Mechanical Lift Technology: The Parent Experience of Caring for an Adult Child With a Physical Disability

BY

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THESIS

Submitted as partial fulfillment of the requirements
for the degree of Masters of Science in Disability and Human Development
in the Graduate College of the
University of Illinois at Chicago, 2017

Chicago, Illinois

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ACKNOWLEDGEMENTS

I would like to thank my thesis committee Michelle Bulanda, Sarah Parker Harris, Patricia Politano, and Brenda Sposato. A special thanks to all of the University of Illinois at Chicago, Department of Disability and Human Development and Assistive Technology Unit staff for sharing their knowledge and support through my classwork and years working at the Assistive Technology Unit. Love and gratitude to all of my family, friends and especially my husband for their encouragement and support throughout this program and this thesis writing adventure.

Most importantly I would like to express my appreciation to the parent participants and their children who welcomed me into their homes and shared their experiences with me for this project.

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SUMMARY

This research aimed to understand the impact of transfer lift technology on the experience of parents caring for their adult children with a disability. Seven parent caregivers between the ages of 53-69 participated in individual interviews. For aging parent caregivers, the physical effort of daily lifting responsibilities places them at risk for back pain, fatigue and other health problems. To ease the physical load, transfer lifts are frequently recommended. Transfer lift devices function to lift individuals up mechanically from one surface, transport them to another location and safely lower them onto the new surface.

A mixed methods approach was utilized for this research, including a quantitative survey, the Caregiver Assistive Technology Outcome Measure, and open-ended interview questions. Both approaches were employed to gain insight into changes in the parent participant's experience as caregiver since acquiring a transfer lift. Comparison of data revealed shared findings that showed transfer lift technology positively impacts the experience of middle and old age parent caregivers.

Findings confirmed that transfer lifts are consistently utilized in the home by the parent participants and/or by other caregivers to transfer the adult child with a disability. The study also provided insight into emotional and physical stress that parent participants reported in relation to transferring adult children with disability. Since acquiring a transfer lift in the home, parent participants reported significantly reduced levels of worry over safety for their child and themselves and decreased physical strain. The major advantages of having a transfer lift in the home were identified as the decreased level of emotional

stress and physical lifting load. Due to this reduced physical load and increased level of safety, parent participants benefit from having a wider group of caregivers available to care for the adult child. Findings also revealed challenges of using transfer lift technology. These include difficulty managing the sling before and after transfers and an increased amount of time required when using the lift. The results of this study lead to meaningful considerations for clinicians to share with individuals with disabilities and their caregivers who are considering transfer lift technology.

I. INTRODUCTION

A. Background

In my role of physical therapist at the Assistive Technology Unit of the University of Illinois at Chicago, I participate in home-based team assessments for individuals with disabilities who are living in the community in their family home. The goal of this state-funded program is to identify and provide the necessary home modifications and assistive technology to support these individuals in continuing to live in their home with safe practices for the client and his/her caregivers. These referrals include recommendations for transfer lift technology used to move individuals who are physically disabled safely from one location to another, such as between their bed and a wheelchair. There are many different types of transfer lifts and styles of support slings and the cost of these transfer technology systems and installation can be expensive. It is crucial that recommendations are made for the transfer lift system that will best match the needs of the clients and their families since the technology is not easily changed or replaced.

B. Purpose of the Study

To provide the best possible support to clients, it is necessary for Assistive Technology Unit (ATU) clinicians to be informed of what impact the recommended Assistive Technology is likely to have on the individuals' and their caregiver's function. Clients are referred for a transfer lift technology assessment to reduce the demands of physical lifting on parental caregivers. Therefore, it is the parents' perceptions of their day-to-day experience in caring for their child with a disability that is the focus of this study. During ATU transfer lift evaluations, we often meet adult clients in their twenties or thirties living at home with their parents who are now entering middle or old age. These parents have been lifting to transfer their child with a disability for decades, which is often the most

physically demanding task in caregiving (Darragh, Sommerich, Lavender, Tanner, Vogel, & Campo, 2015). In our country many adults, without disabilities, who are typically aging will begin to show musculoskeletal concerns associated with arthritis by the time they are in middle age (40-59) or older age (>60) (Yamaki, Hsieh, & Heller, 2009). For aging adult caregivers, the physical effort of their daily lifting responsibility places them at significantly increased risk for early onset and advanced effects of aging on their musculoskeletal system (Alamgir et al., 2008; Hammel, Lai, & Heller, 2002; Raina et al., 2004; Yamaki et al., 2009). During transfer lift evaluations, many parents talk about their personal age-related conditions of back pain, fatigue and other health problems. A frequent concern reported by these parent caregivers is the fear of no longer being able to meet the physical challenge of full time care for their child and the fear that they may need to seek residential placement for the child when that time comes (Hammel et al., 2002).

The purpose of this study is to understand better if and how a transfer lift impacts the experience of an aging parent caregiver by exploring the following questions: (1) do middle and older aged parents who care for an adult child with physical disability utilize a transfer lift once it is provided in their home; (2) does having transfer lift technology available change their experience in caring for their adult child with a disability; and (3) what are the advantages and/or disadvantages that parents have found since the transfer lift technology was delivered to the home?

C. **Assistive Technology Definition**

The term assistive technology (AT) covers a wide range of products and devices used by people with disabilities. One definition of AT is contained in Public Law 108-364, the Assistive Technology Act of 1998, amended 2004. Cook and Polgar (2008) support this

definition, “Any item, piece of equipment or product system whether acquired commercially off the shelf, modified or customized that is used to increase, maintain or improve functional capabilities of individuals with disabilities” (p. 5). Some examples include wheelchairs, communication devices, bath chairs, adapted clothing and hospital beds. The specific type of AT under investigation in this study is a transfer lift device, which is routinely recommended to reduce physical lifting by caregivers in the home (Haworth & Nichols, 1980; Shepherd, Stewart, & Murchland, 2007).

D. **Transfer Methods**

There are two methods of assisting an individual who is physically dependent to transfer between support surfaces. The first method is to move the person physically, using lifting techniques and proper body mechanics to optimize safety for the individual being lifted as well as the caregiver(s). Most families continue using the same lifting techniques to transfer their adult child with a disability as were used when the child was young. When the child grows and is too big to lift or if the parent acquires physical limitations, the family must find a different approach to transfers. If it is a two-parent household, often the healthier, stronger parent takes over the majority of transfers. Another technique is to use a two-person lift transfer, where the parents work together sharing the load between two caregivers. A viable alternative to these methods is the use of transfer lift technology. As discussed above, a transfer lift may be incorporated into the caregiving routine for the purpose of reducing the physical labor and musculoskeletal stress on the caregiver. A transfer lift device functions to lift individuals mechanically up from one surface, transport them to another location and safely lower them onto the new surface. The transfer lift technology consists of a motor and a supportive sling (or a

support) which replaces the caregiver's arms in holding the person while he/she is being lifted. The motor is supported on an overhead track that is either installed in the ceiling of the home or is supported by a floor-based frame. An alternative to the overhead lift is a floor-based lift where the motor is suspended from a wheeled base that is pushed between the surfaces by a caregiver. These types of transfer lift technology are shown in Figures 1, 2 and 3. All three types of transfer lifts are designed for use in the home.

Figure 1. Ceiling-mounted overhead lift with a sling.

Figure 2. Floor-based overhead lift with the SureHands® Body Support.

Figure 3. Floor-based lift with a sling.

Funding for transfer lift assistive technology (AT) in the United States is not available for all individuals with a disability. Federal Medicare funds do not routinely pay

for a lift and state-level Medicaid funds are often limited to a basic floor-based, hydraulic lift. Funding prospects are better for individuals with private insurance to secure funding for the appropriate transfer lift. However, most states have a department that provides financial support to help individuals with disabilities to continue living in their homes. The cost of transfer AT varies based on the type of lift, features and manufacturer. The most basic floor-based, hydraulic (not powered) lift starts at approximately $500 with a powered floor-based lift closer to at $1200 or more. Overhead track lifts start at $2000 for a floor-based frame (Figure 2) with a motor and sling. Installed track in the ceiling for an overhead lift have a wide range of costs. A permanent motor may cost $2,000 with the track sections and installation from $3,000 up to $10,000 or more, depending on the length, configuration and features of the track.

II. LITERATURE REVIEW

Due to medical advances, there have been increasing survival rates for children born prematurely with birth defects or with genetic disorders (Boyle et al., 2011). Babies who are born with a developmental disability function within a wide range of ability, from independent to having significant intellectual impairment, physical disability or both. The whole family is impacted by a child with a severe disability and in most cases, it will fall on one or both of the parents to provide the intense level of care required by their son or daughter (Henderson, Skelton, & Rosenbaum, 2008; Raina et al.,2004; Yamaki et al., 2009). Through this effort of supporting their child with a significant disability, parents often experience a heavy burden that places them at risk for physical and emotional burnout (Demers et al., 2016). While many families find great meaning and joy in caring for a child with a disability, the emotional and physical strain is a significant concern, especially as the child gets older and ages out of infant and youth support services and programs (Demers et al., 2016; Raina et al., 2004).

As the child with a disability grows into adolescence and adulthood, the caregiving role becomes more complex and parents encounter increased stressors (Jennings, 1987; Raina et al., 2004). In looking specifically at the responsibilities of caring for a teenage or adult child with a severe disability, physically challenging work is required of the caregiver (Alamgir et al., 2008). Even when the adult child is small in stature, considerable exertion is required for repositioning and transfers. This manual labor is multiplied by the number of transfers the child requires each day, and over many years this becomes a high-risk occupation for the parent (Alamgir et al., 2008). In the study by Darragh and his colleagues (2015), 94% of the caregivers reported having musculoskeletal discomfort and over half of

these participants had been providing care for less than five years. Though each family is unique it is expected that every parent who cares for the child with a physical disability over decades will experience musculoskeletal pain at some point (Raina et al., 2004). An important factor in this family dynamic is the typical effects of aging on the parent's body that causes deterioration over time. This essentially creates an increasing caregiving load even when the child is fully grown and remains at the same size and weight.

In our country over half of the caregivers for individuals with developmental and intellectual disabilities are over 40 years old, with older age caregivers (those over age 60) constituting 25% of these families (Yamaki et al., 2009). In my clinical experience, we encounter parents into their 70's and 80's who continue to provide care for their adult children with disabilities. This ongoing physical demand of caregiving, coupled with the aging parents' health concerns, may come to present a dangerous situation for the parent, the child or both (Seltzer, Floyd, Song, Greenberg, & Hong, 2011; Yamaki et al., 2009). When the caregiving load becomes too much for them, the family may seek monetary assistance for paid caregiver support or privately pay for an outside caregiver. In some cases the parents might need to seek residential placement outside the home for their child with a disability (Haworth & Nichols, 1980). Placement outside the home is usually the last resort for a family and even if this becomes necessary, there are not always residential services available to meet the needs of adults with disabilities (Johnson, Kastner, & Committee/Section on Children with Disabilities, 2005). Another means of support for parental caregivers is to introduce transfer lift assistive technology to reduce the physical burden of care.

The usefulness of transfer lift technology in reducing the risk for fatigue and injury in middle and older aged caregivers of adult children with disabilities is explored in this study. A review of the literature shows little research that addresses the physical challenges faced by unpaid caregivers in the home or the use of assistive technology to reduce this load (Darragh et al., 2015; Demers, Fuhrer, Jutai, Depa, & DeRuyter, 2009; Jennings, 1987; Nicolson, Moir, & Millsteed, 2012). Of these studies only two address the use of transfer lifts in the home setting and only one study by Shepherd and colleagues specifically addresses the parent caregiver perceptions (Haworth & Nichols, 1980; Shepherd et al., 2007). In that qualitative study specific to parent caregiver perceptions (Shepherd et al., 2007), the researchers concluded that introduction of a transfer lift had an overall positive impact on both the parent and child. Along similar lines, information related to the physical challenges faced by paid caregivers is prevalent in the literature (Darragh et al., 2015). There is much research to substantiate the use of transfer lifts by nurses and other professionals in medical and residential settings. Specific to those paid caregiving roles, findings show that use of transfer lift technology leads to reduced perception of pain, discomfort and risk of musculoskeletal injury in workers (Alamgir et al., 2008; Miller, Engst, Tate, & Yassi, 2006). Since lifting and transferring an individual with a disability present similar challenges whether they are performed in the home environment, a hospital or a residential care setting, those findings related to paid caregivers may be generalized to parental caregivers in the home setting. In support of generalizing these results, the transfer lift technology that Assistive Technology Unit clinicians recommend for home use is identical to the technology used in hospitals, nursing homes and residential care facilities. This study seeks to strengthen the hypothesis that use of transfer lift

technology is effective in the home setting to create a safer environment for both the parent caregiver and his or her adult child with a disability. It also seeks to gain a better understanding of the experience of aging parent caregivers.

III. RESEARCH DESIGN

A. Method

This research study utilized a mixed inquiry methodology based in the phenomenological approach. Phenomenology is the best suited qualitative approach to learning about and understanding the parent participant's experience as directly as possible (Mertens, 2010). Though clinicians may care for adults with physical disabilities in a therapeutic role, that care provides only a limited awareness of the day-to-day caregiving experience. This study was designed to learn about the parent caregiving experience through meaningful and detailed descriptions from parent participants willing to share their personal stories. To further explore the portrayal provided by parent participants, quantitative data was gathered through the Caregiver Assistive Technology Outcome Measure (CATOM). The CATOM was not published at the time of this study. However, Louise Demers, who developed the CATOM along with her colleagues, shared the outcome measure with the primary researcher for use in this research (personal communication, November 3, 2015). The CATOM was specifically developed to measure the impact of assistive technology, focusing on device-specific outcomes for the family caregiver experience (Mortenson et al., 2013, 2015; Rushton et al., 2017).

The primary researcher collected the quantitative and qualitative data through individual interviews conducted in the home setting. This served to situate parent participants in the environment where they care for their adult child with a disability and afforded them the opportunity to point out features of the transfer lift while talking about their experience. Comparison of the data gathered from both sources allowed for triangulation of the findings and provided a deeper insight into the experience of parent

caregivers. Credibility of results is also strengthened when strong support emerges between shared outcomes (Patton, 2002).

B. Sample

1. Criteria for participation

Purposeful sampling was used to identify potential participants for this study. This sampling technique identified information-rich participants who were able to provide critical details to illuminate the parent participant experience in caring for an adult child with a disability living at home. This sample pool was comprised of parent participants of Assistive Technology Unit clients who received home modifications services and were recommended to receive a transfer lift device. These home assessments were all performed by a team that included the primary researcher. Each participant is the parent of a client who ultimately received the transfer lift technology and meets three inclusion criteria:

(1) The child requires maximal assistance for transfers due to a physical disability;

(2) The child is over 18 years old and resides full time with the parent participant; and

(3) The family has had a transfer lift device in its home for over one year.

2. Recruitment

After receiving ethics approval for this study from the Internal Review Board of UIC, the primary researcher reviewed Assistive Technology Unit (ATU) client files to identify potential participants. Phone calls were made to families by ATU scheduling staff to determine eligibility (establish if the transfer lift had been acquired) and ascertain interest of parent participant(s). For each family that met the criteria and expressed

interest, further discussion and scheduling were completed by the primary researcher through follow-up phone calls and e-mail correspondence.

3. **Participants**

The Assistive Technology Unit scheduling staff identified six clients that met the inclusion criteria. One of the families did not respond to the primary researcher by phone until the interviews had been completed and another family did not agree to participate in the study. Seven parent participants were recruited from the families of the remaining four clients. As a small sample size is appropriate in studies designed for in-depth exploration of a topic, the intended sample size for this research was between six to ten participants (Mertens, 2010).

Table I presents demographic information for the study participants, which includes three couples who share caregiving responsibilities for their child and one recently widowed parent. The parent participants ranged in age from 53 to 69 years old, with three males and four females. By self-report, six of the seven participants identified as having medical concerns that affect their ability to perform lifting activities such as transferring their child. Although the viewpoint of the client who is utilizing the transfer lift is important, this study focused on the caregiver perspective. Therefore, demographic or experiential information was not collected pertaining to the adult children with disabilities except for body weight, which ranged from 70 to 125 pounds.

TABLE I
DEMOGRAPHIC INFORMATION OF STUDY PARTICIPANTS

Participants	1	2	3	4	5	6	7
Age in years	68	69	63	63	55	53	53
Gender	Female	Male	Male	Female	Female	Female	Male
Medical concerns reported	No medical concerns	Multiple musculo-skeletal concerns	Minor musculo-skeletal concerns	Left shoulder surgery	Multiple musculo-skeletal concerns	Other Medical concerns	Multiple musculo-skeletal surgeries
Parents in the home	2	2	2	2	1	2	2
Client	A		B		C	D	
Client's weight	125 pounds		97 pounds		70 pounds	95 pounds	
Type of transfer lift and support	Track supported on floor with SureHands® Body Support		Ceiling mounted track with sling		Ceiling mounted track with sling	Ceiling mounted track with sling	

C. Data Collection

1. Materials

After a review of the available tools, the Caregivers Assistive Technology Outcome Measure (CATOM) was identified as the ideal tool to gather quantitative data for this study. The CATOM was developed specifically to measure the impact of Assistive Technology (AT) use on an informal, unpaid caregiver providing care to an individual with a disability (Mortenson et al., 2015). In preliminary testing of the CATOM, it showed excellent reliability and construct validity (Mortenson et al., 2013, 2015). The CATOM has not previously been used to study specifically the use of transfer lift AT. Per Mortenson (personal communication, March 4, 2015), one of the CATOM developers, modifications of the CATOM may include select questions that target the specific technology being investigated. CATOM modifications for this study included use of only seven questions that were pertinent to the use of a transfer lift in the home. (Refer to Appendix A for the list of CATOM questions.) The yes/no questions on the CATOM reflect the participant's experience in caring for his/her child after receiving the transfer lift and recall of performing transfers before having the lift. When the caregiver reports a change in the before and after experience he/she is asked to rate the degree of change on an ordinal scale. This number quantifies the parent participant's perception of the degree of change that occurred in either a positive or negative direction. The CATOM is being used as a descriptive instrument for this study. The participant responses will be analyzed, looking for commonalities between participant responses within each question and for comparison with themes identified from participant's qualitative responses gathered in open-ended interview questions.

2. **Interview format**

Three questions were included in the open answer portion of the interview. These questions afforded parent participants the opportunity to use their own words to describe their unique experience and to relate any important information that had not been collected by the survey. The first two questions expand upon the content introduced in questions four, five, six and seven in the Caregiver Assistive Technology Outcome Measure questionnaire. The last question was intentionally left unstructured for the participants to report on any thoughts, feelings or aspect of caring for his/her child that had not already been addressed. The primary researcher sought to gain depth and details of each parent participant's experience for an intimate familiarity and fuller understanding of the caregiver's day-to-day experience. These three questions were developed by the primary researcher with input from two peer reviewers to establish clarity and significance. Both of these peer reviewers have past experience and have published work based on qualitative research. The three prompts posed to participants in this study were:

(1) Please tell me more about the physical assistance required when you are transferring your child.

(2) Tell me about any concerns you have for the safety of your child and/or for yourself during transfers.

(3) Please tell me about any changes experienced in the physical assistance required for transfers and/or in your concerns for safety since acquiring the transfer lift in your home.

3. **Procedures**

After informed consent was obtained, the primary researcher interviewed each of the parent participants in his/her home. When two parent caregivers were present, the interviews were conducted privately to prevent one participant's answers from

influencing the other participant responses. Each participant was given a printed copy of the modified Caregiver Assistive Technology Outcome Measure (CATOM) to refer to the questions and the rating scale while the seven questions were read aloud. Following the CATOM questionnaire, each parent participant was asked the three open-ended questions. During the interview, the researcher wrote down answers to the questionnaire on a printed copy of the CATOM. With the open-ended questions, parent participant responses were audio recorded while the researcher wrote down major themes for verification at the end of the interview. The interviews lasted approximately 30 to 60 minutes. At the end of each interview, the participants' responses were reflected back to them by the primary researcher for verification of ideas and meaning. The full audio recorded responses from the open-ended questions were transcribed by the primary researcher into a document.

D. **Data Analysis**

The primary researcher and two peer reviewers analyzed the qualitative raw data independently, identifying themes. To facilitate this, the primary researcher uploaded the document with the transcribed text from the open-ended interview questions into NVivo10, qualitative data analysis software. The NVivo10 program was used by two of the reviewers to categorize each participant's statements into nodes, organizing and storing the data by thematic category. The third reviewer used a printed version of the document with the transcribed text. The three reviewers then met to discuss and compare thematic categories. Discussion during this meeting revealed four categories or themes that were common to all three reviewers. Using these four themes, each reviewer again worked independently to code the data. The coded data from each reviewer was then cross-checked by the primary researcher for consistency between all three reviewers. When a

discrepancy was present, coding of the statement was discussed via e-mail and the three reviewers came to an agreement or else the statement was excluded in the final data. The process of having three reviewers independently dissect the interview responses and of cross checking for both theme development and coding of statements enhanced the rigor of this study. Throughout the interviewing and data analysis process, the primary researcher kept a logbook of personal experience and reactions. This was done to maintain awareness of any preconceptions or judgments that could affect interpretation of the data. In a phenomenological study, rigor is maintained through an ongoing self-examination to identify personal bias that could skew the data through personal involvement or personal factors.

IV. RESULTS

Results include parent participant's responses to the seven questions from the Caregiver Assistive Technology Outcome Measure and responses to the three open-ended questions.

A. Caregiver Assistive Technology Outcome Measure Results

All parent participants provided responses to the seven two-part questions from the Caregiver Assistive Technology Outcome Measure. The responses for each question, including part A and part B, were analyzed for commonalities between participant responses and are summarized below. Data reflecting the number of parent participant responses per category is presented in graph format beneath each question summary (Figures 4 through 17).

Question 1a

Responses to question 1a were varied among participants (Figure 4).

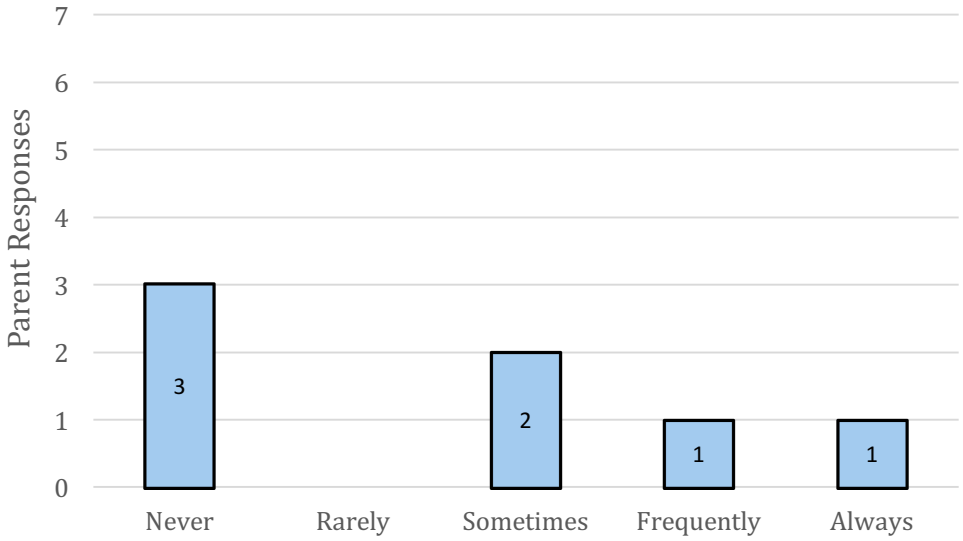

Figure 4. Responses to CATOM question 1a "Do you ever feel that helping your child with transfers requires too much of your time?"

Question 1b

Responses to question 1b were varied among participants (Figure 5).

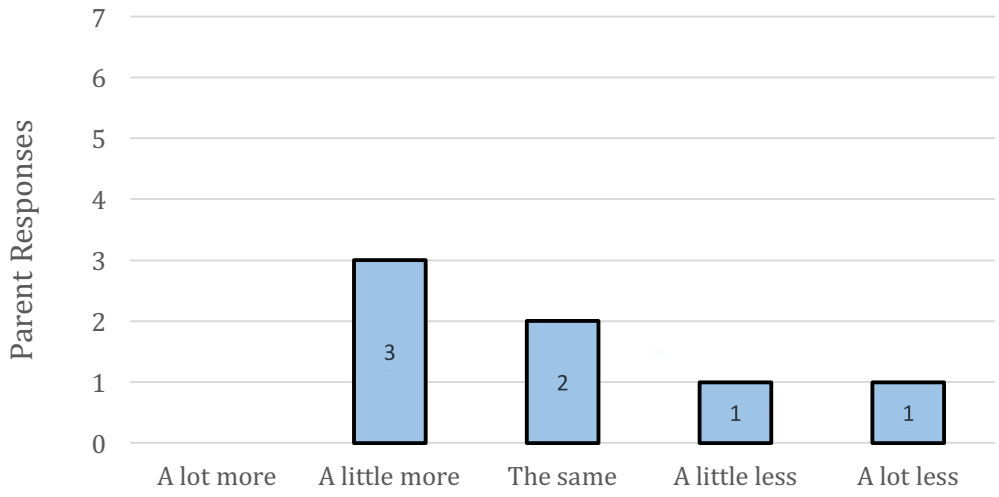

Figure 5. Responses to CATOM question 1b, "Since getting your lift, do you feel that helping your child with transfers requires more, less or the same amount of your time?"

Question 2a

Responses to question 2a were all affirmative ranging from "rarely" to "always" among participants (Figure 6).

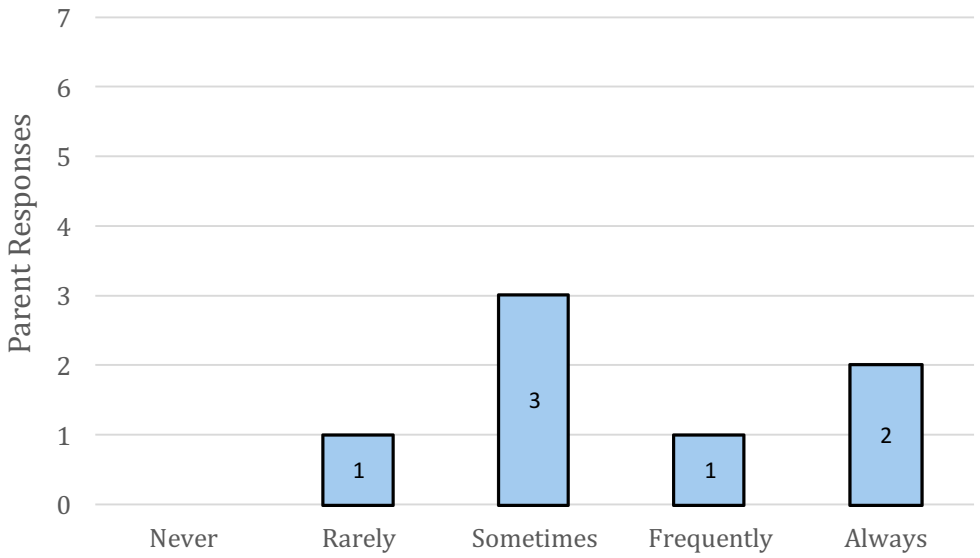

Figure 6. Responses to CATOM question 2a, "Do you ever feel that your child may be harmed when he or she is being transferred?"

Question 2b

Responses to question 2b showed all participants reported a decrease in concern and six of seven participants reported “a lot less” (Figure 7).

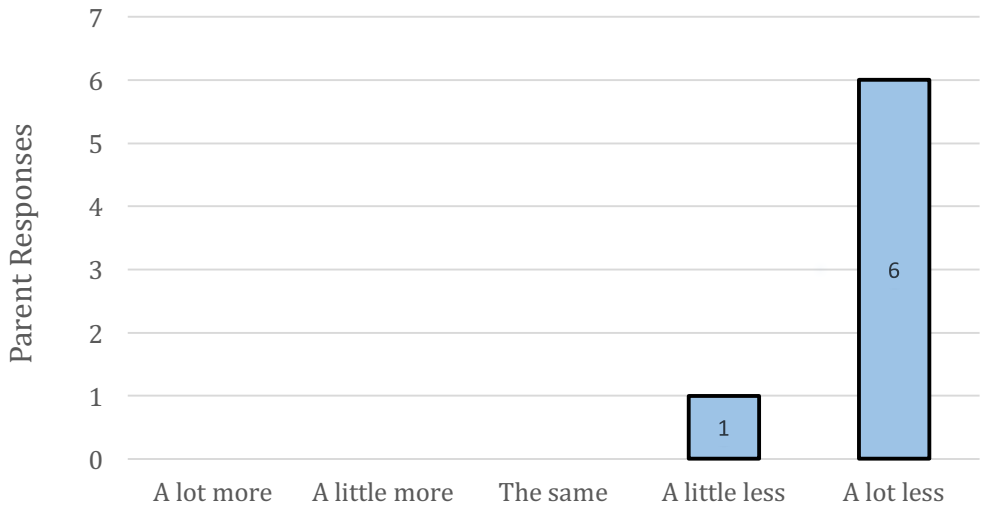

Figure 7. Responses to CATOM question 2b, “Since getting your lift, do you feel that your child may be harmed more, less or the same when he or she is being transferred?”

Question 3a

Responses to question 3a showed six of seven reponses were affirmative, ranging from "rarely" to "always" among participants (Figure 8).

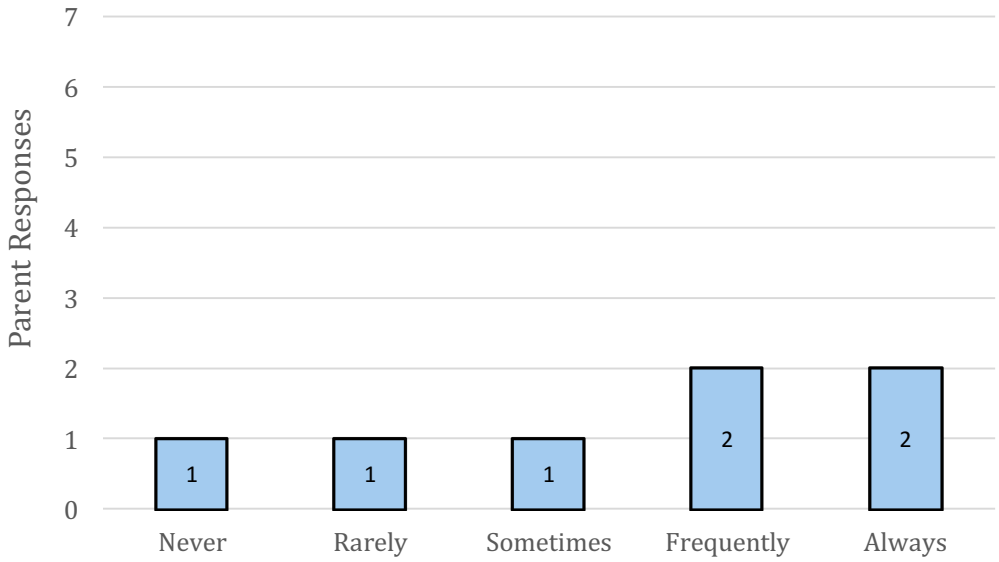

Figure 8. Responses to CATOM question 3a, "Do you ever feel that you may be harmed when you are helping your child to transfer?"

Question 3b

Responses to question 3b showed all participants reported a decrease in concern and six of seven participants reported “a lot less” (Figure 9).

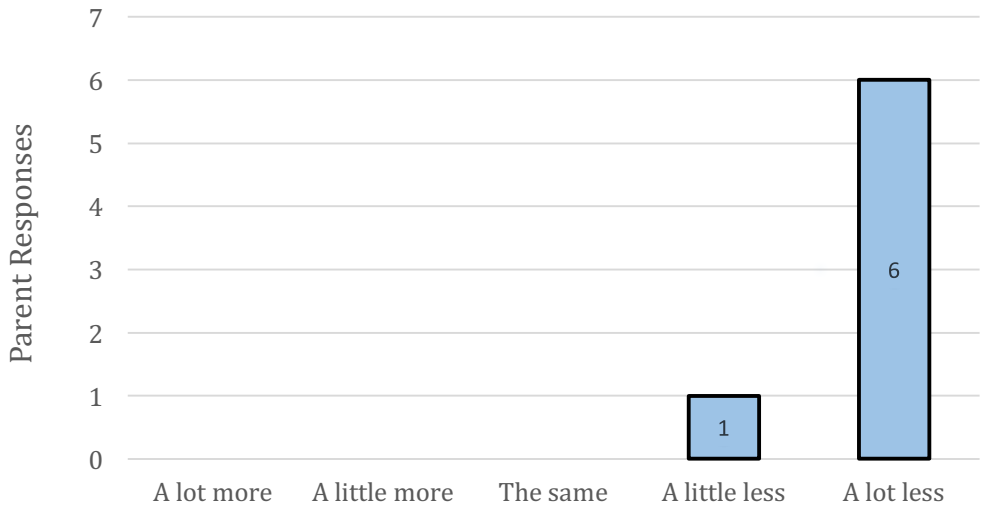

Figure 9. Responses to CATOM question 3b, “Since getting your lift, do you feel that you may be harmed more, less or the same when you are helping your child to transfer?”

Question 4a

Responses to question 4a show that five of seven participants reported feeling physically tired after helping their child transfer between their bed and the wheelchair (Figure10).

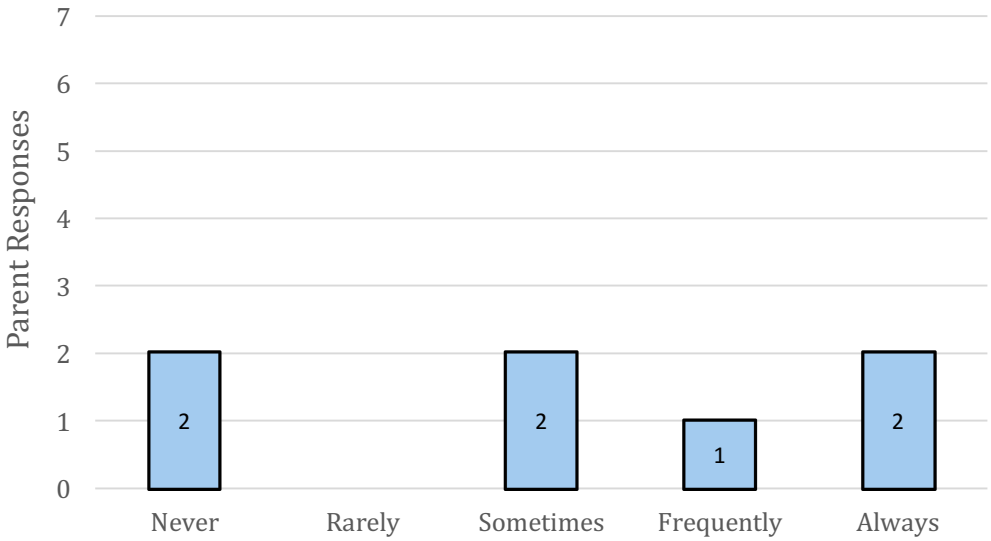

Figure 10. Responses to CATOM question 4a, "Do you ever feel physically tired after helping your child transfer between their bed and the wheelchair?"

Question 4b

Responses to question 4b were varied among participants (Figure 11).

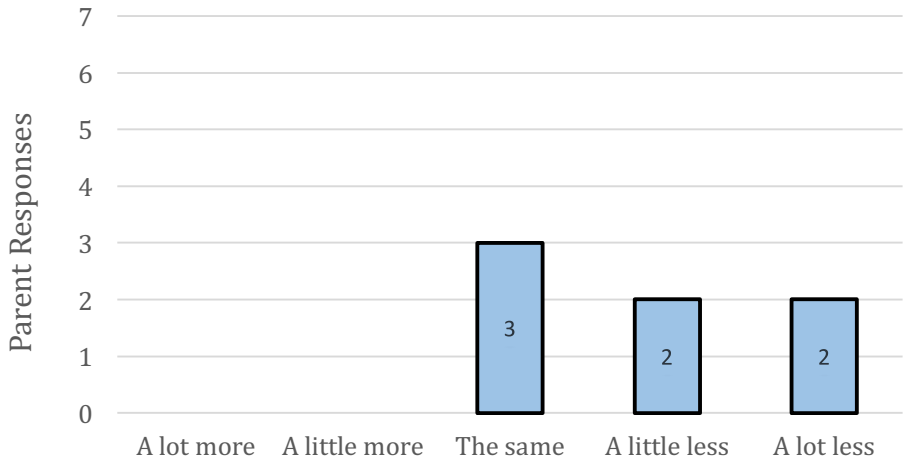

Figure 11. Responses to CATOM question 4b, "Since getting the transfer lift, do you feel physically tired more, less or the same after helping your child transfer between their bed and the wheelchair?"

Question 5a

Responses to question 5a were varied among participants (Figure 12).

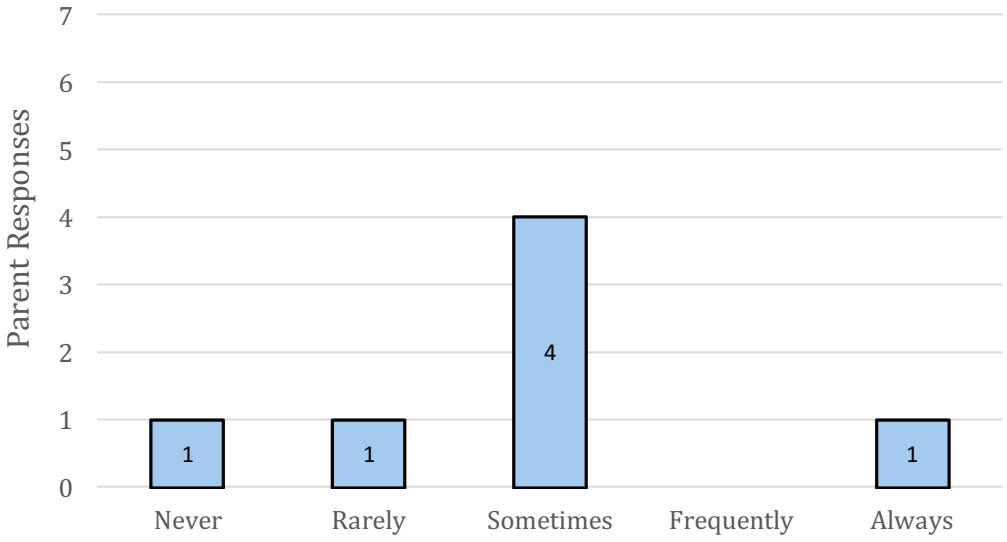

Figure 12. Responses to CATOM question 5a, "Does the help you are providing to transfer your child ever result in pain or physical strain?"

Question 5b

Responses to question 5b showed all participants reported a decrease in physical strain or pain with, three participants reporting “a little less” and four reporting “a lot less” (Figure 13).

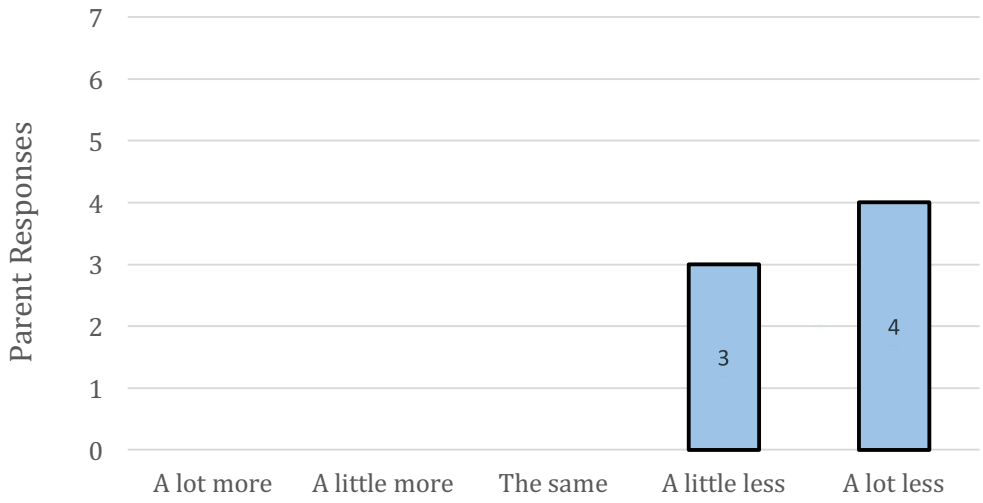

Figure 13. Responses to CATOM question 5b, “Does the help you are providing to transfer your child result in more, less or more pain or physical strain?”

Question 6a

Responses to question 6a were varied among participants (Figure 14).

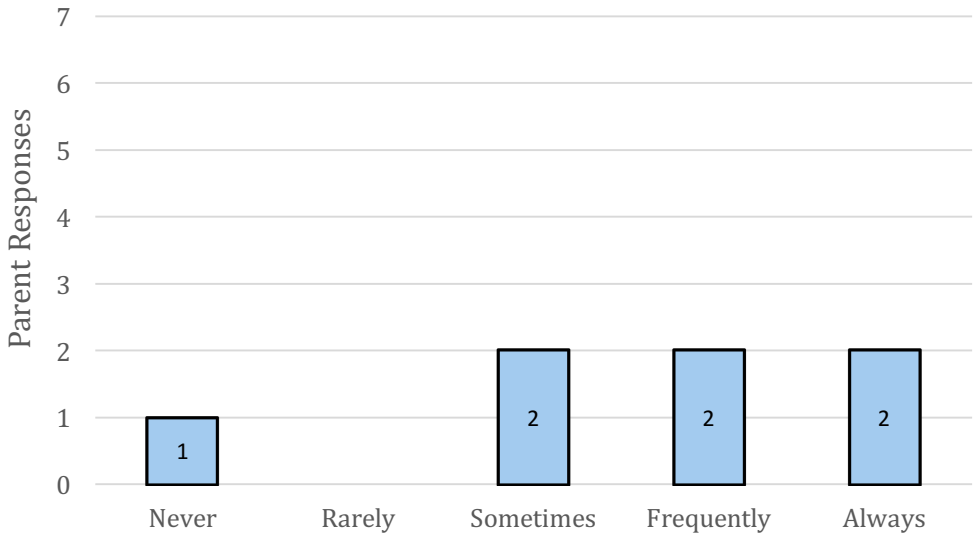

Figure 14. Responses to CATOM question 6a, "Do you ever feel anxious while your child is transferring (whether you are there to help or not)?"

Question 6b

Responses to question 6b showed six of the participants reported feeling a lot less anxious when their child was transferring with them or with another caregiver (Figure 15).

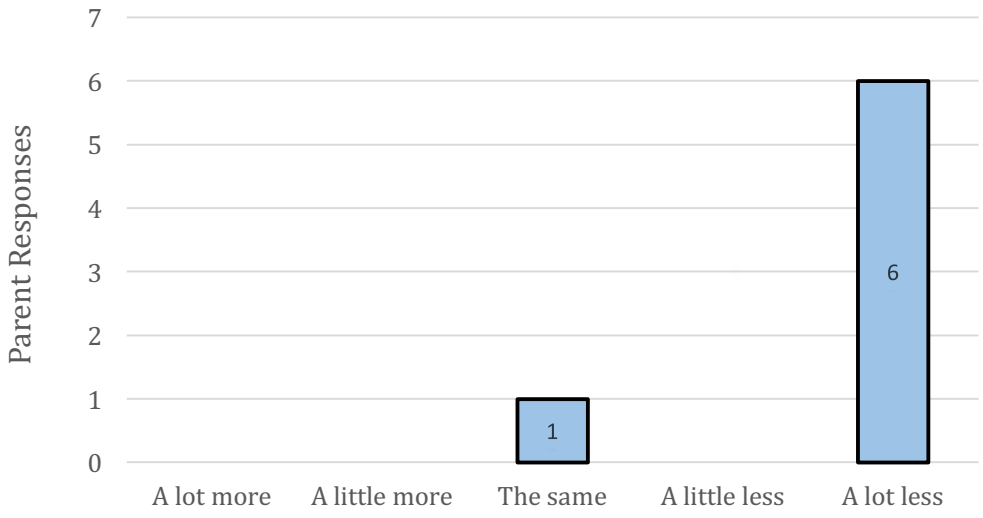

Figure 15. Responses to CATOM question 6b, "Since getting the transfer, do you feel anxious more, less or the same, while your child is transferring (whether you are there to help or not)?"

Question 7a

Responses to question 7a were consistent among participants. No participant had transfer equipment in the home prior to receiveing the transfer lift (Figure 16).

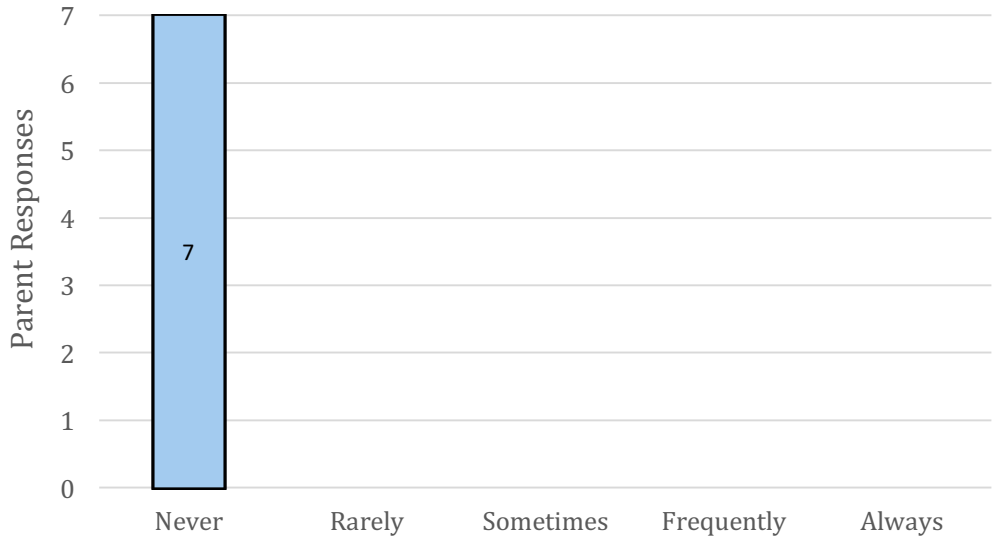

Figure 16. Responses to question 7a, "Do you ever feel that the equipment used for transfering your child limits the use of space within your home?"

Question 7b

Responses to question 7b showed that six of seven participants did not feel the lift limited space in their home (Figure 17).

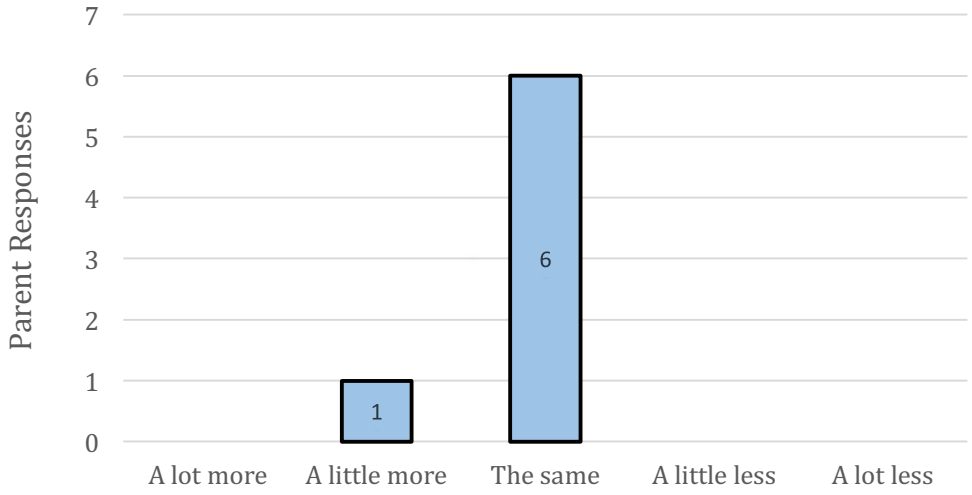

Figure 17. Responses to question 7b, "Since getting the transfer lift, do you ever feel that the transfer lift limits space in your home, more less or the same?"

B. **Open-Ended Question Results**

All participants provided in-depth responses to the open-ended questions regarding his/her caregiving experience. Qualitative analysis of these responses led to four major themes and 10 minor themes. These themes are presented below and are summarized in Table II.

TABLE II
QUALITATIVE THEMES

Major Themes	Minor Themes	Examples
1. Emotional stress	a. Safety	"I used to feel like he could be hurt all the time before we had the lift when we were transferring my son."
	b. Age related physical changes and health concerns	"…but as I age my biggest concern is balance, my own balance and my own steadiness…"
2. Physical stress	a. Physical load of lifting for transfers	"We still have to help him with the lift but we don't work physically as hard. A lot less physical exertion. I'm still tired at the end of the day but using the lift makes me a lot less physically tired."
	b. Long term caregiving concerns	"…as they get older you get older too, so the physical stress becomes, increases over time…"
3. Advantages to having the transfer lift	a. Improved safety	"…the amount of safety is mechanically increased."
	b. One caregiver able to perform transfer	"…transfers can be easily done with minimal assist, minimal manual labor or lifting exertion of a care provider. So one person can do it…"
	c. Outside caregivers available	"The transfer lift will permit me to have help from other caregivers who are not able to lift her."
4. Drawbacks to having the transfer lift	a. Use of the lift takes more time	"…it may take a little bit more time with the lift, it would be safer obviously but it takes a little more time."
	b. Sling positioning issues	"The only physical assistance is getting the sling out of out of the way…"
	c. Impact of having the lift in the house	"At first having the lift sticking out in the room was horrible, I didn't think we'd get around it. But we got used to it."

1. **Theme 1: Emotional stress**

Every participant conveyed multiple statements relating concern that his/her child or that they themselves might be harmed when using a physical lifting technique for all transfers. All of the parent participants described reduced concerns since acquiring the lift. These statements about emotional stress fell into two subthemes, safety and age-related physical changes and health concerns.

a. **Safety**

Every one of the seven participants expressed worry and concern for his/her child's safety when he/she was transferred using physical lifting techniques. One parent participant said, "I mean it could get scary sometimes" when she transferred her adult child with a disability before having the lift. Another parent participant expressed, "I am always worrying about (my son) being hurt when not using the lift." Parent participants also shared distress that they might be harmed themselves when helping their adult child with a lift transfer. This was succinctly stated by one parent who said, "I frequently felt I could be injured transferring my son without the lift." Once the transfer lift was acquired in the house, every parent participant reported feeling less concerned about safety. This parent participant described her relief since acquiring the lift by saying, "now even if you catch your foot, he's OK, he's not going to fall down, you might fall down, but he's not going to fall down." A second parent participant described feeling reassured for both himself and his child by stating, "Having the lift is safer for everybody". And a third participant said, "the physical load and the associated emotional concerns that are inherent within that, have greatly, have just, just gone away, they have decreased and the sense of security has greatly increased."

b. **Age related physical changes and health concerns**

Many parent participants reported they have experienced age related, declining physical abilities. Participants described feelings of fear that this placed both them and their adult child with a disability at higher risk for harm during transfers. The concerns they described included diminished strength and balance which could lead to falling during transfers. These statements were made by parent participants, "your balance while lifting him that was the biggest concern. If you went off center, you know, he can't save you. It's your balance that was the biggest concern", "but as I age my biggest concern is balance, my own balance and my own steadiness", and "I was afraid always that he was going to fall over or fall and I'd land on top of him or I'd fall and he'd land on top of me and there we'd be just a mess of humanity." Several participants explained that they plan out falling techniques to try and prevent injury to their child if it happens. One participant described a sense of dread, as she said, "I'm waiting for the day my back will go out. And then I think will I fall to the ground? Will I hurt my daughter? That's what I think about."

1. **Theme 2: Physical stress**

Parent participants all described feeling their caregiving responsibilities were physically taxing on their body. Statements about physical stress centered around two subthemes: physical load of lifting for transfers and concern related to their ability to continue long term in the caregiving role.

a. **Physical load of lifting for transfers**

All of the parent participants reported that they have experienced pain or fatigue as a result of lifting their adult child with a disability over the child's lifetime. In addition to their adult child's size and weight, several parent participants

described how the adult child's increased tone (spasticity) added to the difficulty of transfers. As one father talked about when transferring his son, "my son needs maximal assist, where I mean, you're lifting 95 pounds of dead weight, which is also stiff dead weight-with stiff muscle tone."

Since acquiring the transfer lift all parent participants reported that they rely on using the lift to ease the load of physical lifting for transfers. Some parent participants use the lift for every transfer with his/her adult child with a disability and some use it only for select transfers. For example, one mother doesn't use the lift routinely but she depends on it at times when she is too tired after work to lift her son physically. Other parents reported using the transfer lift for specific transfers based on the surfaces, such as when their adult child with a disability was being transferred into the shower chair. The two oldest parent participants in their 60's rely on use of the transfer lift for every transfer. As the father described, his health is better since he is using the transfer lift and not physically lifting his son, "whereas two months ago I was getting where I couldn't walk, I'm back to where I spent six hours walking around last weekend without a problem at all." Overall, five of the seven parent participants reported significantly less physical strain since acquiring the transfer lift in the home. In the words of one mother, "We still have to help him with the lift but we don't work physically as hard. A lot less physical exertion."

b. **Long term caregiving concerns**

Only the oldest participant, age 69, related concern about his child's future if he, as the father, were unable to continue as a caregiver. He discussed specific fear over what will happen to his adult child when the physical stress of caregiving becomes too much. This parent participant described his feelings as, "Eventually you're going to reach a

point where you just can't handle it anymore. And at that point there's psychological stresses there. Because you feel guilty on the one hand that you're not providing the necessary help and care and there's guilt in the fact that you're not, that I'm not capable of doing it anymore".

2. **Theme 3: Advantages of having the transfer lift**

Responses showed that acquisition of a transfer lift had a positive effect on the parent participants' caregiving experience. Participant statements about advantages of transfer lift technology were sorted into three subtheme areas including improved safety, ability of a single caregiver to perform a lift safely and increased availability of outside caregivers.

a. **Improved safety**

All of the parent participants reported having reduced safety concerns related to transferring their adult child with a disability since getting the transfer lift in the home. This was reported by one father in this way, "You still have to use caution, there's still concerns, but just the mechanical level of safety is just, is just, it's on the order of magnitude of 100 or something." In addition to the high safety factor of the transfer lift, two of the participants pointed out that their adult child with a disability also felt safer when the lift was used for a transfer. As one parent participant described her son's reaction to being lifted, "he notices the difference (between using a sling or physically lifting) you can tell that he's a little bit nervous or anxious" and "he feels safer in the sling." Another parent participant in describing her son's response to use of the transfer lift said, "the sling is just perfect for him and he relaxes in it."

b. **One caregiver able to perform transfer**

Two parent participants commented specifically on advantages of the transfer lift enabling one person to perform transfers using less effort and having increased safety (instead of requiring two caregivers to share the load of lifting). One mother described being able to transfer her son again by herself. She explained she had transferred him alone when he was younger, but then he had gotten too tall for her to transfer him alone, "…before I used to be able to do it by myself. And now, with the lift I continue to be able to do it by myself." Another participant gave this description of the advantage of using the lift as, "So with a lift it can be, transfers can be easily done with minimal assist, minimal manual labor or lifting exertion of a care provider. So, one person can do it".

c. **Outside caregivers are available**

The advantage of one person being able to perform transfers safely with reduced effort increased the number of alternate caregivers available for families. Since acquiring the transfer lift in their home, four of the parent participants reported they now have additional people who are able to provide care to their child. One parent participant described the importance of having the transfer lift for this reason, "I don't think we could get anyone to stay with him, not if they had to put him in bed, there's no way I would ask someone if we didn't have the lift." This was also reported to be particularly important for one parent participant who recently became the single parent caregiver for her daughter. She said, "The lift will permit me to have help from other caregivers who are not able to lift her" and having family members provide care for her daughter will permit this participant to return to working part time.

3. Theme 4: Drawbacks of having the transfer lift

Participant statements also included descriptions of three drawbacks to transfer lift technology. These statements fell within three subtheme areas of increased time required to use transfer lifts, issues related to sling positioning and the impact of the transfer lift on the environment.

a. Use of the lift requires increased time

Three of the seven participants commented specifically that use of the transfer lift requires more time than lifting their adult child with a disability. This was succinctly stated by one parent participant, who said, "The lift absolutely takes more time."

b. Sling positioning issues

Of the four families represented in this study, three of the four adult children with a disability are positioned in a sling during the mechanical lift transfers (Figures 1 and 3). Two of these parent participants discussed the extra work involved in managing the sling to position it before the transfer and to remove it afterwards. As one parent participant said, "The thing with the sling is getting it just right when he's getting from the bed into his power chair. That takes time." Another parent participant discussed how managing the sling made the evening routine more difficult, saying, "I need to remove the sling because he sleeps on his stomach. That's the tricky part."

c. Impact of having the lift in the house

Only one parent participant reported any concern with the transfer lift technology taking up space in the home. This is the only family in this study using a floor-based frame to support the overhead track system (Figure 2). During the interview, the parent participant mentioned that the track was bulky and one support post takes up

space in the middle of her son's room. She did not report this to be intolerable however, as she said "At first having the lift sticking out in the room was horrible, I didn't think we'd get around it. But we got used to it."

V. DISCUSSION

A. Findings

The mixed methods approach proved effective in gaining useful information about parent participants' experience of transferring their child using transfer lift technology. Specifically, this study confirmed that transfer lift technology positively impacts the experience of middle and old age parent caregivers. The study provided insight into emotional and physical stress related to transferring adult children with disability and the advantages and challenges of using transfer lift technology. These findings lead to meaningful considerations for clinicians to share with individuals with disabilities and their caregivers who are considering transfer lift technology. Participant responses to the Caregivers Assistive Technology Outcome Measure questions quantified areas of concern related to transfer activities. In addition, the open-ended questions provided in-depth descriptions of the parent participants' experience. Consistency in the findings from the two approaches strengthened the credibility of results.

Shared results of this study revealed that transfer lifts are consistently utilized in the home by the parent participants and/or by other caregivers to transfer the adult child with a disability. Haworth and Nichols (1980) showed similar lift usage in their study that looked at adults with a physical disability and their unpaid caregivers. Results from their survey showed that three to nine years after receiving a transfer lift in their home, 70% of the lifts were being used by the caregivers (Haworth & Nichols, 1980). In this study, there was a variety of usage patterns; there were parent participants who reported the lift is used for every transfer with their adult child with a disability while other participants reported that the lift is only used for some of the transfers through the day. When the lift

was only used part time, this was based on the surfaces involved in the transfer or on the particular caregiver assisting with the transfer. In every case, however, all parent participants reported the transfer lift positively impacted the caregiving experience and both they and their adult child with a disability benefitted from having it in the home. The themes that emerged in this study revealed the benefits that parent participants found in having the transfer lift in their home.

Distress reported by parent participants in this study was primarily focused on fear of their child or themselves being harmed during lifting transfers before they had the lift assistive technology in the home. Parent participants rated this concern high on the Caregiver Assistive Technology Outcome Measure and made statements related to this concern more than any other topic during the interview. This high level of emotional stress was also found in a study by Darragh et al. (2015) whose results showed participants experienced both physical and emotional stress related to caregiving, with the highest level of emotional stress at 58%. In addition to emotional stress, parent participants in this study also discussed significant concern related to the physical load of lifting their adult child with a disability for transfers over the years. Parent participants described having pain or strain that was either caused by or exacerbated by their caregiving activities. This reported level of physical stress was less than the emotional stress experienced by parent caregivers, but it was significant as it was discussed by every participant in this study. Darragh and colleagues had similar findings with 38% of caregivers in their study experiencing high levels of physical strain (2015).

Due to the mechanical features of transfer lift technology, a high level of safety is inherent and the physical effort required for transfers is significantly reduced compared to

transfers using physical lifting. The parent participants in this study related significantly reduced levels of emotional stress and physical strain after acquiring the transfer lift assistive technology in their home. The perception of reduced pain and strain are consistent with reports from professional paid caregivers when transfer lift technology is introduced in the medical or residential settings (Miller et al., 2006). Findings showed that having the transfer lift in the home provided peace of mind to parent participants, and this change is best expressed by one participant as, "the physical load and the associated emotional concerns that are inherent within that, have greatly, have just, just gone away, they have decreased and the sense of security has greatly increased."

Middle and old age parent participants in this study discussed worry related to diminishing physical abilities due to the aging process. This concern centered on increased risk of injury to their adult child with a disability or themselves which contributed to the emotional stress that was discussed earlier. The impact of this "aging process" preventing the parent participant from continuing in the caregiving role at some point, is addressed in the literature and often discussed by clients during assessments with the Assistive Technology Unit clinicians. In this study, however, concern related to this question did not emerge as a common theme as it was only discussed by one of the parent participants in his interview. This was the oldest participant at age 69, who expressed concern about the physical toll of caregiving adding to the adverse effects of aging on his body. This participant openly discussed his fear and guilt over what will happen to his adult child when he is no longer able to provide care for him at home.

Another important theme that emerged from the open-ended questions in this research was that parent participants gained support from additional caregivers after

acquiring the transfer lift. Participants described that access to having a relative, friend or paid caregiver care for their child increased when they acquired a lift for transfer. This was due to the reduced physical effort and increased safety afforded by use of the lift. Parent participants reported this advantage afforded them both social and economic benefits. In the study by Shepherd et al. (2007), mothers also identified the availability of additional caregiver support as an important advantage of getting the transfer lift in the home. The parent participants in this study discussed their appreciation of having a grandparent, aunt, sibling and a larger pool of paid caregivers available since acquisition of the lift in their home. Participants also described that it was meaningful to their extended family members to be able to participate in care for the adult child with a disability.

There were two disadvantages of transfer lifts reported by a small number of parent participants. Two parents described the increased amount of time needed when using the transfer lift. Results reported in the study by Shepherd et al. (2007) showed similar findings that use of the lift required an increased amount of time. In addition, three parents reported difficulties associated with positioning the sling before and after transferring which created an extra step. However, neither of these disadvantages detracted from the value of having the transfer lift in the home. Each parent participant that expressed one of these drawbacks also reported that use of the transfer was essential at times due to the increased safety factor. The benefits of using the transfer lift outweighed any disadvantages.

B. **Implications**

The findings from this study provide guiding concepts for clinical practice to direct discussions with families during assessments for transfer lift technology. First, there are

benefits to families obtaining transfer lifts even though they're still physically capable of lifting for transfers. Many parent participants described benefits to having the lift even when they were continuing to do the majority of transfers by lifting. Second, the peace of mind for the individuals with disabilities and their family that is gained from the availability of a transfer lift in the home may be just as important as the assistance with physical lifting provided. Since parents report they often don't realize the full value of a transfer lift until it is in their home, it is the clinician's role to make families aware of this. Third, the transfer lift may benefit both the parent caregiver(s) and the adult child with disability beyond safety considerations and reducing physical stress. One example is accessing additional caregiver support. This may help procure respite care for parents and may also increase socialization for the child. Another advantage is that use of the lift may allow the child to be transferred more frequently, providing increased choice within his/her daily routine or more opportunities to go out in the community. Though medical necessity is important in securing funding for transfer lifts, families should be aware of additional advantages that may improve the quality of life for children with disabilities and their families. The identification of potential drawbacks will also be useful to clinicians in guiding and advising families in the decision-making process. Information about the space needed for floor-based lifts should be offered for consideration. In addition, reports about the time and difficulty associated with use of slings could help educate families trying to decide between use of a sling or use of a SureHands® Body Support.

C. **Study Limitations**

This study purposely utilized a small sample size for the qualitative interviews. While this was necessary for an in-depth focus on the participant's stories, it is important

to note that variability within the sample was limited. For example, the parent participants in this study were homogeneous in terms of race and home ownership. All participants were white and owned their own homes. Perspectives of parent participants from other cultures and socio-economic groups might have yielded useful information for clinicians serving a more diverse group of clients. Another limitation of this study was the narrow focus on gaining only the parent participant view. There were no opinions gathered from the adult children with disabilities related to their experience of being transferred with a physical lift verses with a transfer lift device. This information is valuable and especially important for clinicians to know when evaluating individuals with severe disabilities who are unable to provide feedback.

D. **Further Studies**

Supplementary research should be considered to obtain quantitative data from a larger size sample using the Caregiver Assistive Technology Outcome Measure (CATOM). Use of the questionnaire alone would present less detailed responses but a wider range of families could be reached. The findings from this study revealed that the post-lift participant responses on the CATOM correlated closely with the qualitative data on most of the themes. Though this is a small study, these shared outcomes show support for use of the CATOM as an appropriate tool for use when investigating transfer lift technology use in the home setting.

Additional qualitative research would also be beneficial for addressing more of the variables involved in the use of transfer lifts. Some of these include the type of lift, style of sling, amount of training and the home environment. Variables related to the sample might also reveal important correlations, for example in the caregivers age. In this study, the

participants' ages ranged from 53 to 69. It's possible there are concerns distinctive in older age parents that were missed in this study. The oldest participant at 69 discussed unique concerns that might indicate this. Research focusing on how and when transfer lifts are acquired would also provide needed information to guide policies related to provision of lifts and family education about this technology. Unfortunately, assistive technology is often recommended without trial of equipment or even discussion of options with families.

VI. CONCLUSION

The majority of past research related to assistive technology (AT) has been focused on usage patterns, technology abandonment and the capacity of AT use to reduce the time that caregiver support is needed by an individual with a disability. The individuals with disabilities addressed in this study require full assistance for transfers. In this case, the parent caregiver essentially becomes the AT consumer, thus it is necessary to have knowledge of the parent perspective. To address this need, the target population of this study was middle and old aged parents caring for their adult child with a disability. Parents are a unique and vulnerable group of caregivers as their role spans decades and is likely to continue as they reach old age and often throughout their lives. This research showed transfer lifts are highly effective in reducing both the physical and emotional load associated with transfer activities for the parent participant caregivers. Though the sample size was small, specific advantages and disadvantages emerged from the findings. These results provide clinicians a foundation on which to base discussions when assisting an individual with a disability, and their families, to acquire a transfer lift for use in their home. Further study is important to address transfer lift features, the child's perspective on transfer lift AT and to gain perceptions from a wider sample of parent caregivers.

APPENDICES

APPENDIX A

Caregiver Assistive Technology Outcomes Measure Questions

1a) Do you ever feel that helping your child with transfers requires too much of your time? If answer is "YES" How often do you feel like this?	No Yes: Is it Rarely Sometimes Frequently Always	5 4 3 2 1
1b) Since getting the transfer lift: -do you feel that helping your child with transfers -requires more of your time -requires less of your time - or is it the same as before If answer is more- -is it a lot more or a little more? If answer is less- -is it a lot less or a little less?	A lot more A little more The same A little less A lot less	1 2 3 4 5
2a) Do you ever feel that your child may be harmed when he or she is being transferred? If answer is "YES" How often do you feel that?	No Yes: Is it Rarely Sometimes Frequently Always	5 4 3 2 1
2b) Since getting the transfer lift: -do you feel that your child may be hurt more often during transfers -do you feel that your child may be hurt less often - or is it the same as before If answer is more- -is it a lot more or a little more? If answer is less- -is it a lot less or a little less?	A lot more A little more The same A little less A lot less	1 2 3 4 5

Appendix A (continued)

3a) Do you ever feel that you may be harmed when you are helping your child with to transfer? If answer is "YES" How often does you feel that?	No Yes: Is it Rarely Sometimes Frequently Always	5 4 3 2 1
3b) Since getting the transfer lift: -do you feel that you may be hurt more often during transfers -do you feel that you may be hurt less often - or is it the same as before If answer is more- -is it a lot more or a little more? If answer is less- -is it a lot less or a little less?	 A lot more A little more The same A little less A lot less	 1 2 3 4 5
4a) Do you ever feel physically tired after helping your child transfer between their bed and the wheelchair? If answer is "YES" How often do you feel that?	No Yes: Is it Rarely Sometimes Frequently Always	5 4 3 2 1
4b) Since getting the transfer lift: -do you feel more tired after helping your child with transfers -do you feel less tired after helping your child with transfers - or is it the same as before If answer is more- -is it a lot more or a little more? If answer is less- -is it a lot less or a little less?	 A lot more A little more The same A little less A lot less	 1 2 3 4 5

Appendix A (continued)

5a) Does the help you are providing to transfer your child ever result in pain or physical strain? If answer is "YES" How often do you feel that?	No Yes: Is it Rarely Sometimes Frequently Always	5 4 3 2 1
5b) Since getting the transfer lift: -does the help you are providing your child result in more pain or physical strain -does it result in less pain - or is it the same as before If answer is more- -is it a lot more or a little more? If answer is less- -is it a lot less or a little less?	 A lot more A little more The same A little less A lot less	 1 2 3 4 5

6a) Do you ever feel anxious while your child is transferring (whether you're there to help or not)? If answer is "YES" How often do you feel that?	No Yes: Is it Rarely Sometimes Frequently Always	5 4 3 2 1
6b) Since getting the transfer lift: -do you feel more anxious when your child is transferred -do you feel less anxious when your child is transferred - or is it the same as before If answer is more- -is it a lot more or a little more? If answer is less- -is it a lot less or a little less?	 A lot more A little more The same A little less A lot less	 1 2 3 4 5

Appendix A (continued)

7a) Do you ever feel that the equipment used for transferring your child limits the use of space within your home? If answer is "YES" How often do you feel that?	No Yes: Is it Rarely Sometimes Frequently Always	5 4 3 2 1
7b) Since getting the transfer lift: -do you feel that the transfer lift limits space in your home more -do you feel that the transfer lift limits space in your home less - or is it the same as before If answer is more- -is it a lot more or a little more? If answer is less- -is it a lot less or a little less?	 A lot more A little more The same A little less A lot less	 1 2 3 4 5

APPENDIX B

Institutional Review Board Approval

UNIVERSITY OF ILLINOIS
AT CHICAGO

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

Exemption Granted

July 19, 2016

Lori Peculis, BS
Disability and Human Development
1640 W. Roosevelt Rd, M/C 726
Chicago, IL 60612
Phone: (312) 413-2339

RE: Research Protocol # 2016-0710
"Mechanical lift technology: The parent experience of caring for their adult child with a physical disability"

Sponsor(s): None

Please be reminded of the need to always submit the current version of the application. You submitted Claim of Exemption Application version 2.03, but the current Claim of Exemption Application is version 5.2. The current version of the application is available on the OPRS website (http://research.uic.edu/compliance/irb) and via OPRS Live once electronic submissions have been released to your department. Failure to submit the current version of the application will result in your application being returned to you without the reviewers taking any action.

Dear Ms. Peculis:

Your Claim of Exemption was reviewed on July 19, 2016 and it was determined that your research protocol meets the criteria for exemption as defined in the U. S. Department of Health and Human Services Regulations for the Protection of Human Subjects [(45 CFR 46.101(b)]. You may now begin your research.

Exemption Period:	**July 19, 2016 – July 19, 2019**
Performance Site:	UIC
Subject Population:	Adult (18+ years) subjects only
Number of Subjects:	10

The specific exemption category under 45 CFR 46.101(b) is:
(2) Research involving the use of educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures or observation of public behavior, unless: (i) information obtained is recorded in such a manner that human subjects can be identified, directly or through identifiers linked to the subjects; and (ii) any disclosure of the human subjects' responses outside the research could reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, or reputation.

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