed stroke rehabilitation, and who were dissatisfied and wanted to increase their full participation in homes and communities.

A small number of participants is not unusual in case study methodology (Patton, 2005) as it allows for a deeper and broader understanding of the participants. Participants were chosen using criterion sampling (Patton, 2005). Time since stroke plays an important role in PWS approach to the environment (Lawton et al., 1982); thus, it was used as a selection criterion. This study used maximum variation sampling, according to Patton (2005) and Fulton (2011), to select six cases that represented a wide range of variation in the time since they had the stroke. Participants were selected as follows: two participants who had a stroke more than five years ago, two participants who had a stroke more than a year ago but less than five years ago, and two participants who had a stroke more than three months ago but less than a year ago. Participants had experienced a mild to moderate stroke (as defined in the NIH Stroke Scale) and represented diversity across age groups, race, ethnicity, gender, socioeconomic status, living condition, geography, level of previous home and work participation (refer to Table III for participants' demographics).

The following inclusion criteria were used: people aged 18–60, with at least three months after stroke incident, who had completed initial acute rehabilitation care, and who were interested in returning home. The following exclusion criteria were used: people without a documented history of stroke, with severe stroke or aphasia, who were not medically stable or able to participate in home activities, who were unable to give informed consent (self or via assent form with guardian), and who resided in institutional living establishments.

TABLE III
PARTICIPANTS' DEMOGRAPHIC CHARACTERISTICS

Participant	Gender	Age	Race	Time since the stroke
1	F	60	Caucasian	26 years 10 months
2	M	65	Asian	5 years 5 months
3	F	55	African American	3 years
4	F	68	African American	1 year 3 months
5	F	48	Hispanic	5 months
6	F	52	Caucasian	7 months

4.   **Data collection**

Data was collected in the participants' homes over a three–month period. The home is a private environment where PWS experience life, but also a place where they can exert authority to transform or intervene. Since PWS may have trouble walking, speaking, seeing or feeling, movement aids such as canes, walkers, and wheelchairs may be part of their environmental context, and a component of their design focus.

Each participant was visited two times. During the first visit, the researcher conducted an interview and an observation. A semi–structured interview using a guide was used (Table IV).

After the interview and during the home visit, participants were introduced to the Photovoice technique. They were asked to take photographs of their home environment during the week immediately after the home visit. A follow–up interview to verify and further investigate issues that emerged from data analysis took place during a three–week period.

a.   **First phase: issue identification**

The objectives of this phase were: 1) to identify changes in activities and/or changes in interactions that the participants have experienced with space and objects in their home environment following their stroke; and 2) to provide an initial focus to direct Photovoice data collection. This initial approach consisted of a semi–structured interview, a participant observation, and the introduction of the Photovoice technique to the participants.

i. **<u>Interview</u>**

Six participants were asked to identify activities they engaged in modifying their environment to better meet their needs (Table IV). Interviews were conducted following semi–structured guides and were recorded by the researcher. Audiotaping the interviews ensured the researcher could review data after each event. A professional company transcribed the interviews.

TABLE IV

INTERVIEW GUIDE QUESTIONS

Main question	Probe
Tell me about your experience of returning home after the stroke.	How did the way you do things changed?
	What do you have to do different now that you did not have to do before?
	Describe any changes in how you do things now.
How does having a disability influence your daily experience?	How does being disabled affect you in doing basic domestic activities?
	Having a disability can affect the way you do things in different ways. Some people might need help from a caregiver, some might need assistive technology and some might need changes to the space where they live. How has it affected you?
Have you or someone on your behalf changed or modified the space or objects in your home to help you perform activities?	

ii.   **Participant observation**

Participant observation took place at each of the six participants' homes. Detailed field notes were taken on the interactions: 1) between participants and their home space; and 2) between participants and the objects or products they interacted with, including AT.

Experience is built through one's relation with a context and is mediated by one's culture, but sometimes experience seems so obvious that it is necessary to have someone else observe. Through the observer's (the researcher's) eyes and expertise, not only are participant's internalized actions and activities elicited, but also the environment tells its own story. Interactions, spatial relationships, behavior, movement, and action are best captured in video. Thus, observations were videotaped to register the interaction, use, and accessibility of the environment. During the observation, some issues pertaining to changes in space, objects or interactions emerged. Participants were asked to elaborate deeper on those emergent issues by taking photographs.

b.   **Second phase: understanding user–initiated design**

The objectives of this phase were: 1) to gain basic understanding on how PWS engage in design processes and solutions to modify their environment or change their interactions with it; and 2) to identify factors (barriers and supports) influencing this engagement.

As explained above, the processes of PWS have not been identified as design processes in previous design research. Thus, an expert observation to identify activities commonly associated to design process was necessary to guide analysis of photo and interview data. Photovoice helped participants recognize, remember, and share how they adapted their home environments and how those design efforts enabled their daily activities. The Photovoice process was introduced in the first visit to the participants' homes and developed during the second one to verify previous information. The home provided a safe and open space for communication about participants' experiences with the home environment (Bergold & Thomas, 2012)

i.   **<u>Follow–up interview</u>**

A follow–up interview was scheduled to verify and further investigate issues that emerged from data analysis. To ensure validity of findings and analytical triangulation (Creswell & Miller, 2000), the participants were invited to provide feedback and member check the findings. During this second visit, the participants were also invited to talk about the photos they had taken to provide more detailed examples of the design process they went through to strategize their participation in this home space.

ii.   **<u>Photovoice</u>**

Because most design interventions have multidimensional characteristics and may change the way people interact with objects and/or space, the approach to data collection must be tailored in a way that participants can recognize, remember, and talk about their design interventions and interactions. A good instrument to collect data was photography. Photographs can be used to identify intangible factors (Harper, 2002). They capture an event occurring at a certain time in a particular space. They can also serve as a concrete way to retrieve something that has disappeared or document something that has appeared or changed.

Each person was encouraged to take photographs during a ten–day period. The purpose was to record and reflect on the participants' interactions with or modifications to their home environments. Participants were asked to take pictures of barriers and aids for the activities they carry out while at home. For example, the space and objects they interact with while doing tasks that they consider challenging after their stroke. The Photovoice technique was implemented to capture representations of the participants' realities, to which the researcher would not normally have access (Wang & Burris, 1994). Once the ten–day period was over, the researcher asked the participants to e–mail their photographs. Then, they were printed and used during the second visit to the participants' homes. Photographs incentivized the discussion on whether and how PWS engaged in design processes. An example can be seen in Figure 4.

Ph-2 Cane colection	
2	This one is old canes. I ____ them. I don't really use them any more. I keep them in case I need them, and a constant reminder of where I started and where I am now. Okay. I don't know, it's so hard to get a good foot on canes. If you see one you like, let me know. I'll send that one on. I didn't – one of those.

ESPEJO	Ph-1 Pill Organizer
2	"But the purpose for me getting this is to show you – see the red down the side. I have orange down this side. When we have lectures, guest speakers, I would also kind of do a very, my own caricature of the person that was speaking. Because along with the notes when I review the notes and that picture, it would remind me, oh that was the guy that said, "Blah, blah," even though I didn't have it written down".

Figure 4. Photovoice examples explained by PWS

c. __Third phase: Barriers for active engagement in user–initiated design__

The objective of this phase was to elicit information about the participants' individual and collective experiences with home modification. PWS are forced to adapt themselves to the existing environment, or to find creative ways to make the environment work for them. They often do so in isolation since they are usually unaware of other PWD struggling with similar issues.

i. __Focus group__

The participants were given the opportunity to hold a conversation with each other in a safe setting to process findings regarding user initiated design (Bergold & Thomas, 2012). Using pictures of the barriers and supports present in their home environments, participants talked about their experiences while navigating and modifying them. To ensure the participants' access and participation to the focus group, the research-

er used different probes and guided questions, in addition to the pictures taken by the group to illustrate abstract

concepts. The focus group took place in an accessible space at UIC. Refer to Table V for the list of questions used as

a guide during the focus group.

TABLE V

FOCUS GROUP GUIDE QUESTIONS

Question	Probe
Tell everyone a little about yourself.	When was your stroke? What do you do now?
Describe your experience returning home after the stroke.	Describe any difficulties in performing daily activities around your home.
Let's talk about changes you or someone on your behalf did to the space or objects in your home.	Did the space in your home change after the stroke? Do you use AT? Do you buy things designed for PWD?
What would you say to people about how those changes were done?	What made changing things easy? What made changing things difficult?
What changes where done to improve the conditions in the performance of daily activities?	Can you give us an example?
If you could speak to the people who designed some of the things you use to help you in doing daily activities, what would you tell them?	

5.   **Data Analysis**

All documents (transcripts, photographs and descriptions) were open and axially coded (Corbin &

Strauss, 2014). The researcher used a constant comparative iterative approach to analyses until themes emerged and

findings were saturated. In this approach, initial data was collected, transcribed, reviewed, and coded. Data sources were constantly compared with each other. Codes were revised, recoded, refined and organized as themes and criteria emerged related to user-initiated design.

In addition to stand–alone case analysis, cross–case pattern analysis among cases was used to examine evidence through multiple lenses. The selection of categories or dimensions across cases, within–group similarities, and inter–group differences also allowed patterns to emerge (Eisenhardt, 1989; Kaarbo & Beasley, 1999).

a. **<u>Within-case analysis</u>**

Codes were used to draw descriptive conclusions about individual cases. As part of the analysis, reflective remarks were gathered and transcribed for each case and later used to reveal underlying themes. Researcher remarks also were used to retain mindfulness during the coding process. Pattern coding (Miles & Huberman, 1994) was proposed to attain a second level of analysis. Patterns of recurring themes were bounded within cognitive maps, a cognitive map displays the person's representation of concepts and the complexity of a particular domain (Miles & Huberman, 1994) for each case. Later on, these maps set the foundation for cross–case analysis.

b. **<u>Cross–Case Analysis</u>**

A comparison among cases was used. Patterns emerged as the comparison of categories and dimensions across cases advanced. Patterns regarding within–group similarities and inter–group differences were also evident (Eisenhardt, 1989; Kaarbo, 1999). Patterns among PWS who strategize to adapt their environment, similarities and differences on who influences this process, and inter–group patterns among PWD as active agents in the environmental change emerged in analysis as well. Comparisons between participants in the same range of time since the stroke and between maximum variation in time where also done. Fragments from comparison can be observed in Table VI.

TABLE VI

EXAMPLES OF COMPARISON BETWEEN RECENT STROKE SURVIVORS-AND
LONG -TERM STROKE SURVIVORS

Participant (time from stroke)	Researcher observation	Participant Statement
P5 (Less than a year)	Strategy as in OT or design activity Equipment not used. Adapting the body to the requirements of the environment	"When I was going to rehab, they had different devices to help out. With working in the kitchen, they had **special cutting boards** that would hold the vegetables or fruit so that you could cut it with only one hand. I found them helpful when I went to rehab. **I do not have any of those devices at home because I make myself do as much as I can** with my right hand".
P1 (More than 26 years')	Strategy as in OT or design activity	"It's a **bag that I have created**. It's a bag that is a **book bag, water bottle holder combination**. I have the **divider sewn in with the fabric** so that I can put the water bottle in and not have any fear that it's going to fall over on my books or anything else that I have".
P6 (Less than a year)	Challenge Faced in Solitude Adapting to a new situation	"I have to **be dependent**. In a way this is an experience. I used to be very independent, be by myself. Now I have to depend on others. That is a challenge."
P5	Adapting to a new situation	"I've been learning how to deal with the situation. At first at home it was difficult because I had to get assistance, and **I'm not the kind of person that really sought assistance before**. I've learned to be **accepting of people's help"**.
P5	Challenge Faced in Solitude	"**I felt like a burden to everyone.** If I wanted to just go to the bath-room or get anything, I had to ask them".
P6	Challenge Faced in Solitude	"Sometimes my husband does the laundry for us, for the three of us. **But I feel guilty"**
P1	Independence	"If somebody gets upset that I walk slower or that I can't do things nor-mal people would do it, I just say, "That's the way I have to do it." Initially, I couldn't say that. It took a while for me to accept my stroke".
P3 (More than 3 years)	Adapting to	Go slower and think about stuff before I say something. **That's mainly about it.**

TABLE VI (continued)

EXAMPLES OF COMPARISON BETWEEN RECENT STROKE SURVIVORS-AND
LONG -TERM STROKE SURVIVORS

P4 (More than 1 year)	Strategy as in OT or design activity	"I love stick notes for the **reason of accomplishment**. It gives me a sense of accomplishment as though I actually got something accomplished that particular day. And so whatever's written on that stick note, once I take care of it, I can toss it. And it's out of my brain. It's out of my sight, and I feel as though I got something done today, which may not seem really critical to a lot of people. But **for me, it's important that I feel that I didn't waste the day and that I actually am making some progress and moving forward** and not just being stagnant".
P1	Share Knowledge Strategy as in OT or design activity	"I have made a couple of these for other friends. If someone sees it and says, "I'd love to have one of those." I will make one for them, but I don't mass-produce them or anything like that".
P2 (More than 5 years)	Share Knowledge Strategy as in OT or design activity	"Even that is – I had the **bigger horn, and that was a lot better**, but this is a second horn that we found and put on there because we gave my original horn to somebody else".

Finally, questions such as to what extent are people with disabilities given voice in the home environment adaptation process; which are the implications of collaborative design for people with disabilities, OT professional and designer were addressed. Nevertheless, this study had as its central goal the description and exploration of user initiated design proposed by PWS in the home environment modification process.

F. **Participatory Methods to Make User–Initiated Design Visible? A Critical Reflection**

Design is a human capability. Non–professional designers engage in activities to transform their environment on a regular basis, but there are different reasons for why those processes are not acknowledged. The first and foremost important is that, until not long ago, non–professional design had been neglected from the design space[2]

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2   Design space denotes the freedom one has to select from different options and to explore design alternatives; it also refers to relevant information in a design process (Westerlund, 2009)

because it had not been defined as design or validated as a genuine purposeful design activity. The second reason has to do with design educational programs that teach students that the traditional approach is the only valid way to design. Thus, if someone was not trained as a designer, designing is unthinkable for that person. This led to believe that any kind of activity regarding change through design had to be something else but design.

A process that is not recognized, has no name, and is done by no one is a nonexistent process. Participatory methods in this study served the purpose of shedding light on this user initiated design phenomenon. Reflection during the process of photo–taking, photographic evidence of how something had changed, and reflection on this evidence was sufficient to participants to recognize their engagement in the change process. Participant observation and Photovoice illuminated engagement in design processes, and resulted in an empowering experience for PWS as they took pride in speaking of their lived design.

G.   **Conclusion**

Contemporary design has advanced in understanding that in a fast-changing world people, groups, communities, companies, institutions and regions can, and in fact, design (Manzini & Coad, 2015). Design is a human skill used to devise life strategies and put them into practice. This means that if everyone can design, there is change needed in design research to document and respond to this user-initiated and directed approach. From a disability studies perspective, understanding PWS's experience with their environment, their embodied design cognitions, and how they served to solve challenges in the interaction with their environment can be empowering because it recognizes the ability, agency and creativity of PWS. This article helps address the gap in the design research literature that calls for exploration on how participatory research methods can be adapted to unveil who designs, but most important, to reveal why PWS engage in design.

V.   UNDERSTANDING USER INITIATED DESIGN:

THE STRATEGIES IMPLEMENTED BY PEOPLE WHO HAVE

HAD A STROKE TO TRANSFORM THEIR RELATIONSHIP WITH

THE HOME ENVIRONMENT. A QUALITATIVE STUDY

A.   **Abstract**

People who have had a stroke (PWS) face many challenges when returning to their everyday life after the stroke. This includes the fact that they come back home with a new disability experience. Recovering from a stroke is a lifelong process where the environment plays an important role. Many PWS solve the problems imposed by their inaccessible home environments through actions of adjustments, adaptations or transformations, based on their new body, mind and social interactions with the home environment. The current study argues that some of those strategies can be identified as design activities, aimed at changing existing situations into preferred ones.

To designate design activities, originated and carried out by PWS and highlight their importance as an empowerment agent, this research proposes the concept of user-initiated design (UID). UID is design led and directed by their lived experiences. Findings of this research show that these design actions impact PWS in positive ways as they gain agency and control over their own environments. To support this experience, PWS, their families and professionals such as occupational therapists (OT), designers and environmental designers need to understand how the user initiated design process unfolds and how PWS actively engage in it. The current study explored designs actions people with disabilities PWD —particularly PWS— generated in their home environment and the factors that enhanced or interfered with their active participation in these design processes.

The study used participatory methodologies (interviews, Photovoice, observations, and a focus group) to meaningfully engage PWS in research and to reveal how PWS design, how they intentionally strategized changes to their home environments and what role their lived disability experience played within this design process.

Through content analysis and triangulation of data, two-mayor areas of interest were considered to answer research question. The first, deals with the exploration of the existence of design activities initiated by PWS and the

understanding of the processes involved, and second is focuses on understanding the barriers and supports to the active engagement of PWS in UID.

In general, findings show that: PWS engage in design processes to transform their relationship with a specific environmental configuration; they perform activities to improve their own "user experience". They do so to find better responses to their needs, desires and deep aspirations. Engaging in UID requires PWS to: 1) reflect on and evaluate their current situation; 2) create desirable but achievable "experiential scenarios" per their embodied learning process; and 3) develop strategies to realize these scenarios based on their access to knowledge, experience and resources. This process is empowering for PWS as it challenges them to autonomously face issues and actively design or strategizes ways to address them. Although the time–since–the–stroke factor may be important to determine how PWS engage in design, it is also affected by the way PWS understand their own experience and motivations to change their life experience (Hassenzahl, 2010). This study generated recommendations to include PWS in design research, and to create initiatives for the stroke community to fully participate in UID processes, so they can develop skills, share knowledge and empower themselves and the broader community.

This research helps to inform the disability community, as well as the fields of design and rehabilitation, both of which play key roles in creating enabling or disabling living environments, depending on whether they incorporate the voice and experiences of PWS in the environmental design decision–making process or not.

B. **Introduction**

During the 1960's, the Civil Rights Movement demanded equal treatment, access and opportunities for PWD, thus challenging negative attitudes and stereotypes. In the 1970's, law protected the civil rights of PWD. The Rehabilitation Act, Section 504 of 1973 (United States Department of Labor, 2014), provided equal opportunities for employment within the federal government and in federal funded programs; it also established the Architectural and Transportation Barriers Compliance Board, which regulates equal access to public housing, public transportation, and vocational training. In 1990 The Americans with Disabilities Act was passed and it reinforces accessibility requirements' in the private sector (U.S Department of Justice, 2015). Designers have responded to the equal access

approach and to disability law by framing universal design (UD), barrier–free design and inclusive design. Under the concept of UD products and environments are designed to be used by as many users as possible, without the need for extensive or individualized adaptation or stigmatization (Connell et al., 1997).

The Architectural and Transportation Barriers Compliance Board is devoted to guarantee accessibility for PWD and develops design information and requirements for the design of the built environment with a non-discriminatory approach. The law covers private housing, housing that receives Federal financial assistance, and State and local government housing (United States Department of Justice, 2015). The act also requires owners of housing facilities to make reasonable exceptions to afford PWD equal housing opportunities, permitting reasonable modifications to improve accesses for PWD to their homes and to common use spaces. Additionally new multifamily housing must be design to be accessible for PWD (U.S. Department of Justice, 2015). However, PWS report difficulties with doing different activities in their private homes; even though they use assistive technology, accessible products and, in many occasions, a redesigned space. Environmental barriers to participation also deserve further examination for people with stroke, considering that stroke is the leading cause of long–term disability in the United States. The American Heart Association has estimated that about 795,000 people experience a new or recurrent stroke in the United States every year (Mozaffarian et al., 2015).

PWS report difficulties in home activities (Pound et al., 1999), which may impact their quality of life and their health outcomes (Ch'ng et al., 2008). A person's wellbeing is related to their home environment (Wahl et al., 2009), that is why design issues in domestic home environments have been studied in the disablement process and are considered an important public health concern (Wahl et al., 2009). Ideally, home habitation provides security and privacy. Nevertheless, these provisions can be challenged when impairment appears is (Imrie, 2004) such as experienced after a stroke. This is due in part to design conceptions that do not acknowledge and respond to impairments as part of the home habitation (Imrie, 2004). PWS are forced to deal with this issue by engaging in their own design processes to transform their home environments. This phenomenon can be defined as *user–initiated design* (UID), which is the process by which PWD negotiate and strategize inaccessible environments. For PWS, it involves

cognitions about what could be (scenarios) that develop into active design processes and solution testing to modify their home environment or the way they interact with it in their everyday life.

The physical environment is composed of space and objects in it (Habraken, 2000). PWS can interact with and modify space or the objects in it. They can also be satisfied with the way they perform an activity and the value it has for them, and choose not to actively design or redesign, or may also be frustrated with lack of knowledge on how to redesign and accept inaccessible spaces and objects. Research has shown that PWS can resume an activity if it is important, if it is satisfactory, and they receive support to do so (Robinson et al., 2009). If these conditions are not present, they stop doing this activity. Robinson et al. (2009) investigated who and what helped people resume previously valued activities after a stroke. They concluded that people learned how to modify their environment, use assistive technology, and accept help. Adaptation strategies, such as creating new ways of doing things to deal with the inaccessible environments after the stroke, may also be developed (Pound et al., 1999).

Despite the findings in OT that identify strategies developed by PWS to control the environmental impact after the stroke, research on these issues has not been conducted in the field of design which ultimately designs new places, spaces and objects for the general population. Although the access needs of PWD are articulated in public policies and practices through regulations of the physical environment as in the Americans with Disabilities Act and designers have developed approaches such as Universal Design, Inclusive Design and Design for All, the ability of PWS to solve problems have not been studied from a design perspective in social and physical environments (Connel et al., 1997; Clarkson et al., 2013; Gitlin et al., 2006a, 2006b; Lawton et al., 1982).

Although UID can be considered design done by non–designers, it has not been studied as such in the design field or how it may impact the future design and manufacturing of a product (Gorb & Dumas, 1987), nor in the field of innovation to understand the needs of users' unknown to the market (Von Hippel, 1986). Additionally, a significant number of researchers have asserted that this phenomenon is not recognized or referred to as *design* (Candi, 2010), instead opting to only recognize "professional design". This has two methodological implications: 1) there is no established framework to study the phenomenon; thus, it is necessary to propose one; and 2) the phenomenon

needs to be explored to determine if user-initiated design exists, how it works, and what implications it has for home design and the broader design process.

This study was part of a larger federal grant project titled *Evaluating Community Living and Work Participation Environments and Technologies for Use by People who Have a Stroke: A Consumer–Directed, Dynamic Assessment Methodology* (College of Applied Health Sciences Annual Report 2008). This research project focused on environmental design and its influence on home, community and work participation of PWS. It involved consumer–directed participatory assessments of everyday living environments, on–the–fly problem solving of barriers, and team work with peer mentors who also had a stroke and with access specialists including an occupational therapist.

C.   **Methods**

1.   **Participants**

Participants were selected from a group of individuals who had had a stroke and were in the rehabilitation group at the University of Illinois at Chicago (UIC). An amendment to protocol #2005–0001 entitled, Evaluating Community Living and Work Participation Environments and Technologies for Use by People who Have a Stroke: A Consumer–directed, Dynamic Assessment Methodology (College of Applied Health Sciences Annual Report 2008) was submitted to the UIC Institutional Review Board (IRB) prior to data collection (Appendix A). All participants signed an informed consent agreement. Consent forms contained detailed information about the purpose of the study, the participants' involvement in it, and the possibility to withdraw from it at any time (Appendix B). The form also explained that participation would be anonymous and completely voluntary. The researcher used a Letter of Invitation to Participate that explained the purpose and process of the study (Appendix C). For the follow–up, the researcher called and e-mailed the participants.

The participants were individuals who had had a stroke, who were at or had completed stroke rehabilitation, and who were dissatisfied and wanted to increase their full participation in homes and communities. They were selected through criterion sampling (Creswell, 1998). Time following a stroke incident plays a crucial role in one's approach to the environment (Lawton et al., 1982); therefore, it was as a criterion for the selection of participants.

Participants clearly fitted the following criteria: 1) experienced a mild to moderate stroke (as defined in the NIH Stroke Scale); and 2) represented diversity across age groups, race, ethnicity, gender, socioeconomic status, living condition, geography, level of previous home and work participation. The inclusion criteria: people aged between 18 and 60 years with a post–stroke period of at least three months, who had completed initial rehabilitation care and were interested in returning home. Exclusion criteria: people without a documented history of stroke who were not medically stable or able to participate in home activities, with severe stroke or aphasia, unable to give informed consent (self or via assent form with guardian), or residing in institutional living establishments.

2. **Study design**

The study took place in the participants' homes. Responses were collected over a three-month–period and a qualitative design was implemented using semi–structured interviews, participant observations, Photovoice, and a focus group. A comparative case–study design and participatory methodology allowed for an in–depth exploration in a group of PWS as they strategized to adapt their home environments following a stroke. In addition, the study utilized a participatory approach to involve PWS in the research process. Participatory methods helped to elicit silent and underlying design processes in which participants engage to transform their environment. Refer to Figure 5 for detail information on the study design for the present research elaborated by the author.

Cross case Analysis

Case Analysis

Semi - structured interviews

Participant observation

Photo voice

Facus Group

Debriefing

Member Cheking

Emerging themes

Open Coding

Axial Coding

Themes

Relating emerging themes + sub-themes

Patterns

Nodes

Matrix

Interpretative Synthesis
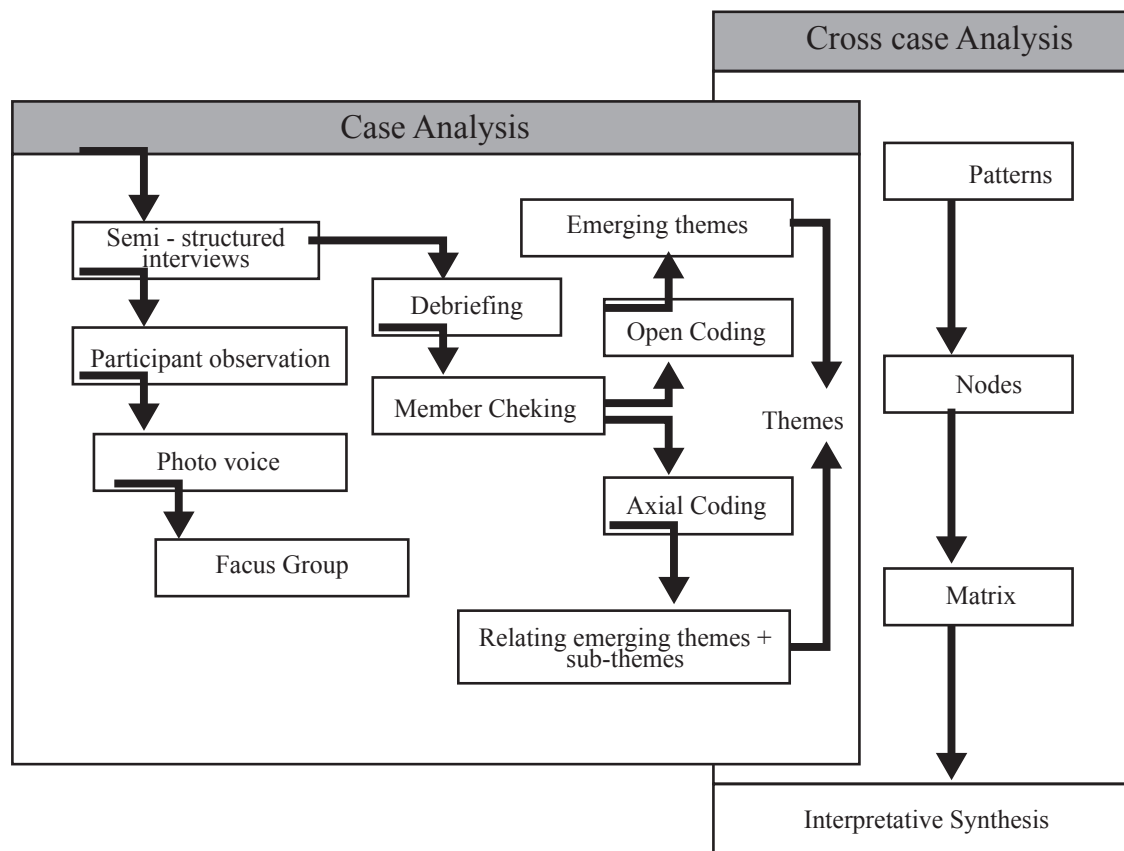
Figure 5. Study design.

Stand–alone case analysis and cross–case pattern analysis was used to see evidence through multiple lenses. The selection of categories or dimensions allowed patterns to emerge through within–group similarities and inter–group differences (Eisenhardt, 1989; Kaarbo, 1999).

For within–case analysis, the constant comparative method was used (Glaser & Strauss, 2009), since it allows similarities and differences to be examined within and across different types of data. This ensures that participants' experiences are approached in a systematic way resulting in theme identification, description, and organization (Corbin & Strauss, 2014). The researcher used visual formats such as cognitive maps and matrixes to facilitate data viewing. These matrixes presented data for detailed analysis and were used later for cross–case analysis. All data sources were

read several times for the researcher to get completely familiarized with them, only then the coding process began. To

analyze data, open coding followed by axial coding was used (Corbin & Strauss, 2014). Codes were assigned to raw

data for all data sources and then compared, identifying similarities and differences for each case. Afterwards, they

were grouped to present the triangulated methodological approach. Primary themes emerged from grouped codes (Pat-

ton, 2005). Refers to Table VII, to observe examples of how themes emerged from raw codes.

TABLE VII
EXAMPLES ON HOW THEMES EMERGED FROM RAW CODES

Open codes	Sub-themes	Emergent themes
• Develops and modifies products for their own use • Awareness of the need to adapt the environment • Adaptation to new needs • Evaluation of the conditions the home environment offers after the stroke • Degree of control over the home environment	Recognizing a new set of abilities Feeling able of performing the transformation Desire for independence	Motivations that trigger design activities in PWS
• PWS participating in and adapting the environment • Changing the configuration of a space in the home • Changing the structure of a space • Adaptation strategies to maintain independence	Skill acquisition Sense of space and place Social understanding	Experience associated to the body

TABLE VII (Continued)

EXAMPLES ON HOW THEMES EMERGED FROM RAW CODES

• Adapt standard solutions given by market design to meet needs, capabilities or expectations • Active adaptation and modification of the environment to support continued performance and participation in life. • Courses of actions aimed at changing an existing situation into a preferred one	Implementation	
	Evaluation of a situation	Process of engagement in design activities
• PWS who recognize a new set of design possibilities • PWS who explores change in products		
• Implement transformation to the environment • Adaptation of the home environment	Projection-ideation of possible solutions	

D.   **Results**

Researching of the activities PWS engage in to design and modify their home environments, and whether

this can be defined as design, requires a multilevel analysis that challenges the conventional concept of who is

designing and who is in control of that design process. The lack of research to understand design processes under-

taken by PWS is troubling particularly because: 1) Design theorists' have orbited around the question of how and

why we design. They have criticized the artifact-centeredness of design arguing its orientation to function, aesthetics

and technology as opposed to user–experience (Hugentobler et al., 2004); 2) Design researchers have advanced in the understanding of design processes advanced by non–designers (Bredies, 2015; Bredies et al., 2010; Hara et al., 2013); and 3) Design theorists suggest that design space be expanded to include actions taken while using products (Botero et al., 2010). All three points are related to UID.

A disability studies approach on UID can help inform design theory about how, by whom and where design is done by everyday disabled people as they experience accessibility and usability issues. A design approach on UID can help inform disability studies on the importance of UID as an empowering tool for PWS and occupational therapy on why PWS engage in design and what kind of impact it has on their lives. Themes on PWS engaging in design activities as well as on barrier and supports for active engagement emerged from interviews, observation, Photo-voice, focus group discussions.

Three themes emerged from analysis to understand PWS's active engagement in design: 1) Factors and motivations that trigger design processes; 2) Understanding design activities, (unfolding the process); and 3) Empowerment after enhancing their experience of use. Refer to Table VIII for detailed information on themes for active engagement in UID.

TABLE VIII
THEMES ON PWS ENGAGING IN DESIGN ACTIVITIES

Themes	Sub-themes	Implication
Factors and motivations that trigger design processes	Motivations to engagement.	Recognition of new abilities
		Desire to be independent
		Power to transform the environment
	Experiences associated with the body.	PWS find specific ways to perform an activity. UID done by PWS, acknowledges the needs and preferences of doing things on our own.
		Autonomously executing an activity is related to embodied knowledge. Most of the time appropriated design should be tailored to each person.
	Feasibility of the chosen alternative.	Modifications to the built environment can be done when there is ownership, functional and technical knowledge, and availability of resources.
Understanding design activities	PWS who engage in UID, analyze carefully, problematic situations in their interaction with environment. (problem sphere)	Understanding a problematic situation includes the simultaneous consideration of their embodied knowledge, along with the requirements of the activity and demands from the used layer(s) of built environment.
	PWS who engage in UID, can imagine solutions that could be implemented to overcome problematic situations. (creative thinking sphere)	Analytical, creative and synthetic thinking is required in UID.
		Non-intentional design, design-in-use, and silent design are used by PWS as alternative forms of UID.
	PWS who engage in UID, undertake the task of implementing their own designed solutions. (synthesis sphere)	PWS, needs to develop criteria to evaluate designed solutions considering functional, technical and financial aspects.
		PWS need confidence and agency to implement solutions. Family and community support is crucial. Starting with small projects or low cost prototypes, helps PWS to gain confidence.

TABLE VIII (continued)
THEMES ON PWS ENGAGING IN DESIGN ACTIVITIES

Empowerment after enhancing their "user experience"	PWS who engage in UID are continuously learning by doing.	PWS needs to be encourage to try and make mistakes, as these processes refine solutions and lead to more effective and efficient implementation of the design.
	Designing and implementing their own solutions change the perspective of PWS about the built environment.	
	PWS who engage in UID, feel the power of controlling their own environment, and have greater control over the life they want to live.	

i.   <u>**People with stroke engaging in activities to transform the environment**</u>

Design is an intellectual process oriented to modifying or transforming the material environment to adapt it to individual or collective needs, requirements or desires. The existence of a design process comprises at least three phases: evaluation of the situation, ideation of possible alternatives of transformation and making the chosen solution feasible. Findings show that people with stroke frequently carry out design activities in search of better responses to their needs, desires and aspirations. Findings show participants evaluate the situation they want to transform, devise alternative solutions and implement small or large transformations in their home environments to improve their life condition and overall participation. Once the goal is achieved and depending on the results, the solutions are improved in a continuous design process. To exemplify this P3, comments:

> I think because the [lack of] mobility and the fatigue early on, I would make sure that whatever room I was in, I had everything. I needed to do whatever it was to do, whatever it was to do for three or four hours at a time. That being maybe a book, definitely the telephone; I always kept nearby. Meals, any kind of snacks that I might need, I did a lot of cereal bars and yogurt.

P3 and her family ideated solutions to overcome the situation and implemented them. The first solution consisted of modifications to the use of an object as well as changes in the configuration of the spaces in the home to adapt them to the needs and conditions of the P3 after the stroke. The solution and its implementation was described as follows:

We had a small refrigerator …the boys put it in my bedroom for me, and the wheelchair was in the room.

But, as her conditions improved and she wanted to move around, the second ideated solution and its implementation was described:

As I got stronger, I used a backpack to get from room to room. So, for instance, meals that would have were typically things that were transportable and convenient: Cereal bars, Yogurt. And so, from the kitchen to here, which is –what- about 20-30 feet, I would have my backpack and put my eating utensils, napkins, whatever it was, my yogurt, my cereal bar, put that in my backpack and then walk to the table.

For most people these adaptations may seem trivial, but for people with disabilities, particularly for people with stroke, every transformation of their environment is vital to increase their autonomy and to promote their participation in the community. This can be observed in the followed comment by P3:

So that enabled me to really carry and transport more things that I was physically able to do with my hands and then still use my cane"; "…It seemed small, but it really empowered me. I felt as though I could do something by myself.

Designers do not easily enter PWS´s homes; rather they work from design studios. So, it is very difficult for professional designers to understand these lived experiences; consequently, they can not generate appropriated solutions even using participatory design approaches. Thus, something such as a backpack targeted specifically for PWS is not available in the market, and has not been designed despite the number of people that have a strokes per year who could use such a redesigned product.

Once the existence of design processes initiated by people with stroke was verified, the next phase was to understand how those processes were developed. The main questions in this phase were to understand: 1) what are the factors that trigger or motivate people with disabilities to advance design processes; 2) how those processes unfold; and 3) what are the effects of these processes on the participation and empowerment for people with disabilities.

a. **People with stroke's factors and motivations to trigger design process**

In understanding the factors or motivations that trigger design processes three findings arose as driving forces to trigger design processes initiated by PWS: 1) Recognizing and accepting their new set of abilities; 2) Increasing desire for autonomy; and 3) feeling able to transform things in the home environment to fit their needs. P1 commented on the process of adaptation to new needs:

> Ok, first off, I had to learn how to write and how to navigate everything left handed because I was dominate-right-handed person. So everything is on the left side because it's very hard for me to reach over the right side to get anything.

Results showed that without the recognition and acceptance of the new set of situated abilities after the stroke, it is very difficult to undertake appropriate transformations of the home environment. For PWS, a central challenge is to understand and accept the new set of abilities their bodies and minds have when trying to perform the same tasks they carried out previously in their home environment. Recognition and adaptation are part of a long process that varies from person to person with the degree of motivation to adapt to the new condition, and the support or barriers within the environment (built, social, economic, sociocultural) to support these adaptations.

For many of them, when returning home after the stroke, there is a feeling that their space is now a threat, as Participant 4 pointed out:

> Well, I was afraid to go up and down stairs because I Thought I would fall. I didn't go up and down. I just stayed in the house. I didn't drive. I didn't bowl. I didn't do anything. I just stayed in the house so I wouldn't fall, until I got my strength back.

A second challenge for people after the stroke is to evaluate the conditions of the domestic environment in relation to the possibility of those conditions to facilitate or hinder the execution of daily activities under the new capacities of the body and mind. The faster people with stroke become aware of this bodily condition, the possibility of initiating design processes is favored. PWS build their experience of interaction with their environment based on how they solve these two challenges.

Consequently, "user experience" or the experience of use that PWS have can be defined as a subjective valuation of a person as a result of their occasional or permanent interaction with things or elements which belong to the environment (objects, spaces, digital environments, public environment, etc.). In terms of accessibility, usability, allowed autonomy, empathy, pleasurable, or desire.

People gain experience interacting with their environment. Experiences are stories where people dialog with the their world through actions (Hassenzahl, 2010). An experience is subjective, holistic, situated, dynamic, and worthwhile. *User experience* is a subcategory of experience, focusing on the motivation, perception, cognition, action and emotion, of a *user* when doing an activity on a layer of the built environment to obtain an expected result.

As users, PWS face an environment that remains unchanged even though their bodies have changed. PWS constantly build embodied knowledge from their experiences as users, and implement that knowledge to exert control over the environment to gain independence, freedom and control. They usually do so by interacting with their environments and adapting and modifying them to fit their needs and desires.

But to understand PWS experience of use and how this experience influences the undertaking of design processes it is necessary to study the role situated embodied knowledge plays as part of building the process of experience of use. To illustrate the importance of this aspect P1's comments are enlightening:

> I had to learn how to write and how to navigate everything left-handed because I was dominate-right-handed before…Change, yeah. You realize now, I have everything on my left side. Everything is setup here for left-handed people or a left-handed person.

P1's comments alert us about the importance of space been modified after the stroke. Places such as laundry rooms and kitchen elements and configurations should fit PWS's bodily new conditions. Unfortunately, P5 comments:

> Now, nobody actually came out to do an assessment of our home for us. And it was really kind of disappointing to know that they show have done that.

An important point is that a person's experience cannot be dissociated from the body. Our body always mediates interactions with the environment. To explain this Merleau-Ponty (2012) used the concept of "lived body".

He states that our body manifests to us as a possibility to act in the world and change our point of view about it. To

illustrate importance of the experience-body relationship P5 comments:

> I try to be myself, meaning cooking, washing dishes, but it takes me a long time. My energy is not the
> same. For example, if I want to cook something, I get tired. I have to stop doing what I'm doing and rest,
> and later go back. Sometimes it takes me hours what used to take me have an hour.

Consequently, our body plays an important role in engaging in design and in generating new ideas.

Embodied knowledge —derived from Merleau-Ponty's phenomenology — is a type of knowledge (including the

process of embodied learning) in which the body knows how to act. PWS must recognize a new set of abilities after

a stroke and start an embodied relearning process. Per Tanaka (2013), PWS continuously use that acquired embodied

knowledge to transform the environment so that it better responds to their needs and desires (Gitlin et al., 2006a;

2006b; Lawton et al., 1982).

But recognition and acceptance of the new abilities of their bodies, additionally requires a strong moti-

vation to undertake modifications of the built environment. This motivation comes mainly from the desire PWS

have to perform their daily activities autonomously, looking for the least dependence on other people. this process

includes: 1) skill acquisition; 2) sense of space and place; and 3) social understanding

PWS develop adaptation strategies to maintain their independence, freedom and control over their environments

and choice of daily activities (such as feeding, bathing, dressing, grooming, working, homemaking, or leisure). In this way,

they actively improve their *experience of use* in daily life in the home context, and in turn, gain a sense of independence and

control affiliated with that experience. For PWS, quality of life is related to actively engaging in meaningful life situations

(Hammel et al., 2006). Talking about the use of an object to gain independence, P3 pointed out:

> So that [the backpack] enabled me to really carry and transport more things than I was physically able to do
> with my hands and then still use my cane. I think that was big for me, the idea of the backpack, which was
> what my OT suggested. It seemed small, but it empowered me. I felt as though I could do some things by
> myself.

Finally, as part of the user experience, another factor that triggers design processes is related to the degree

of control that people with stroke have or feel about the built environment (an element, or space) they want to trans-

form. This degree of control to intervene is related to factors such as the ownership of the element, the knowledge to

transform it and the available resources to support both. Participant 1 pointed it out:

> I have rearranged this place a couple of times. Getting out of bed – it's easy for me to walk through the bed
> area. Yet, I wanted a little bit of a divider from the bed part to my living space. I have the divider up there.
> Yet, I wanted to watch TV whenever I am in bed. I had to clear a space and move my chair over to the left
> side of the room, so I can watch TV while I'm in bed if I want to. [P1]

Built environment denotes surroundings humans have intervened to respond to their life activities. In

housing studies the home the place that gives shape and meaning to people's everyday lives (Imrie, 2004). Empow-

erment for PWS is a result of being able to alter their own environment, to select objects they want to use within it,

and to choose a daily routine. It is also derived from having a personal space that reflects and upholds their identity

and interests (Bratt, 2002).

The built environment consists of a multiple–layered structure organized by the orders of form or mate-

rial organization, place or territorial organization, and understanding or cultural constraints referred to as levels of

controllable objects and spaces. Agents who are able to make decisions over the environment exert control. Change

is caused by our interventions Control can be determined by rules or agreements such as characteristics and develop-

ment of a neighborhood and culture or traditions such as spaces for educational activities (Habraken, 2000). As P2

pointed out, talking about modifications to the home space and structure.

> So, we hired a contractor to come in and put in a shaft. And then the elevator company came in and in-
> stalled the elevator. That was a saving grace for us because it gave me a lot of mobility to be able to go up
> to the second floor, into our bedroom, and into the shower and everything else like that. Then we also made
> a decision to take out our tub in the master bedroom and put in a walk-in shower. That was another big
> expense too.

Change is caused by our actions on the environment; thus, when we have control of the environment, we have

learned how to be agents acting upon and exerting control over it. By assessing user experiences while performing activi-

ties in a specific layer for example activities within a room, PWS can determine the degree of control they have over that

specific portion of their home environment. If they have control of that specific layer, they can change elements (add,

eliminate, combine) or configurations (dispositions of elements) such as remodeling a room or rearranging the furniture

to make an accessible path. If they have control, they can advocate for change of, for example, the configuration of the objects in the room to improve mobility, or change in the structure of a building to enable greater accessibility; they can even change an element outside the home, such as a sidewalk, to further support community participation.

The structure of a layer is composed by the elements used by a person to achieve a specific result such as objects, and the specific configuration or disposition of those elements that will determine the interactions in terms of usability as well as the user's perception in terms of sensible valuation. Thus, another form of control is achieved when changes are executed over the structure of a layer such as the ones P2 had done in their house:

Then we took out all the carpeting and put in hardwood floors so I wouldn't trip.

The configuration of objects such as furniture and assistive technology and the arrangement within the space can be understood as control over the layer room. But if the room is rearranged, all objects in it are modified and, thus, control over a higher layer of the environment is exerted, just as P2 pointed:

Well, when we remodeled the kitchen, one of the things that was important was to make it functional.

b. **<u>Understanding the process of engagement in design by people with stroke.</u>**

Results of this study show the existence of three design processes in which PWS engage to modify their home environments and adapt to their new body condition. The first process deals with the individual taking a different perspective on their daily life post stroke, and identifying representations of challenges that they would like to transform if they could. The second process considers ways to devise solutions that includes hunting the market and self-conception of possible solutions. The third process involves the decision to implement one of the solutions and to find ways to manage barriers and enable supports and resources needed to do an effective implementation. The implemented, used and evaluated solution generates a feeling of satisfaction or dissatisfaction that promotes or stops new processes. This can be a long process with many obstacles, but for them it means having the empowerment to improve their living conditions and participation.

Very often, PWS can describe an annoying situation in their daily lives, but they cannot go forward in the search for solutions to change it. At other times, they imagine solutions that do not respond adequately to the situation they are trying to transform. In some other cases, they clearly know the problem, imagine solutions, but cannot implement them for different reasons, including lack of knowledge or lack of resources to make these solutions a reality. Findings show that a design process, capable of transforming realities, requires the ability to advance the three processes previously described, and which can be defined as analysis, projection and synthesis. During the analysis phase or problem understanding sphere, there is an embodied understanding produced by living and directly experiencing a challenging situation. Practices create an engagement with the environment; they configure and embody awareness that then mediates the offers or opportunities within the environment (Degen & Basdas, 2010). PWS have knowledge about their body and they can decide if they want to engage in an activity or not and how it could be done. As P3 stated:

> So, I think I find that I have to really plan simple tasks in to get them done more than I did before. I would just do things. But because of the limited mobility and the way my brain functions now, I find that I have to write things down, make a note, and really plan things out a lot before I do things.

PWS gain this embodied knowledge when dealing with a layer of the environment. P3's experience with the environment after the stroke depicts it as:

> So, it is a kind of strategy that when I walk in the kitchen, 90 percent of the time I'm walking from the bathroom or bedroom. So I see that. It draws my attention to note that I have on the cabinet to take my medication. My big green cup is there to remind me to drink water. But to your point also, when I walk out of the kitchen and I see this mirror again, each stick note has a story behind it. My eye is drawn to the stick note. I can see the reflection of the flip chart there.

Embodied knowledge also builds our understanding of activities that take place on a specific layer of the environment, such as a specific room. P2's spouse points out changes made to a room:

> Well, when we remodeled the kitchen, one of the things that was important was to make it functional. So, as you saw, Jim was able to maneuver from here to get to the coffee. And he doesn't do much in the kitchen because I'm afraid that he's going to drop something because he only has one arm. So he has to be able to balance and hold something. So, with this, at least a little bit he's able to lean against it, so if he does have to, he's up against it and he walks and slides the stuff around. So, that was important to lay out the kitchen.

As evidenced in the previous examples, understanding in depth the situation that wants to be transformed, is a fundamental step in the process of design initiated by PWS. This process requires establishing the interacting relationships between the new abilities of the person in relation with the activity to be performed and the different layers of the environment that support it (elements, spaces, etc.). Once the situation that PWS wish to transform is understood, the phase of ideation-projection begins. The purpose is to find solutions adjusted to their needs and conditions as well as to the conditions of the environment.

In design, projection requires the ability to foresee the future during the present through a projection. That means, to envision the experience we want to live (Hugentobler et al., 2004). For PWS, it requires they anticipate possibilities in the environment that respond to their embodied knowledge. It is to imagine the possibilities the future environment can offer based on the way they do activities now. Projection involves imagining our intervention and our experience with inhabiting that environment (Pallasmaa, 2014). There is always a purpose when an intervention to the environment is imagined. P2's spouse comments:

> When we opened the kitchen, it was for the main purpose of keeping him engaged with safety as number 1, but also with disability, there is isolation. And this way, with an open kitchen, he can be part of what I'm doing, even if it is sitting and watching.

When PWS establish or anticipate possibilities around their body, the process of anticipation gives them the opportunity to consider, plan and design solutions that can improve their experiences. While designers should use emphatic imagination to approach PWS experiences (Pallasmaa, 2014), PWS only need to use their own memory and cognitions.

Memories of human experience and the sensory stimulation that they provide are fundamental for creative actions (Treadaway, 2009). Furthermore, PWS can respond to future demands from the environment (Lawton & Nahemow, 1973); this means that by maintaining their sense of competence they may in fact solve problems in other layers of the environment too. On memory and cognition P6's comment is a good example:

> But learning to be left-handed when I've been right handed for over 50 some odd years that was the biggest struggle. But I've done pretty well.

Through empathic methods, designers gain a good understanding of PWD experiences (McDonagh et al., 2010; McDonagh & Formosa, 2011). However, by using their own creativity, only PWS can propose design solutions that give them voice and control at the same time. Since designers do not typically share this lived disability experience, they cannot use the same sense of control P5 and one his relatives pointed out how by transforming an object (Figure 6) he gained control over a different layer:

> Well, the cane was originally designed for… for Christmas. You make light of what you have. A disability is no fun… but really, it was to say, yes, you're disabled, but why be boring? ... And of course, it serves its purpose because…at the theater… for others to see him as you're coming.

Figure 6. Christmas cane taken by P2.

Another case to illustrate projection is that of P1, who mentioned how she gave up an activity because it did not respond to what she knew about her body or what she wanted and enjoyed. This situation established different possibilities for a solution that involved the way she could do an activity if she could control a layer of the environment.

> I used to be a professional seamstress. I tried sewing after I was released from the hospital, probably a couple of years after that. I found it such hard work and that wasn't what sewing used to be for me. It used to be a very enjoyable thing I would do as relaxation. I couldn't do it as relaxation any more. So, I gave it up. P1

Considering the possibilities of their body, PWS can anticipate solutions, even if they must control a specific layer of the environment, for instance, an object in a room.

> My aunt passed away. She had this sewing machine and my cousin said, 'Do you want it?' So, I said, 'Yes, I'll take it'. At that time, I was thinking of sewing. P1

Finally, PWS search for new ways to do activities in a specific layer of the environment:

> I can't do any hand sewing. So, I learned how to sew one–handed. P1

Or several objects in a configuration P1:

> I have rearranged this place a couple of times. Getting out of bed – it's easy for me to walk through the bed area. Yet, I wanted a little bit of a divider from the bed part to my living space. I have the divider up there. Yet, I wanted to watch TV whenever I am in bed. I had to clear a space and move my chair over to the left side of the room, so I can watch TV while I'm in bed if I want to.

Finally, PWS need to synthesize and to envision improved solutions. Design synthesis is generative; it requires the ability to organize in a logical way, prioritize and see relations in the data you have. Through design synthesis, sequences of change allow the existing components to evolve into new ones (Kolko, 2010). Design synthesis also involves creating abstractions and, sometimes, simplifications. During the synthesis process, people who design evaluate as they prioritize solutions. When engaged in UID, PWS also go through all phases of synthesis. P1 shows a synthesis process as she talks about the bags she has made:

> I've made several different bags because the first bag, I put a pocket on the outside. Then I thought, well now, I probably better put a flap over the pocket. So, a few bags later I started putting a flap over the pocket.

> Then I started making it wider because I wanted larger books. Also, my iPad, to put my iPad in there. Then the most recent modification I did it on was to put extra fabric on the inside where the water bottle sits.

> I have bags that I just use for – I made for just the water bottle.

> Well, no. No, it's one of the first bags because it has a flap. It's about four or five generations.

> I put a little pocket on the outside to carry my keys or my CPA Pass, that sort of thing. So, I was doing that for a while. I made a bunch of these for people too.

A different designed object by P1:

> I made vests. I have about three or four vests. I don't wear them much anymore, but I refuse to give them up. I made vests for people. They would say, "Oh, I want a vest this color." I made probably five or six vests for people.

c. <u>**Enhancing the experience of use of people with stroke, through design**</u>

User-Initiated Design as a tool for enhancing daily experience is a learning process associated with reflection. Knowledge remains after the experience of conceiving, implementing and improving solutions to fit needs and desires. This process is more specifically defined as learning through reflection by doing. Learning is hence the process of knowledge creation by means of transforming experience (Kolb, 1984, p 41).

There are modes to grasping experience and of transforming it. Kolb (1984) describes two modes of grasping experience this are: feelings or concrete experience and thinking or abstract conceptualization. To transforming experience Kolb (1984) proposes: reflecting or reflective observation and acting or active experimentation. For PWS, learning from their daily user experiences and designing strategies to improve them is a continuous process. Some designed solutions work well in practice; others need to be redesigned to obtain better results, as in the case of P3:

> So, it may be just a name –I have a sticky note with your name on and today's date or next week's date– or a task that I may do. And I have them color–coded to help me because I do have a visual deficiency. So, the bolder the color, the more important it is to me, and it will draw my eye to it first. So, that's a strategy I use.

This was also P2's situation:

> So, one thing that my wife came up with, which was a very inexpensive way, was we bought the circular chair that rotates, the pad. It was about $30, and it turns. And it didn't work that well. The concept looks good, but actually what it works out well for us was she bought contractor's plastic bags and put it over the seat and was able to put on that.

On the other hand, interacting with and changing their home environment gives PWS's lives meaning. It contributes by improving their physical comfort and safety according to their embodied knowledge. Solutions devised by PWS promote their emotions; because these solutions are embedded within personal and cultural meaning, and simultaneously, symbolize personal histories and values. This creates a sense of belonging and empowerment. As an example of finding meaning through design, P2's spouse remarked:

> But the openness of the kitchen was also designed so he can maneuver. It's small, but it's functional. Items are placed where he can get them. He can sit and feel safe and be a part of what is going on in our lives.

> But I think the three key things with disability is keeping the person engaged, being a part of what is going on, and feeling isolated. And walls do that. Furniture does that. Everything does that. So, that was our key focus. How can we keep him a part of what's going on and engaged in our daily lives?

Finally, as a result of exerting control over the environment PWS gain power over their lives. For Rappaport (1987) empowerment is a process to gain control over important issues. There is a difference between individual empowerment and organizational or community empowerment Zimmerman (1995). He argues that in individual empowerment sociopolitical and contextual factors are always present. Empowering processes are where people are given the opportunity to control their life. UID can be an empowering process for PWS as they can gain control over different layers of the environment and, ultimately, feel proud of themselves. When asked if the researcher could see some more things she had made, P1 answered:

> Well, sewing is the main thing. I can't show you anything, except I can show you what I've learned from them. I've walked two half marathons… both for the American Stroke Association.

> To the question about bags that she would keep, P1 replied:

> I'll show you the one that I will keep… I sewed on this patch for the American Stroke Association. This is the one I used whenever I was walking my half marathon. So, I will keep it for that reason.

> This comment shows the power of design.

To argue PWS develop a complete process of design the author elaborated a visual representation of all the elements Wolfgang Jonas proposed a design process model proposed contained (Hugentobler et al., 2004). On the right side of Figure 7 the design process model Projection-synthesis-Analysis is depicted (Hugentobler et al., 2004, p. 7) On the left side the authors adaptation based on findings in the current study. For example for PWS analysis will depend on their new set of abilities or their embodied knowledge, projection will be aimed at solving the interaction person-environment during daily activities and synthesis will be in the form of interventions to the environment. All this process is mediated by PWS's experience. The left side also represents the process of reflection in action or the process of creation while the lower circle depicts the process of reflection on action or the capability PWS have of learning from the design process. Figure 8 shows how the three figures look together in a user-initiated design process model. Figure 8 is then used to show three complete design processes done by participants in this study and serves the purpose of answering the question about if PWS design.
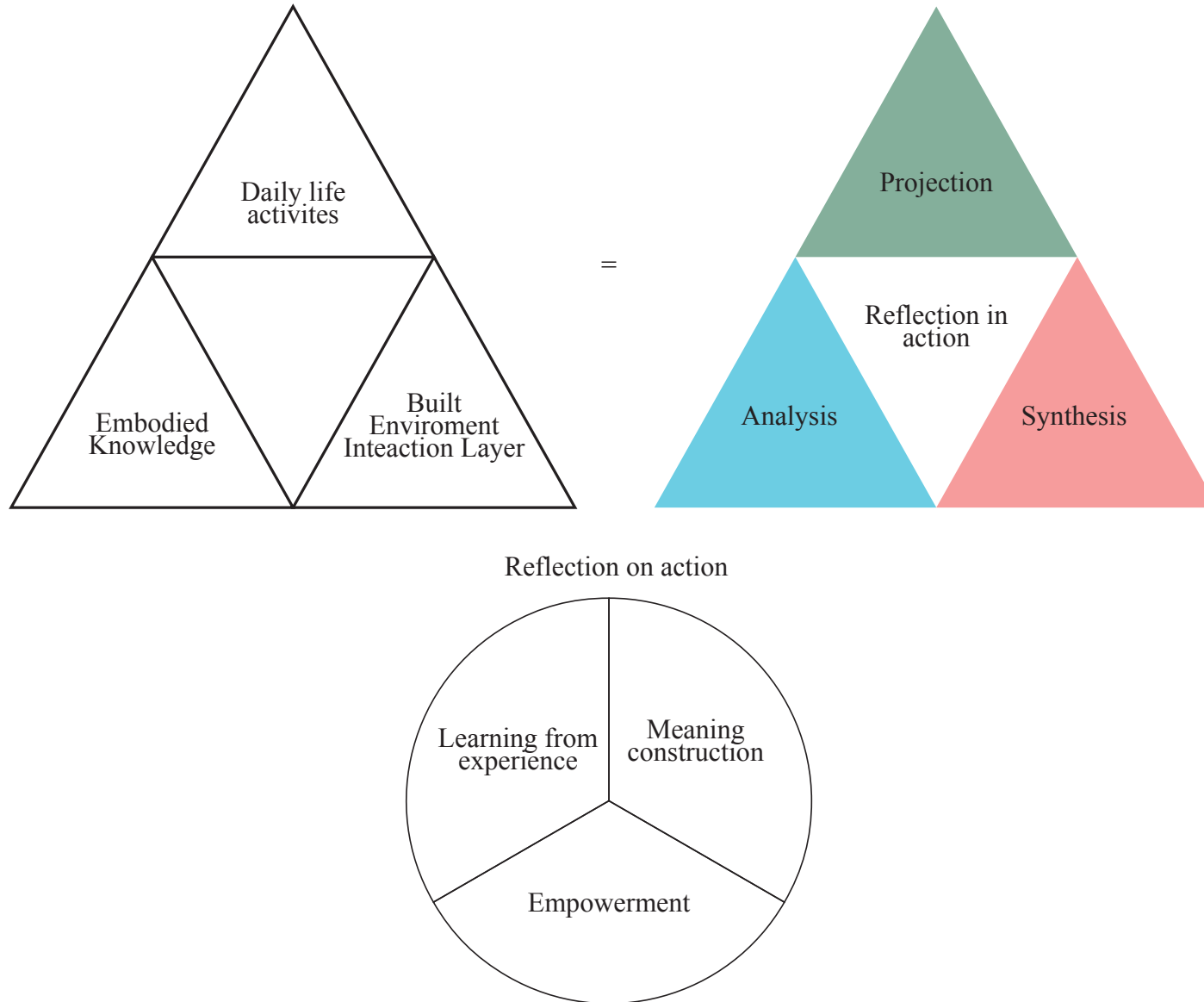
Figure 7. Transformation cycle of by design.
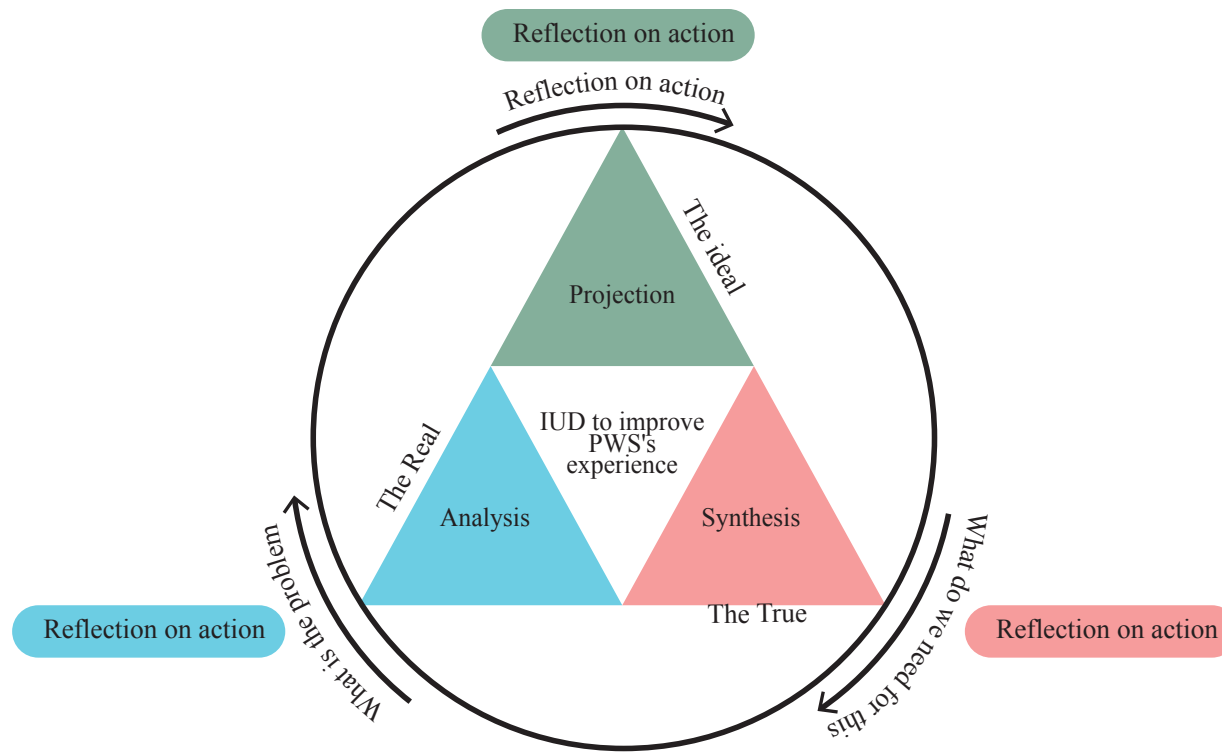
Figure 8. UID process model.

P1 summarized a complete design process, from an initial idea or inspiration into the design and implementation of several generations of bags. The initial need —"one with longer straps"— turned into a design project where definition and interpretation objectives were defined. Prototyping served the iterative process and the solutions were tested (Figure 9).

What shall be

"I put a little pocket on the outside to carry my or my CPA pass"

Reflection on action

The ideal

"But I wanted one with longer straps could go across my body"

The Real

"My stepmom had made me a water bottle holder, and it had a strap on it"

Fig. 12 Bag taken by P1

"So I created this Book bag water bottle holder"

The True

What is the problem

Whats is

I know you buy a lot of equipment of assisted technology equipment. Why not a bag?
"Because I haven't found any"
"I haven't found anything that is relevant to what I need"

What do we need for this

Whats is shall be

"I put a pocket in the front here for all my sundry things. Inside here I can put my books. I can put my Ipad in there if I want. Then the thing thet I really wanted was a divider in here, so I can put my water bottle here and it won't dump over. The divider is right there"

Figure 9. Design process by P1.

P2 also developed several design processes, among which one had a "social recognition" initial desire, as he points out:

> Well, I have sidewalk rage… I'm driving one of these scooters or one of these chairs, and people walk in front of me to pass me, and then they slow down. And I run into them, and they look at me, 'What did you do that for?' And I said, 'You got to be careful when you're walking pass somebody. You've got to keep on moving.'

P2 needed the horn in his scooter to make him visible, so he redesigned his scooter with two different goals: 1) to be noticed; and 2) to be able to use the scooter at night. A scooter with no lights to be used at night talks about how designers see PWS. For P2, both initial desires were to control the environment and gain independence, freedom, control, recognition and social participation (Figure 10).

P3 developed a flexible memory system that works using different spaces in her apartment and different objects in each layer. The front door, the hall, the kitchen and the side of the refrigerator act as the structure that supports her flexible colored–note posting memory code.

P3 not only developed a codified system that is flexible enough to change every hour and gives her the sense of achievement, she also changed the way she interacts with the mirror. It now provides her with an expanded vision to control information on the door and on the side of the refrigerator. This is a complete new interaction with the object mirror that is used to see ones' own reflection, it now acts as a link between the door chart and the refrigerator chart as the mirror is placed at the angle formed by two hallways. Refer to Figure 11 for the design process developed by P3.

What shall be

"You can't hear it even if you're standing right next to it."

Reflection on action

The ideal

"Yes it honks"

The Real

"If you turn the chair on, the electronic horn is - You can't hear it all" "They don't have lights"

Fig. 13 Bag taken by P2

"Yes, we put a light in there" "I had the bigger horn, and that was lot better"

The True

Whats is

"This is for camping" "And it's for your head. It's just elastic. It fits over everything"

What is the problem

What do we need for this

Whats is shall be

"So that's why I put that on there to make louder"

Figure 10. Design process by P2.

What shall be

"You can't hear it even if you're standing right next to it."

Reflection on action

The ideal

"Remembering to do certain things"

"I use -besides the back of my front door as a chart board, I also hace on the side of the refrigerator a flipchart page where I put sticky notes." The bolder the color, the more important that task, or whatever's written on that the more important it is. And then later, when i'm reading through that sticky note, I maybe condense it or pull out something important

The Real

"I have to write things down, make a no ... I find that I have to really plan simple task"

Fig. 14 Memory syst. taken by P2

"I have to a system. It isn't rigid"...

The True

What is the problem

What do we need for this

Whats is

The intention really is the placement of the flip chart, the sticky notes on the side of the refrigerator because the mirror has been here for 12 years. But that is put there venry intently. It does reflect the mirror

Whats is shall be

"So there's a story behind each sticky note,"...
"I love sticky notes for the reason of accomplishment. It gives me a sense of accom-plishment as thoug I actually got something accomplished that particular day. And so whatever's written on that stick note, once I take care of it, I can toss it"
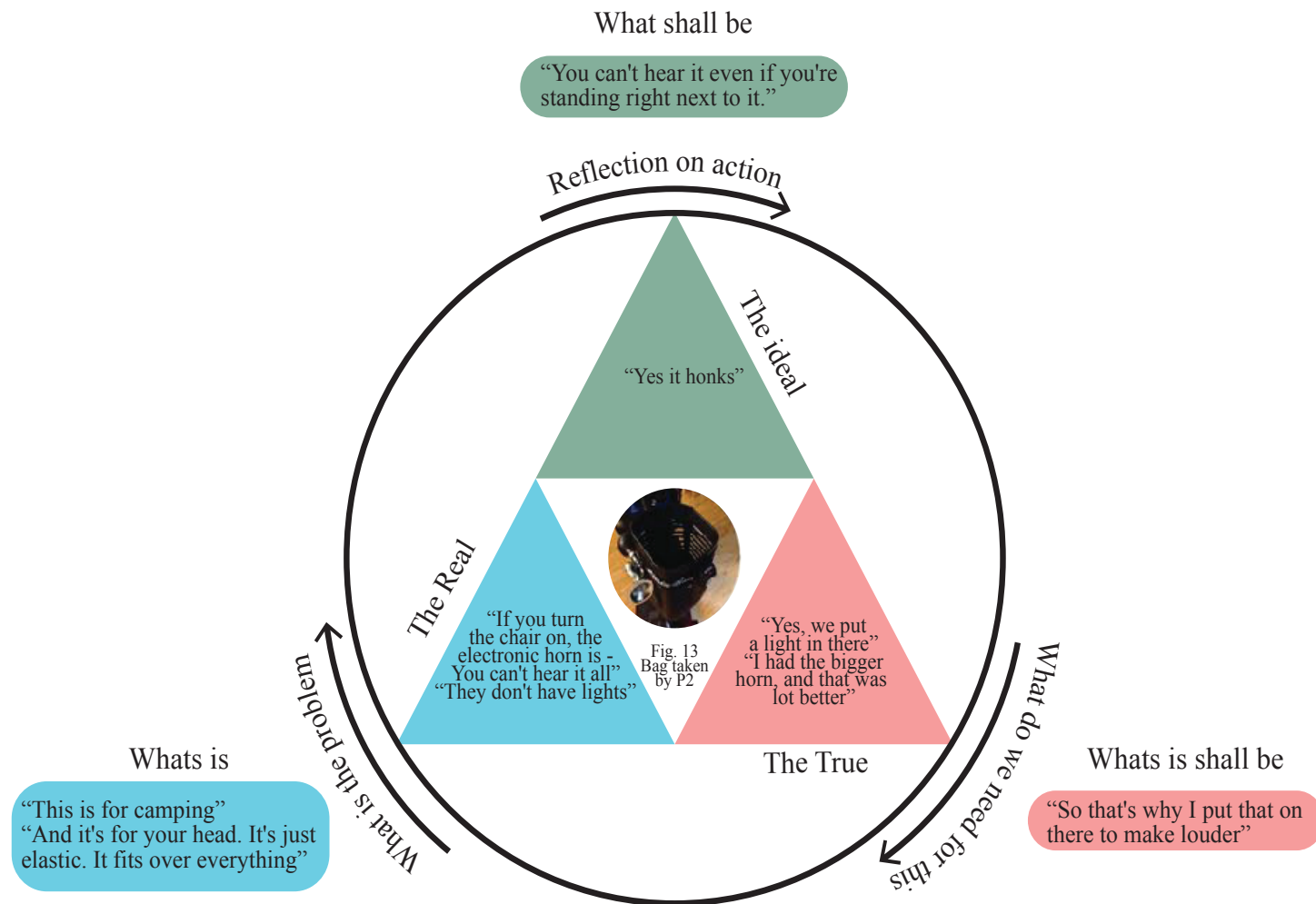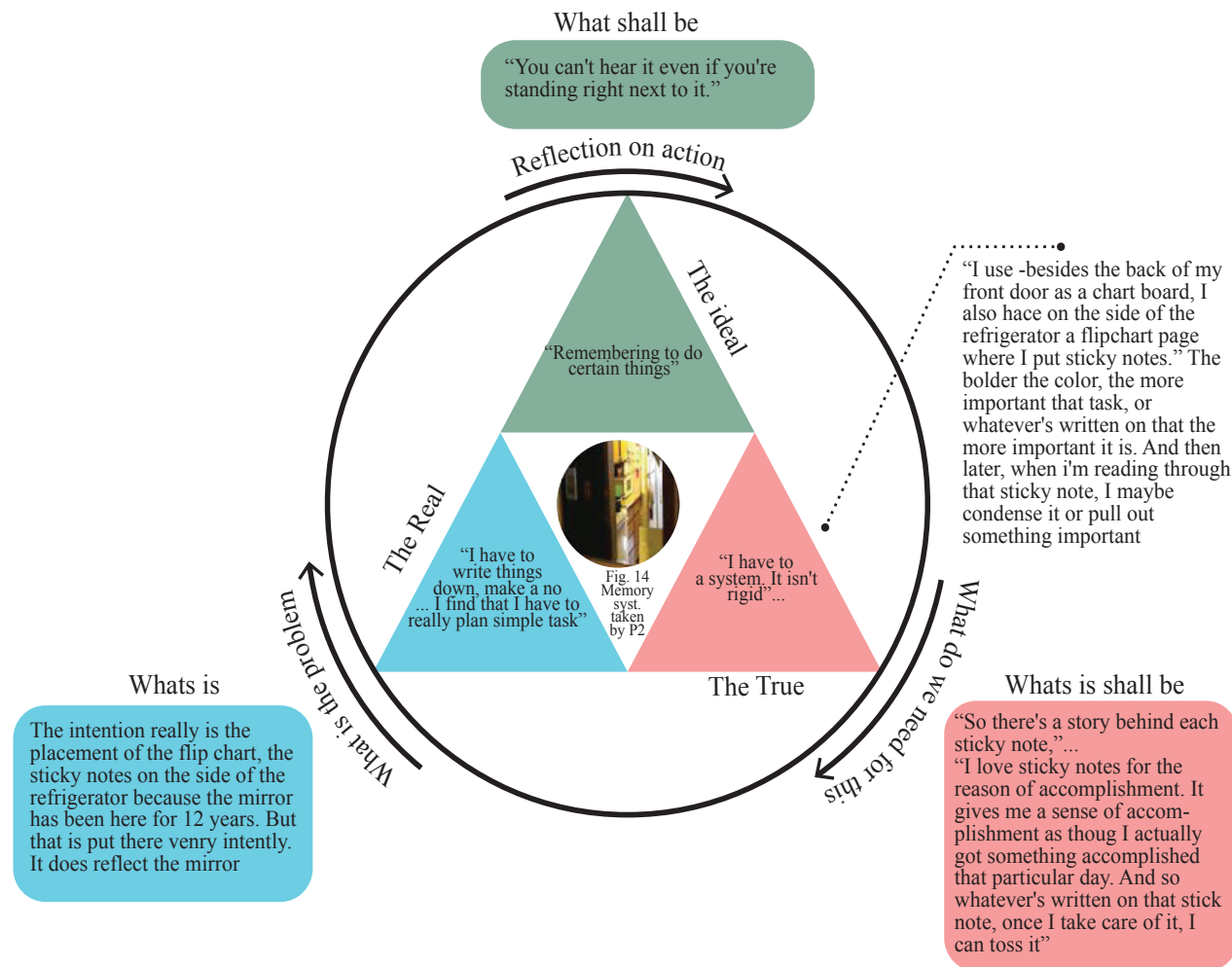
Figure 11. Design process by P3.

2. __Barriers and supports to active engagement in user–initiated design__

PWS who engage in transformations to their environment to attain environmental support and remain healthy, stay in the home and the community, and pursue life goals (Lawton et al., 1982). PWS are often forced to adapt themselves to fit the existing environment. When adapting to the existing environment is not possible or desirable, they find creative ways to make the environment work for them. To achieve this, they clearly engage in design processes even though they are not professional designers.

Three themes to understand supports and barriers that facilitate or impede PWS's engagement in design emerged from analyses: 1) The extent to which PWS understand and are aware of the new capabilities their body has to interact with the environment in the execution of daily activities; 2) personal desires and motivations to improve the experience of use; and 3) the degree of control and confidence they have to transform an uncomfortable or un-desired situation into an improved situation that responds to their new set of situated abilities (refer to Table VIII for detailed information on themes of barriers and support for active engagement in UID).

TABLE IX
USER-INITIATED DESIGN: BARRIERS AND SUPPORT
FOR ACTIVE ENGAGEMENT IN UID

Themes		Barriers	Supports
Building new experiences of use	Recognition of embodied knowledge.	Difficulties to understand and adapt to a new body condition.	Recognition of situated abilities and awareness of embodied knowledge.
		Facing solitude: a "sense of guilty" of not being the same.	Recognition and awareness of their identity as PWS
	Autonomy to engage desired activities.	Doing nothing due to fear.	Previous experiences and skills help them to perform activities in their new condition.
		Feelings of not being able to handle new abilities.	
		Fear of becoming completely dependent on others.	
	Exclusion/inclusion from environment	Feelings that the built environment becomes hostile, and there is nothing to do about it.	Learning how to evaluate accessibility of places or usability of (concrete and virtual) objects
		Lack of assistance from experts.	
Desires and motivations to Improve the experience of use	Using their embodied knowledge.	Desire to use the environment given their new and different sense of self and abilities.	A strong desire to acquire or improve new abilities to cope with changes in their bodies.
	Desire to improve performance of activities		Strong desire to learn or develop new ways of doing things to cope with changes in their bodies.
			Independence

TABLE IX (Continued)
USER-INITIATED DESIGN: BARRIERS AND SUPPORT FOR ACTIVE
ENGAGEMENT IN UID

	Adapting or transforming the environment	When UID is an unconscious activity not recognized as a value.	Market offers a great amount of possibilities to improve safety or to improve performance
Controlling situations through design	Standardized solutions	Thinking "If there is nothing in the market, there is no solution for it."	Changes on traditional use of things to perform new activities. Each person has a unique set of abilities. Sometimes standardized solutions barely adjust to them.
	Feeling proud of their achievements	Thinking that design Solutions are for specialists and enterprises.	Feelings that taking control of built environment is taking control of their own lives

a. **Improving the experience of Use of People with stroke**

After a stroke, people must build new experiences in their interaction with spaces and objects that surround them and that facilitate or hinder the realization of daily activities. Awareness of this everyday process builds their new experience as a user of an environment that often becomes hostile to the new condition of their bodies. The more awareness about that condition, the more likely the person engage in design actions. User experience is a subcategory of experience that focuses on the motivation, perception, cognition, action and emotion of a user when doing an activity on a layer of the built environment to obtain an expected result.

To engage in design, PWS need to evaluate their experience of use in the present situation. Adopting an apathetic attitude toward changing the environment, and focusing only on fixing the actual bodily situation, can be a barrier to UID in people who have had a recent stroke, because PWS's active engagement in UID involves a tacit acceptance of what the environment requires from their new set of abilities and a desire to change the situation.

For people who have had a stroke and live with long-term body impairments, time since the stroke acts as a support, because active engagement in design activities depends on the recognition of new capabilities.

Findings in this study also show that recent stroke survivors need time to accept their situation after the stroke before they are in a place and space ready to change the environment as corroborates P1:

Initially, I couldn't say that. It took a while for me to accept my stroke.

People who had had a stroke less than a year expressed guilt about having to depend on family or significant others, fear of not being good enough, and a strong desire to recover their body-related functions and abilities as P5 acknowledged:

So, not having my dominant hand to work my camera or the Mossberg Photoshop is very difficult. I sew, but not being able to sew because I can't push things through the sewing machine is hard. Or to paint, or to draw, I'm like, that's too much of my life to give up. So, I will work hard on getting better and not giving up. Does that make sense?

I do things to make my hand work. It's part of me. It belongs to me. It should do its job… I do not have any of those devices at home because I make myself do as much as I can with my right hand, the one that's not working up to par.

This picture [Figure 12] has a clock, _____ clock in and a bottle of water. It's a device that's the last time I'll drink water, so that I don't have to wake up in the middle of the night to go to the bathroom and have to put my brace on to walk. Okay.
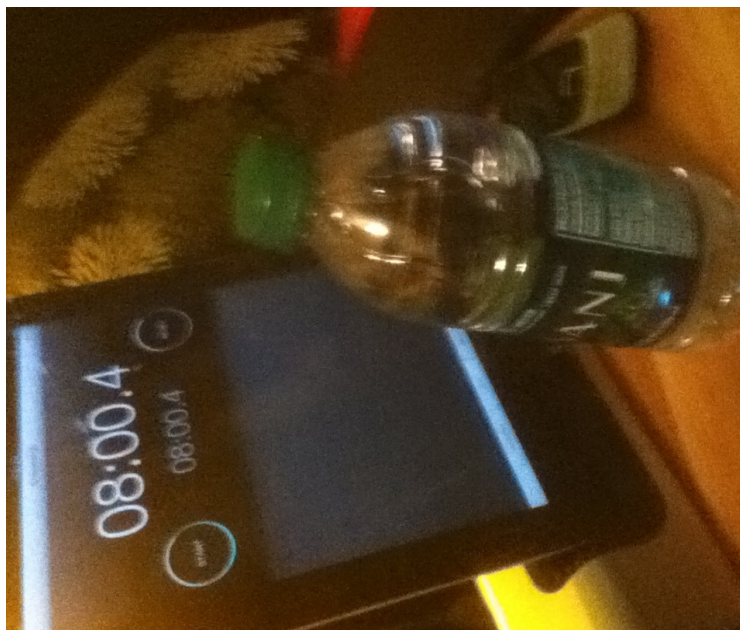
Figure 12. Clock and water bottle taken by P5.

Recent PWS may focus mainly on returning to their body situation before the stroke and need time to accept that there might be environmental press they can only change by adapting their environment. Figure 12 is a good example of how environmental press acts controlling the person who would rather adapt the body by not drinking water after 8 p.m. than battling with the brace through an inaccessible environment and has no strategy to solve the problem imposed by the environment yet.

About guilt and fear of facing the changing situation, P6 expressed:

Now, I depend on other people. I cannot drive… I have to be dependent.
Maybe I can be volunteer here or there… Oh, God… But it seems that I'm not good enough.

On the other hand, active engagement depends on the recognition of new capabilities and on the desire to gain control over the environment (Habraken, 2000). A first step into change is strategizing how to ask for, accept and control help from other people or objects. Basically, when PWS strategically use help, they are creating a positive "press" in the environment that supports their ultimate participation (Lawton & Nahemow, 1973), as P4 explains:

So, as a care partner with me those first few weeks, I was not really able to do a lot of things because of my limited mobility. But as I got stronger, and as I did my physical therapy, I began to be able to be a partner with my care partner, rather than… doing things for me.

Likewise, P6 expressed:

Now, I depend on other people… In a way, this is an experience."

About coming home after the stroke, P5 stated:

At first, at home it was difficult because I had to get assistance, and I'm not the kind of person that really sought assistance before. I've learned to be accepting of people's help.

And, on strategizing the use of objects, including assistive technology, P5 asserted:

It's very, very much a part of who I am now to make me mobile and being mobile is very important. Being able to stand, to walk, to stop suddenly to turn a corner, I couldn't do that without the brace that I'm wearing.

Barrier to active engagement in UID is the automatic assessment of what they can or cannot do after the stroke. On the *I can't* range, P4 said:

I just stayed in the house. I didn't drive... I didn't do anything. I just stayed in the house so I wouldn't fall."

Support: Supports to active engagement are the *I can* and the *I could if* ranges because both have a positive auto–assessment of independence to participate. The *I can* has incorporated the use and control or transformation of the environment as can be seen in all participants, including this statement by P1:

I can do pretty much anything I want. Like, I said I don't cook, so I don't do very much. I do the basic things I can do. I do like to bake. I haven't baked for a while, but I do like to bake things. I don't know. I do love reading. What else would I do? My life is full. [P1]

A good example of the *I could if* range is P1's strategy to hold the pages of a book while she reads:

[Interviewer:] I see you are reading. You have set your table in such a way that you can.

[P1:] That I can read… Yeah. I have to have – it's like a paperweight.

In the same way, P2 expressed:

Then we figured out how to put a wheelchair into the trunk of a car without scratching up the bumpers and everything else like that… We got hold of a moving blanket.

Well, I think one thing that we found out is when I fall… so what we did was we had a stepstool, and she was able to get me up onto that... And then I was able to get up from there.

One of the most important findings is the importance of incorporating previous experience to fit new set of abilities post stroke.

Support: As P5 stated, incorporating previous and new body experience is important to design:

Learning to be left–handed when I've been right–handed for over 50–some odd years that was the biggest struggle. But I've done pretty well. I think I was lucky because I played the piano, the viola, and the guitar. They require both hands to do movement.

Similarly, P1 expressed:

I used to be a professional seamstress… I can't do any hand sewing. So I learned how to sew one–handed.

From analysis emerged fear to use the environment as an important barrier to engaging in environmental transformations.

Barriers: Feeling afraid to use the environment and feeling excluded from an environmental layer can be barriers to full participation and user-initiated design.

P4 pointed out:

Well, I was afraid to go up and down stairs because I thought I would fall.

And P5 stated:

Well, it's the fact my wheelchair doesn't fit in my house. It's not really accessible. It's doesn't fit through doorways or the pathways… Because of that, since I got home from the hospital, I have never been able to use that. In a way is a big incentive to get up and walk, not that I didn't want.

Barrier: Lack of assistance from experts, to make home environments accessible after the stroke and before returning home; represent another type of environmental barrier. This also applies to the case of lack of access to resources to make home modifications. Due to this lack of access, PWS feel excluded and afraid of their own home, as P2 expressed:

Well, we have a two-story home with a full basement in our home. Now, nobody actually came out to do an assessment of our home for us. And it was really kind of disappointing to know that they should have done that.

To finalize this part of barrier and supports to user experience construction, a support involves having a clear assessment of an environment and quality assistance with, how to effectively change the environment, as is evidenced by P2 comments:

> Then they released me in November, approximately, and then we went to our home and realized that there were some difficulties at our home. One, the first floor is carpeted, and so is the second floor. What happened, I couldn't walk, and I couldn't walk upstairs at that time. So, it was very difficult for us to get upstairs to do things. At first, we tried the chair glide that a company came in and installed.

> It's very difficult to get into a car with cloth seats. It's a lot easier for a person with a disability to get into that car and slide over.

b. **People with stroke's motivations to envisioning possibilities to improve their own user experience**

To engage in design activities, people need to envision the experience they want to live (Hugentobler et al., 2004). For PWS, it requires being able to anticipate possibilities in the environment that respond to their changing embodied knowledge. It is to imagine the possibilities the future environment can offer based on the way they do activities now. Projection involves imagining how to interact and change the environment and ergo, improve the experiences of inhabiting that environment (Pallasmaa, 2014).

The degree –low or high- of desire to acquire new abilities to cope with changes in body capabilities is viewed as a support or a barrier to engaging in design activities. Often these "new abilities" involved designing and modifying the environment around them in many ways, including physically, socially, and culturally. About mobility, P1 expressed:

> First off, I had to learn how to write and how to navigate everything left-handed because I was dominate-right-handed before. I had to learn how to brush my teeth, how to put my contacts in, basically how to wash my face and all just one-handed. That took a while to really, adjust to that.

Similarly, P5 said:

> Well, since before I was dominate right–handed. I've had to convert things to using my left hand like, blowing my nose one-handed… Brushing your teeth, eating, and printing, writing my name in cursive, putting my clothes on and off.

And regarding memory, P3 indicated:

When we have lectures, guest speakers, I would also kind of do a very, my own caricature of the person that was speaking. Because along with the notes when I review the notes and that picture, it would remind me.

A positive attitude towards changing and problem solving how things are used was identified as a support.

On memory, P3 stated:

It's on the mirror because this area is where most of my traffic is. So I walk past this mirror at least 15 times a day. And walking past it, I see that stick note, and sometimes I forget what this stick note is for, and it draws my attention.

I use the back of my front door as a chart board and sticky notes to remind me. And I have a big bag that I will put things in and drag them through the floor to get to the stairs.

Support also involved having a positive attitude about implementing new strategies to fit new capabilities, as identified by P3 who speaks about using memory aids:

I find that I have to write things down, make a note, and really plan things out a lot before I do things.

Have a note here that reminds me I need to take my keys, the money for the machines, the detergent… This note is very helpful to me because 90 percent of the time I live by myself… So, one of my greatest concerns is locking myself out.

P5 also commented on memory aids in the environment:

My husband while he does this on a piece of paper, date all my appointments. Yeah. So, I can keep my next appointment, at what time, what doctor. It's a way to keep in mind my schedule for different days.

Talking about mobility, P3 said:

I think primarily because of the mobility and the fatigue early on, I would make sure that whatever room I was in had everything I needed to do whatever it was to do.

The first challenge was to be able to get up the stairs… And the staff was very helpful in training my sons with some strategies to use, which was to put a chair on each level. And once I got to that level, I would sit and rest for however long it would take me.

Another important supporting factor for the engagement of PWS in design activities is related to strategizing all opportunities to adapt an *ideal environment* to improve performance and participation. On mobility, P3 pointed out:

So, we got the equipment in the bathroom, the grab bars for the bathtub and an adaptive toilet seat, a raised toilet seat, for me.

Likewise, P2 commented:

Then we took out all the carpeting and put in hardwood floors so I wouldn't trip because of the drop foot. Walking on carpeting, it's just not very safe. So, we put in all hardwood floors on the first floor and the second floor. So, that was the big major —and then we put in a lot of grab bars to make it easy for me to get

out of the stairs because there's two steps to get into the house. So, we put grab bars along there so that I could hold onto things and be able to get out without falling.

Implementation could be defined as a group of activities done by PWS aimed at pilot testing design strategies within spaces and objects within them. In the field of design, this phase is called *prototyping*. A prototype works as a concrete bridge between *PWS as designers* and *PWS as users*. Through prototypes, PWS as users can test and evaluate solutions. As designers, PWS use prototypes to introduce adjustments and improve their experience of use. The type of designed and implemented solutions can vary. They can include new strategies (process or procedures) in the relationship between PWS and an environmental layer. Thus, adding or eliminating elements or changing configurations of a layer are ways of exerting control. Barriers and supports in this theme can be described as follows:

One barrier involves Lack of control over the built environment, and consequently, not being able to implement change to it. An example of this case is portrayed by P4:

I just stayed in the house. I didn't drive. I didn't bowl. I didn't do anything. I just stayed in the house so I wouldn't fall, until I got my strength back.

When products in the market do not fit PWS's needs, or designed objects do not adjust to their needs, users can face barriers to changing elements or configuration. This barrier is exemplified by P2:

And the other thing that we got was the motorized scooter that allowed us to travel. Now, I do have a power chair, but that thing is too heavy to go onto an airplane.

PWS's ability to evaluate and adopt a designed solution that fits their unique embodied knowledge is a support. P3 explains:

But because of the limited mobility and the way my brain functions now, I find that I have to write things down, make a note, and really plan things out a lot before I do things.

But to answer your question, it's on the mirror because this area is where most of my traffic is.

PWS realize that control over a layer can empower them by giving them independence to do things they like. P2 explains:

And then the elevator company came in and installed the elevator. That was a saving grace for us because it gave me a lot of mobility to be able to go up to the second floor.

In design process and design results, the term *new object* does not refer only to physical things (product design) that support the performance of activities. This term includes conceiving and implementing a new set of strategies to accomplish an activity in a certain way so that it fits expectations (experience design). It also refers to design of new ways or procedures to perform activities (process design). In this way, it is possible to find prototypes for product design:

> Then I wanted something to carry my water bottle and my books. So, I created this book bag water bottle holder. I put a pocket in the front here for all my sundry things. Inside here I can put my books. I can put my iPad in there if I want. Then the thing that I wanted was a divider in here, so I can put my water bottle here and it won't dump over. The divider is right there. So, I can put my water bottle in here. It stands up. [P1]

> So, it is kind of a strategy that when I walk in the kitchen, 90 percent of the time I'm walking in from this way either from the bathroom or my bedroom. So I see that. It draws my attention to note that I have on the cabinet to take my medication. My big green cup is there to remind me to drink water. But to your point also, when I walk out of the kitchen and I see this mirror again, each stick note has a story behind it. My eye is drawn to the stick note. I can see the reflection of the flip chart there. [P3]

And prototypes for process design:

> Then we figured out how to put a wheelchair into the trunk of a car without scratching up the bumpers and everything else like that. We got hold of a moving blanket. And you just put it over the opening of the trunk. And what you do is you lean the wheelchair on it, and you use as a fulcrum as a pivot point. And you lift up from the wheel, and then you slide it in. It makes it a lot easier. It protects the car. [P2]

As time since the stroke goes by people find ways to make the environment work for them by adding or eliminating element in the environment or changing its structure.

Changing the configuration or structure of the environment is also a support, as P2 comments:

> And then the other thing that we made modification to was the horn on this side right here. If you turn the chair on, the electronic horn is —you can't hear it all. So, that's why I put that on there to make it louder... We put a light in there. Also, a light? In the basket. They don't have lights. [P2]

P1 said:

> Yeah. I've made several different bags because the first bag; I put a pocket on the outside. Then I thought, well now, I probably better put a flap over the pocket. So, a few bags later I started putting a flap over the pocket. [P1]

When PWS have engaged in a UID complete process, knowledge remains after the experience of conceiving, implementing and improving solutions to fit their own needs and desires. This process is more specifically defined as *learning through reflection on doing*. Learning theory defines learning as a process by which knowledge is created. This creation is done through the transformation of experience. Thus knowledge results from the combination of grasping and transforming experience (Kolb, 1984).

One of the key motivational factors why PWS engage in UID is the feeling of *doing something* to improve life experience. Feeling well, learning by doing or needing to share experience are emotions mentioned by the participants.

Another supporting factor is when PWS have the sense that they have learned by doing, or the feeling that they are doing something with their lives or they feel proud of a solution they have proposed. Examples from participants speak to this accomplishment and empowerment. P3 said:

> I love stick notes for the reason of accomplishment. It gives me a sense of accomplishment as though I actually got something accomplished that particular day. And so whatever's written on that stick note, once I take care of it, I can toss it. And it's out of my brain. It's out of my sight, and I feel as though I got something done today, which may not seem really critical to a lot of people. But for me, it's important that I feel that I didn't waste the day and that I actually am making some progress and moving forward and not just being stagnant. [P3]

> Here in the bathroom there's two things that I use quite a bit, which has given me a huge sense of independence, which is grab bars. the raised toilet seat with the handles on the side. [P3]

> P2"s spouse commented:

> When we opened the kitchen, it was for the main purpose of keeping him engaged with safety as No. 1, but also with disability, there's isolation. And this way, with an open kitchen, he can be a part of what I'm doing, even if it is sitting watching. [P2]

E.   **<u>Discussion</u>**

Present design approaches involve PWD at different stages of the design process (Sanders, 2002) and advanced participatory approaches involve PWD as co–designers. In resent years designers have identified design activities that non–designers perform as non–intentional design (Bredies et al., 2010), design–in–use (Bredies, 2010; Nelson et al., 2009) and, in the scope of production, silent design (Gorb & Dumas, 1987). However, design activities

that PWD —particularly PWS— autonomously engage in to transform their home environment after a stroke had

not been studied or acknowledged as valid design before despite PWS acting upon the environment on daily basis.

The built environment has a profound effect on the way we live our lives. However, thinking only the environment determines our behavior is simplistic. In a given situation the social environment as well as the physical

environment influence our behavior and our body. Our bodies and movements are in constant interaction with the

environment. Pallasmaa (2014) argues that the self and the world have a mutual influence that redefine each other,

thus the built environment can be challenging when conceived disregarding human experience and bodily variability

as is the case for PWS.

Theoretical frameworks link the person, the disability and the environment; for example, the environmental press model conceptualizes the individual as having a set of competencies, and the environment as presenting

press or demands and expectations upon that individual (Lawton & Nahemow, 1973). The environment can affect

the challenge experienced by the person to the point of eroding their sense of competence and creating a sense of

learned helplessness (environmental docility); thus, when there is too much environmental press, people give up trying to adapt and consequently give up the use of that environment (Lawton & Nahemow, 1973). The direct relation-

ship between press and adaptation can play an important role in understanding why PWS engage in design processes

to transform the environment.

UID is a silent process that takes place in the private environment of the home. The activities people

engage in during this process are usually not understood as design proposals but as isolated and unrelated actions.

The study explored design activities performed by PWS to transform the environment, developed an analytical

framework to understand how the process unfolds and if it could be considered a design process and finally provided

a definition for the phenomenon.

1. **An Analytical Framework**

This study offers an analytical framework to understand design activities PWS engage in and

addressed the phenomenon from a critical perspective. Reflection about PWS's actions and activities guided the

researcher towards a perspective that emphasizes the human centeredness of design and its political, cultural and social implications.

In the case of design processes initiated by PWS, the approach required first an understanding of how traditional design practice exerts power over the activity of ideation, second it required recognizing processes PWS engage to transform the environment as genuine design processes, and third it required recognizing the power this engagement has over PWS's control of the environment.

To develop the analytical framework, this study used the concept of *design process* and the universal framework/platform for the description of design process as proposed by Hugentobler et al. (2004). This process model establishes a universal framework by combining two basic concepts: the general domains of inquiry and the steps of learning to describe design and research related to it.

Furthermore, this study used Habraken's (2000) model of environmental structure and organization to understand the physical organization of the built environment and the way people exert control over it. The framework also includes the concept of *purpose of the transformation*, understood as the driving force for PWS's engagement in the design process, and the concept of *impact* as a change in the user's situation. Finally, it is worth noting that the concept of *time* can have an effect over PWS desires or needs to engage or constantly reengage in design processes and to confidently strategize the built environment and their bodies to requirements and demands of the environment after a stroke.

Findings show that PWS are often forced to adapt themselves to fit the existing environment or, via trial and error, to find other creative ways to make the environment work for them. They do so in isolation, as they are often unaware of other PWD struggling with similar environmental issues. Activities PWS engage in to transform the environment can be typified as design processes and can be studied from a design perspective. To advance on this argument the study provides examples using the design process theory (Hugentobler et al., 2004) summarized in Figure 8 and exemplified in Figures 9,10, and 11. Change is caused by our interventions; therefore, by learning to see changes in the environment, we also learn to understand the ways in which we organize ourselves as agents

acting upon it (Habraken & Teicher, 2000). Key concepts of structure and hierarchical levels in the organization

of the environment where used in the analytical framework to understand that PWS change the environment to

exert control over it. If this control is not achieved then PWS are excluded by the environment and forced to adapt

their body and mind to this exclusion. Findings show that positive change is done in the terms of design, thus UID

contributes to an analytical framework that can be used in future research. Recognizing UID could benefit from a

disability studies to recognize the phenomenon directly from PWS's lived experiences, PWS, OTs, and designers can

learn from it and research its power.

2. __A Descriptive definition__

The author suggested a descriptive definition of UID, recognizing the existence and possibility of

alterations to the built environment, and initiated by PWS as a response to inaccessible and meaningless environ-

ments. User–initiated design was defined as ideation that develops into design processes and solutions to modify

the environment or the interactions with it based on PWS's everyday experience living in those environments. This

descriptive definition offers designers the possibility to contradict or advance on design by PWS, based on the con-

cepts of *lived design*[3] and *design done by insiders*[4] proposed to understand UID. At the same time, it challenges cur-

rent ideas about the participation of PWD in design processes as well as the way in which modifications to the home

environment have been understood in design research from a disability studies perspective. Definitions are important

as they serve strategical purposes for advancing inquiry (Buchanan, 2001) and offer researchers a basis from which

to work.

Findings show that PWS engage in design processes to improve their experience of use and to exert con-

trol over the environment as an empowerment tool. Engagement requires them to: 1) reflect on and evaluate their

current situation; 2) create desirable but achievable "experiential scenarios" per their embodied learning process; and

3) ideate ways to get there in accordance with their access to knowledge, experience and resources. Design has the

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3   *Lived design* is a design rooted in lived experience.
4   *Design done by insiders* is design developed by the people directly involved in the design situation.

power to transform or maintain social, political and cultural structures. For PWS, gaining control through design is empowering. If recognized, UID will facilitate and cultivate opportunities for PWS to fulfill their potential and grow their own capacity. It will enable them to engage in their own development. Recognizing UID, both designers and OT professionals involved in adapting environments with PWS can accelerate the process of adaptation, empowerment and quality of life for PWS.

TABLE X

DESIGN THINKING PROCESS BY PEOPLE WITH STROKE

PARTICIPANTS	How it is today (The true)	How it could be (The ideal)	How it is tomorrow (The real)
P1	"Those of us with disabilities with only one hand have such time with is umbrellas"	" I have thought of this and though of this. I don't know if I told you about my umbrellas. I have not tried anything"	"So I ended up just with the raincoat with a hood on it"
P2	"If you turn the chair on, the electronic horn is-you can't hear it-"	I would be noticed if the horn sounds louder	*The participant has a bigger horn strapped to the chair with a bungee strap*
P3	"I find that I have to really plan simple tasks" "I find that I have to write thing down, make a note"	"The bolder the color of stick note or the bolder the color of pen, the more important it is to get it done"	"I use the back of my front door as a chart board and sticky notes to remind me"
P4	"I've got a caregiver. She comes in three times a week" "She tells me not to forget my medicine"		"I just remember them because I've got it in a little pouch"
P5	"Now my memory is not with me"		Notes on pieces of paper elaborated by the caregiver
P6	"I was dominate right – handed"	"It's kind of difficult, but you figure out how to do it"	"I've had to convert things to using my left hand"

3.   **Reflexivity and photovoice**

    Photovoice is a method that uses photography to actively engage participants in the research

process (Wang & Burris, 1994). When talking about pictures, Douglas Harper (2002) posits that photographs in

research have a potential usefulness that is largely unrecognized. Photographs can be used as a means to identify

intangible factors. They capture the impossible: a gone person, a past event, a time, and a space. They can retrieve

something that has disappeared or be witnesses of something that has appeared.

In this study, the Photo-voice technique was employed to capture representations of the participants' realities related to user initiated design of their home living environments (Wang & Burris, 1994). By using this technique, the researcher sought to enable recording and reflecting on the participants' interactions with and modifications to their home environments.

The mechanism of ideation has two levels of imagination: one that makes formal projections and one that simulates the emotional, mental, and sensory encounter with the imagined (Pallasmaa, 2014). For that reason, this method was a good tool to evidence the imagined (the object) and to verbalize the experienced. The Photo-voice technique allowed capturing the qualities of that which was designed and also the experience of interacting with it (Pallasmaa, 2014). PWS who initiate processes of design bring this complexity to the discussion: the disabled body forging experience on design, that is, *insider design*.

4. **Limitations of the study**

Participants in this study represented diversity across age groups, race, ethnicity, gender, socio-economic status, living condition, geography, level of previous home and work participation. Since the participants in this study were selected conveniently rather than randomly, findings done in and by them are not generalizable. Background data and detailed description were used to characterize UID and participant quotations (Merriam & Tisdell, 2015). Nevertheless, transferability of the results to other PWS groups is limited. Research to address the phenomenon on other groups of PWD needs to be done, even though their experience navigating their home environment is similar (Lawton & Nahemow, 1973).

Credibility of findings is supported by strategies to ensure rigor of the study. Data was triangulated with different sources and methods (Lincoln & Guba, 1990; Miles & Huberman, 1994). Member checking during and after the data collection period was implemented. All the six participants provided feedback. To reduce the effect of researcher bias, besides using triangulation, the researcher's beliefs and assumptions were admitted, as well as the shortcomings in the study's methods and their potential effects.

F.	**<u>Conclusion</u>**

The current study contributes to the knowledge base by providing a multi–leveled systematic analysis of design activities and processes that people who have had a stroke engage in to transform their home environments so that it better responds to their needs and desires. This study is based on the direct perspectives of people with stroke, their experience and designs.

Past research on design–disability has evaluated the effectiveness of design interventions to guarantee accessibility and usability of the built environment. Most research has had the participation of PWD at different stages of the design process. However, not many studies have examined PWD intervention of designed objects to determine innovation. This is the first-time systematic examination to explore design processes by PWD —specifically PWS— has been proposed.

The current study helps address this gap. It explored design activities PWS engage in and demonstrates these activities can be typified as design processes. It provides a descriptive definition of UID and proposes an analytical framework to study the phenomenon. The study also demonstrates how participatory research methods can be used to actively involve PWS in research and to make visible design ideation processes. Finally, communities and agencies that work for PWS can appoint towards the recognition, enablement and development of UID to support them more efficiently.

VI. **CONCLUSIONS**

The built environment is not a neutral place; it is the reflection of thought, culture and society. All the objects integrated within it (public and private spaces, buildings, technological everyday objects, graphics and communication products, etc.) are symbolic expressions and practices of the way we think, feel, construct and re-construct meaning in society. They give meaning to human existence. Design is in the decisional basis for the configuration of the built environment. It is within the process of design decisions that people are integrated or segregated, included or excluded. Design also preserves or leaves behind; thus, design must be regarded as an expression of what we are and want to be as a culture.

The physical environment plays an important role in adapting after the stroke (Lawton & Nahemow, 1973) and can be a challenge for PWS, as disabilities related to stroke demand a new way of interaction person-environment interaction.

PWS are forced to adapt themselves to fit the existing environment, or to adapt the environment to their needs. They do so via trial and error, finding ways to make the environment work for them. Hence PWS actively respond to environmental barriers post stroke by creating new ways of doing things through imaginative and ingenious actions in order to maintain independence (Pound et al., 1999).

Discharge to home and cessation of rehabilitation are milestones for PWS as adjusting to a new self and dealing with discrepancies between rehabilitation outcomes and realities (Ch'ng et al., 2008). After the stroke people mobilized informal social support, created new ways of doing things, took things more slowly, and began the process of relearning to respond to the disability (Pound et al., 1999).

These actions have been studied in the field of OT and are comprehended in terms of coping with and strategizing the context to respond to stroke (Pound et al., 1999). Additionally research focuses on the impact of stroke framed in terms of coping and adjusting (Sarre et al., 2014) and most OT theory based model emphasizes the importance of the environment in the adaptation process, as does the environmental press model. The PEOP model Baum and Christiansen (2005), describes the interaction of personal factors and the environmental factors that either

support or restrict performance of activities. The MOHO (Kielhofner, 1995) argues occupation is dynamic and context–dependent. OT's view modifications to the environment as strategies developed either by the professional therapist to improve the competence of clients or by PWD to overcome negative demands from the environment.

Designers have also studied the relation person-environment and modifications to the environment are considered a core principle of design. Contemporary design has advanced in understanding that in a fast-changing world people, groups, communities, companies, institutions and regions can, and in fact, design (Manzini & Coad, 2015). Participatory design approaches depict design as a social process (Luck, 2003), in this approaches design activity extends to the user thus goes beyond the designer. In doing so, they recognize we all have capabilities. The concept of "design processes initiated by users" seems to be a common concept in contemporary design literature, for example, changes to the environment proposed by non–designer are being studied in the innovation discourse. Furthermore design theorists have argued the need to open "the space of potentials that the available circumstances afford for the emergence of new designs" (Botero et al., 2010, p. 1) acknowledging that the design space is co–constructed. Up to now, this opening has recognized design developed by users in the use stage, and defined it as an unpredictable response from the user to unexpected perturbations in the environment (Bredies et al., 2010). However, this definition does not account for the design activity in which PWD engage when they modify their environment, specifically PWS. Additionally disability scholars have argued that the interactions disabled body-home spaces are seldom investigated in housing studies (Imrie, 2004).

Actions undertaken by PWS as non-designers or actions undertaken by them to transform the physical environment as well as their efforts to try to problem solve the environment have not been researched before despite the understanding of the concept of design done by non-designers (Briedes et al., 2010; Candi, 2010; Gorb & Dumas, 1987; Nelson et al., 2009; Von Hippel, 1986).

Past research on design and disability has evaluated the effectiveness of design interventions to guarantee accessibility and usability of the built environment. Most research has had the participation of PWD at different stages of the design process. However, not many studies have examined PWD active adaptation of designed objects

to determine innovation. This is the first-time a systematic examination to explore design processes by PWD —specifically PWS— has been proposed.

This qualitative–participatory study addressed this gap by offering insights into why and how PWS undertake these actions. The study included three processes: 1) identification of important issues in the relation between the home environment and PWS, including their lived experiences, perspectives, and views on how they relate to the space and objects in it; 2) basic understanding of how and why PWS engage in autonomous self-led design processes; and 3) knowledge about participants' individual and collective experiences with home modifications. Additionally, the study provides a list of barriers and supports to engagement in design activities as well as recommendations for designers and OTs on how to integrate user-initiated design within their services and research about the built environment. The study is based on the direct perspectives of PWS and activities they engage in, and contributes to the knowledge base by providing a multi–leveled systematic analysis of activities and processes that people who have had a stroke engage in to transform their home environments.

Findings show that PWS played an active role in the transformation the home environment to manage different ways of performing post stroke and the impact on their independence, mobility, accessibility to and control of the environment as well as their participation in activities that are important to them. They accomplished this by engaging in actions and activities that require a proactive, critical approach to transform a current situation into a desired one.

Many activities described as strategies in the field of OT require PWS to evaluate the situation the environment offers versus their desires and needs and when the environment does not respond in a satisfying way to ideate changes upon it. These changes are in the form of alteration to objects, organization of the component of a space in the home, a new way of performing an activity or a completely new object. This research studied these alterations from a design perspective to conclude that PWS are creative and innovative designers that in fact transform reality even though they have not received training in the field of design but first and foremost important that they use design processes to respond to the person-environment relationship.

Recognizing that PWS design, as an alternative to inaccessible environments is an important step towards understanding the power they can exert over undesirable situations, the environment, adaptation, rehabilitation and their particular needs after the stroke.

As designers, have very few opportunities to access the home environment of PWS these findings call for a participatory action initiative that encourages all stakeholders to explore UID as a transformative process for PWS. Participatory action research (PAR) is an approach that exemplifies empowering processes. One of PAR goals is to help communities develop knowledge (Greenwood, Whyte, & Harkavy, 1993) to improve quality of life. Since engagement in UID has a positive effect on the way PWS experience use this can be considered as an improved life experience for PWS. PAR can provide mechanisms for developing PWS community empowerment, engaging PWS in design processes, and encouraging academic communities to understand how and why PWS design. On the other hand, designers can learn much from PWS if UID is problematized and theorized. OT professionals can be the bridge to do so as they are well positioned in the disability community.

Understanding UID is not only a design issue or only one that will make us better designers, although understanding UID will advance research in design issues. Rather understanding UID will help us understand the driving forces of individual creation, and hopefully guide collective change to attain a better, safer and just environment.

Future design approaches for disability must make efforts to legitimize and render visible PWS experience with the social, cultural and physical environment. This means design must face the many power conflicts in the disability–design relation instead of smoothing them. Reflexivity on how the UID process unfolds should stimulate the designers' critical reflection about their role in the design–disability relation and awaken their personal political and ethical stance.

A.   **Implications of the Study**

Implications of this study for OT practice are: 1) UID can be used as empowerment tool for PWS, to advance the process of adaptation; 2) UID can inform OT practice about needs, not easily perceived such as the need to control the environment; 3) Stroke is the leading cause of long term disability, UID is the ways PWS control the

environment thus an issue that will always be present in OT practice; and finally 4) OT could be the link between PWS and designers, as designer can't easily approach PWS's homes.

This study suggests PWS do non-professional design, thus implications of this study for designers are: 1) Recognizing UID can expand designer's understanding of how, by whom and where design is done; 2) It can help create new paths of collaboration among different views of design to support meaningful social change focusing in emergent ways of collaboration and cooperation; 3) Because stroke is a leading cause of long term disability, PWS are a target population for design research and design intervention; 4) because poverty is related to stroke and a social and economic issue, design done by PWS can be situate in the social design arena. From an insider's perspective as that of PWS who engage in UID and whose experience interacting with the environment is the driving force of design, design interventions reveal properties that we are just beginning to understand; and 5) This change of perspective should have consequences on design education and design professional practice. It is just a matter of time.

Implications for OT and Design educational programs of study include the need for collaborative efforts to understand the lived experience of PWS, because the type of design PWS engage in, is first and foremost a way of empowering and regaining control. Implication for Disability Studies are: 1) User-initiated Design supports meaningful social change focusing in emergent ways of collaboration and cooperation; 2) User-initiated Design has the potential of profound change in the way we see PWS and their relationship with the social and built environment; and 3) Since design is both shaped and explanatory of notions of standard, membership and desirability and it has the potential of re-signifying environments to represent PWS desirable experiences it is at the core of the intersection design-disability studies and it should be studied beyond accessibility or universal design.

Future research should focus on understanding strategies that involve transformations to the environment, as design processes, and the implications this has on the adaptation processes involved in coping with challenges upon returning home after the stroke. On the other hand, designer should work on understanding the intentions of PWS when they engage in design. Because PWS engage in design activities as a way of gaining control over the environment and this engagement has the power of providing equilibrium in the environment-person relationship. Communities and

agencies that work for PWS can also point to the recognition, enablement and development of UID to support them, and many people with disabilities as a social group more efficiently.

Resilience is a process of adjustment that unfolds over time (Sarre et al., 2014). Sarre et al. (2014) found that physicality and embodiment are rarely considered in studying resilience. But the current study has shown how PWS respond with design to challenges the environment imposes on their daily activities. It has also shows the impart this engagement has on PWS and how their embodied experience plays an important role in UID allowing then to exert control over the environment and empowering them. Future research can point to a possible relationship between UID and resilience.

As part of the study the author provides a descriptive definition of the phenomenon and names it as User-initiated Design. User-initiated Design recognizes that PWD have an understanding based on the context of disability (Haraway, 1988) and that their experience is the product of daily activities they perform in places designed to be used by able bodies (Hansen & Philo, 2007). PWS are faced with the challenge of the inhabiting a home environment that was easy to navigate before the stroke but that does not respond to changes the body has had after the stroke, this body relearns as it experiences and has the ability of changing the environment so that it responds to the new body. This process many times is achieved through design activities such as the ones described in this study.

Finally, the concept of UID has effects on the way in which we understand the process of design, the mechanism of ideation, and the experiences that these designs represent. Hence, user–initiated design might be the new frontier in co–design with people with disabilities, specifically people who have had a stroke.

VII. **APPENDICES**

A. **APPENDIX A IRB Approval Letter**

U N I V E R S I T Y   O F   I L L I N O I S
A T   C H I C A G O

Office for the Protection of Research Subjects (OPRS)
Office of the Vice Chancellor for Research (MC 672)
203 Administrative Office Building
1737 West Polk Street
Chicago, Illinois 60612-7227

Approval Notice
Amendment to Research Protocol and/or Consent Document – Expedited Review
UIC Amendment # 15

January 3, 2013

Joy Hammel, PhD, OTR
Occupational Therapy
1919 W. Taylor St.
326 H.H.D.S.B., M/C 811
Chicago, IL 60612
Phone: (312) 996-3513 / Fax: (312) 413-0256

RE: Protocol # 2005-0001
        "Evaluating Community Living and Work Participation Environments and
        Technologies for Use by People who have a Stroke: A Consumer-Directed, Dynamic
        Assessment Methodology"

Dear Dr. Hammel:

Members of Institutional Review Board (IRB) #2 have reviewed this amendment to your research
and/or consent form under expedited procedures for minor changes to previously approved
research allowed by Federal regulations [45 CFR 46.110(b)(2)]. The amendment to your research
was determined to be acceptable and may now be implemented.

Please note the following information about your approved amendment:

Amendment Approval Date: January 3, 2013
Amendment:
    Summary: UIC Amendment #15, (Response to Modifications) dated December 10, 2012,
    submitted 1/2/2013, is an investigator-initiated amendment to [1] submit new recruitment and
    consent documents (User Design Letter of Invitation version 3 12/5/12, User Design Subject
    Consent version 3 12/5/12; User Design Contact Information, version 1 11/28/2012); [2] revise
    the protocol to add a qualitative component to closely look at what particular
    supports/strategies people with stroke use in their home environment (Protocol version 4
    11/20/12).
Approved Subject Enrollment #:   140
Performance Sites: UIC, Northwestern University-Rehabilitation Institute
of Chicago, Rehabilitation Institute of Chicago, Washington University in St. Louis, American
Stroke Foundation

A.   **Appendix A (continued)**

Page 2 of 3

Sponsor: National Institute on Disability & Rehabilitation
Research
PAF#:   2004-01168
Grant/Contract No: H133B031127
Grant/Contract Title: RRTC on Stroke
Research Protocol(s):
   a) Research Protocol; Version 4; 11/20/2012
Recruiting Material(s):
   a) User Design Contact Information; Version 1; 11/28/2012
   b) User Design Letter of Invitation; Version 3; 12/05/2012
Informed Consent(s):
   a) User Design Subject Consent; Version 3; 12/05/2012

Please note the Review History of this submission:
Receipt Date   Leave box empty - For office use only

A.   __Appendix A (continued)__

Page 3 of 3

Alison Santiago, MSW, MJ
IRB Coordinator, IRB # 2
Office for the Protection of Research Subjects

Enclosure(s):
    1.   UIC Investigator Responsibilities, Protection of Human Research Subjects
    2.   Data Security Enclosure
    3.   Informed Consent Document(s):
        a) User Design Subject Consent; Version 3; 12/05/2012
    4.   Recruiting Material(s):
        a) User Design Contact Information; Version 1; 11/28/2012
        b) User Design Letter of Invitation; Version 3; 12/05/2012

cc: Yolanda Suarez-Balcazar, Occupational Therapy, M/C 811

B. **APPENDIX B Consent Form**

University of Illinois at Chicago
Research Information and Consent for
Participation in Social Behavioral Research
"Evaluating Community Living and Work Participation Environments and Technologies for Use by People
who have a Stroke: A Consumer-Directed, Dynamic Assessment Methodology"

You are being asked to participate in a research study. Researchers are required to provide a consent form such as this one to tell you about the research, to explain that taking part is voluntary, to describe the risks and benefits of participation, and to help you to make an informed decision. You should feel free to ask the researchers any questions you may have.

Principal Investigator Name and Title: Joy Hammel, Associate Professor
Department and Institution: Dept of Occupational Therapy, University of Illinois at Chicago
Address and Contact Information: 1919 W. Taylor, Chicago, IL 60612; 312-996-3513
Sponsor: National Institute on Disability and Rehabilitation Research (NIDRR)

Why am I being asked?
You are being asked to be a subject in a research project to explore modifications to the environment people with stroke initiate. You have been identified as a person with stroke who lives in the community and may be eligible to participate.
Your participation in this research is voluntary. Your decision whether or not to participate will not affect your current or future relations with the University or community agency. You will continue to be eligible to receive existing services and resources whether you decide to participate in this additional research study or not. If you decide to participate, you are free to withdraw at any time without affecting that relationship. Approximately 10 subjects may be involved in this research at UIC.

APPENDIX B Consent Form (continued)

What is the purpose of this research?
The purpose of this research is to explore designs people with disabilities, particularly people who have had a stroke, generate in their home environment and factors supporting them in taking an active role in designing this key living environment.

What procedures are involved?
If you agree to be in this research, we would ask you to participate in following activities:

1) Two 1-2 hours interviews: The interviews will take place at your home. The interviews may ask you questions about what modifications you have done to the home environment and how they helped you in managing home activities. We will also ask you to take pictures or videos of you and your home environment in the first interview in order to record your use of design strategies in everyday life. These pictures and videos will be discussed in the second interview.

2) One focus group: You will be asked to come to 1919 W Taylor St, Chicago, IL to participate in a focus group to discuss recommendations and suggestions for designers or health professionals to include people with disabilities in the design process.

What are the potential risks and discomforts?
The risks of participating in this study are minimal. They primarily include the potential for emotional and psychological reactions to issues related to stroke, community living and participation. None of the activities are experimental or clinical in nature, and all would involve activities that would otherwise be part of typical day for most participants.

Are there benefits to taking part in the research?
The study results may be used to help other people with stroke in the future as the findings from the study can have important implications for future decisions to continue or expand research on environmental modifications, user centered design or design strategies by people with stroke who want to live in the community and participate in activities and roles of choice.

APPENDIX B Consent Form (continued)

What other options are there?

You have the option to not participate in this study.

What about privacy and confidentiality?

The people who will know that you are a research subject are members of the research team. Otherwise information about you will only be disclosed to others with your written permission, or if necessary to protect your rights or welfare or if required by law.

Study information which identifies you and the consent form signed by you will be looked at and/or copied for checking up on the research by the National Institute on Disability and Rehabilitation Research (NIDRR).

When the results of the research are published or discussed in conferences, no information will be included that would reveal your identity. We will replace your name with numeric codes throughout the data; only the investigators will have access to original data. We will ask for your permission if we decide to use your picture or video in scientific publications or presentations or for educational purpose. All data will be stored in locked files in Joy Hammel's office at the University of Illinois at Chicago. The audio files of interviews are primarily used to keep track of information, and will be destroyed once data is recorded. Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law. The information will be kept for five years following the study for analysis purposes, after which time it will be destroyed.

What are the costs for participating in this research?

There are no costs to you for participating in this research

Will I be reimbursed for any of my expenses or paid for my participation in this research?

To compensate you for your time, you will receive $35 for two interviews and a $10 gift card for participating in the focus group. You will also be reimbursed $6 for your transportation to participate in the focus group.

APPENDIX B Consent Form (continued)

Can I withdraw or be removed from the study?
If you decide to participate, you are free to withdraw your consent and discontinue participation at any time. You have the right to leave a study at any time without affecting the relationship.

What if I lose the ability to make decisions during the study?
Either due to your condition or due to the change in your legal status, you may become unable to provide consent to continue in the study. Your ability to consent will be evaluated by the investigator at each study visit. If decided by the investigator, you may be asked to discontinue the participation.

Who should I contact if I have questions?
You may ask any questions you have now. If you have questions later, you may contact Joy Hammel at 312-996-3513.

What are my rights as a research subject?
 If you feel you have not been treated according to the descriptions in this form, or if you have any questions about your rights as a research subject, including questions, concerns, complaints, or to offer input, you may call the Office for the Protection of Research Subjects (OPRS) at 312-996-1711 or 1-866-789-6215 (toll-free) or e-mail OPRS at uicirb@uic.edu.

Remember: Your participation in this research is voluntary. Your decision whether or not to participate will not affect your current or future relations with the University. If you decide to participate, you are free to withdraw at any time without affecting that relationship.

Signature of Subject or Legally Authorized Representative
I have read (or someone has read to me) the above information. I have been given an opportunity to ask questions and my questions have been answered to my satisfaction. I agree to participate in this research. I will be given a copy of this signed and dated form.

APPENDIX B Consent Form (continue)

_____   _____

Signature   Date

_____

Printed Name

_____   _____

Signature of Person Obtaining Consent   Date (must be same as subject's)

_____

Printed Name of Person Obtaining Consent

C. **APPENDIX C Letter of Invitation to Participate in the Study**

Letter of Invitation to Participate:

University of Illinois at Chicago Research Study
"Evaluating Community Living and Work Participation
Environments and Technologies for Use by People
who have a Stroke: A Consumer-Directed,
Dynamic Assessment Methodology"

Dear Sir or Madam,

You are being asked to be a subject in research to explore how people who have had a stroke, adapt the home environment to their needs. The study will also explore the factors that support them in taking an active role in designing their environment.   The study is being conducted by Joy Hammel from the University of Illinois at Chicago. You have been identified as a person with stroke who lives in the community and may be eligible to participate.

If you decide to participate in this research, we would ask you to participate in one 1-2 hours interview, a 1-hour follow up interview and a focus group. The interviews will take place at your home. The interviews may ask you questions about what modifications you have done to the home environment and how they helped you in managing home activities. We will also ask you to take pictures or videos of you and your home environment in order to record your use of design strategies in everyday life. There is no cost to you for participating in this study.

The study results may be used to help other people with stroke in the future. The results may be used to develop new research or expand research on modifications to the environment where people who have had a stroke live, research on the design of objects and building to be used by people who have had a stroke, or research on the plans and actions proposed by people with stroke who want to live in the community and participate in activities they like.

APPENDIX C Letter of Invitation to Participate in the Study (continued)

To compensate for your participation in the two interviews you will receive $35 total, and a $10 gift card for participating in the focus group. Additionally, you will receive $6 for transportation.

The risks of participating in this study are minimal in that none of the activities are experimental or clinical in nature, and all would involve activities that would otherwise be part of typical day for most participants. You may skip any questions or stop activities, as you want. You are under no obligation to participate in this study, and participation in this study is not related to any medical or community services you may use or receive. If at any time you should wish to withdraw from the study, you are free to do so without consequence.

      If you are interested in participating, please let the person who is sharing this information with you know. This person will meet with you later in person to review the study in detail, obtain your consent to participate and schedule the first interview. If you have any questions about the study, please feel free to call Joy Hammel at 312-996-3513 or email her to hammel@uic.edu. If you have any questions about your rights as a research subject, you may call the Office for Protection of Research Subjects at the University of Illinois at Chicago at 312-996-1711. Thank you for your time and consideration.

Sincerely,

Joy Hammel, Ph.D., OTR/L, Principal Investigator

(312) 996-3513 (work phone)

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VITA

NAME:	Martha Patricia Sarmiento
EDUCATION:	Industrial Designer, Universidad Nacional de Colombia Bogota Colombia 1987
	Ergonomist, Universidad del Bosque Bogota Colombia 2003
	Master in Disability Studies, Universidad Nacional de Colombia 2006
	Ph.D. Disability Studies, University of Illinois at Chicago, Chicago Illinois 2017
TEACHING	Escuela de Diseño Industrial, Universidad Nacional de Colombia Bogota Colombia:
	Introduction to Human factors and Ergonomics for Industrial Design Undergraduate students
	Human Factors and Ergonomics Workshop for Industrial design
	Applied Ergonomic levels II and III for Industrial Design and Industrial Engineering
	Universal Design and Social Inclusion, Disability and Social Inclusion, Master program
	Lectures in the Disability and social inclusion Master program
	Seminar I and II on design studies for the master program, Master in design
	Departamento de Diseño Industrial, Universidad de los Andes Bogota Colombia
	Introduction to Human factors and Ergonomics for Industrial Design
	Human Factors and Ergonomics Workshop for Industrial design
PUBLICATIONS:	Sarmiento, M.P. (2007). La participación como horizonte de los procesos de organización de personas con discapacidad: Estrategias de acompanamiento a procesos de organización de hombres y mujeres en situación de discapacidad . In Colombia ISBN: 978-958-701-893-6 ed: Editora Guadalupe Ltda. (Bogotá) , v. , p.75 - 95 ,2007
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	Sarmiento, M.P. La calidad de vida de la familia se activa" in press Faculty of Medicine at the Universidad Nacional de Colombia
	Sarmiento-Pelayo, M. P. (2015). Co-design: A central approach to the inclusion of people with disabilities. Revista de la Facultad de Medicina, 63, 149-154.