

Mechanical Lift Technology: The Parent Experience or Caring for an Adult Child with a Physical Disability

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INTRODUCTION

The purpose of this study was to better understand if and how a transfer lift impacts the experience of an aging parent caring for their physically dependent child in their home. When the child family members require full assistance for transfers, the parent caregivers become AT consumers. Thus, it is necessary to have knowledge of the parent perspective. Parents are a unique and vulnerable group of caregivers as their role spans decades and is likely to continue as they reach old age. There are two methods of assisting an individual who is physically dependent to transfer between support surfaces. The first method is for a caregiver(s) 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). An alternative to physical lifting techniques is the use of transfer lift technology. A transfer lift is often introduced 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 they are being lifted. 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. This research focused specifically on the population of elderly parents who provide care for their adult children with a disability, to understand the impact of transfer lift technology on their experience. The purpose was to understand better 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 advantages and/or disadvantages have parents found with the introduction of transfer lift technology in the home?

METHODS

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). 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. Seven parent ranged in age from 53-69 participated in the study. To explore the portrayal provided by parent participants, quantitative data was gathered through the Caregiver Assistive Technology Outcome Measure (CATOM) developed by Louise Demers, along with her colleagues. 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 CATOM was shared with this researcher by the team for use in this research (personal communication, November 3, 2015). The primary researcher collected the quantitative and qualitative data through individual interviews conducted in the home setting to situate parent participants in the environment where they care for their adult child with a disability. 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.

RESULTS

Participant responses to the Caregivers Assistive Technology Outcome Measure questions quantified areas of concern related to transfer activities, while the open-ended questions provided in-depth descriptions of the parent participants' experience.

Quantitative results from the CATOM are reported in Table 1.

TABLE I QUANTITATIVE RESULTS		
#	Question	Summary of Responses
1a	“Do you ever feel that helping your child with transfers requires too much of your time?”	Responses were varied.
1b	“Since getting your lift, do you feel that helping your child with transfers requires more, less or the same amount of your time?”	Responses were varied.
2a	“Do you ever feel that your child may be harmed when he or she is being transferred?”	7 of 7 responses were affirmative ranging from “rarely” to “always” among participants.
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?”	Responses were affirmative, all participants reported a decrease in concern and 6 of 7 participants reported “a lot less”
3a	“Do you ever feel that you may be harmed when you are helping your child to transfer?”	S6 of 7 reponses were affirmative, ranging from “rarely” to “always” among participants
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?”	7 of 7 reported a decrease in feeling concern that they or their chile might be harmed and six of seven participants reported “a lot less”
4a	“Do you ever feel physically tired after helping your child transfer between their bed and the wheelchair?”	Fi5 of 7 participants reported feeling physically tired after helping their child transfer between their bed and the wheelchair
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?”	Responses were varied.
5a	“Does the help you are providing to transfer your child ever result in pain or physical strain?”	Responses were varied.
5b	“Does the help you are providing to transfer your child result in more, less or more pain or physical strain?”	Responses were varied.
6a	“Do you ever feel anxious while your child is transferring (whether you are there to help or not)?”	Responses were varied.
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)?”	7 of 7 reported feeling less anxious with six of seven reporting “a lot less “anxious when their child was transferring with them or with another caregiver.
7a	“Do you ever feel that the equipment used for transferring your child limits the use of space within your home?”	7 of 7 Responded “Never”
7b	“Since getting the transfer lift, do you ever feel that the transfer lift limits space in your home, more less or the same?”	Six of seven participants did not feel the lift limited space in their home. One family had a portable system (with floor supports) that takes up space in the room compared to a ceiling mounted track.

Qualitative results from the open ended questions are reported in Table 2.

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."

DISCUSSION

The mixed methods approach proved effective in gaining useful information about parent participants' experience and results were consistent with the notion that transfer lift technology positively impacts the experience of middle and old age parent caregivers. Most noteworthy was the insight provided into the emotional and physical stress related to transferring adult children with disability and the advantages and challenges of using transfer lift technology.

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. 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. 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 distress reported by parent participants in this study was primarily focused on fear of their child or themselves being harmed during physical 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. 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.

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. 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."

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.

CONCLUSIONS

This research showed transfer lifts are highly effective in reducing both the physical and emotional load associated with transfer activities for the aging parent 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 user's perspective on transfer lift AT and to gain perceptions from a wider sample of parent caregivers.

REFERENCES.

- [1]Mertens, D. M. *Research and evaluation in education and psychology: Integrating diversity with quantitative, qualitative, and mixed methods* . 3rd ed. Thousand Oaks, CA: Sage Publications; 2010.
- [2]Mortenson, W. B., Demers, L., Fuhrer, M. J., Jutai, J. W., Lenker, J., & DeRuyter, F. (2013). Effects of an assistive technology intervention on older adults with disabilities and their informal caregivers: An exploratory randomized controlled trial. *American Journal of Physical Medicine & Rehabilitation / Association of Academic Physiatrists*, 92(4), 297-306.
- [3]Mortenson, W. B., Demers, L., Fuhrer, M. J., Jutai, J. W., Lenker, J., & DeRuyter, F. (2015). Development and preliminary evaluation of the caregiver assistive technology outcome measure. *Journal of Rehabilitation Medicine*, 47(5), 412-418. `
- [4]Rushton, P. W., Labbé, D., Demers, L., Miller, W. C., Mortenson, W. B., & Kirby, R. L. (2017). Understanding the Burden experienced by caregivers of older adults who use a powered wheelchair: A cross-sectional study. *Gerontology and Geriatric Medicine*, (3), 1-8.