Is Your Hoist Collecting Dust? Better hoist prescription, clinical reasoning and client compliance.

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Abstract
This pilot study was aimed at investigating carers’ perspectives on using a hoist to lift and transfer their children with physical disabilities. The study explored barriers to hoist usage, back pain, psychosocial issues, appropriate follow up, education and recommendations for the future.

The results demonstrated that a high percentage of carers have back pain, although carers did not express that it was caused from manual handling tasks related to their children. Some carers perceived the hoist as a reminder of the deteriorating nature of their child’s condition. Conversely, carers also reported a positive outcome once they starting using the hoist. This study also examined environmental factors that impacted on hoist usage.

Outcomes of this study led to recommendations including: improved education and training regarding back care; the importance for occupational therapists to advocate for early introduction of the hoist; and family centred consultation regarding hoist prescription. Adequate follow up and close monitoring once the hoist has been prescribed were also important implications for therapists to consider.

Keywords
Occupational therapy, children with physical disabilities, hoisting, manual handling, back care and pain, improved quality of life, carers and parents.

Introduction
MontroseAccess is a community based service which provides therapy, respite and recreation services to more than six hundred children and young adults with physical disabilities throughout Queensland. There are four metropolitan offices and regional outreach programs which provide varied and holistic services to clients with varying degrees of disability, some of the most common being neuromuscular conditions, juvenile arthritis, acquired brain injury and arthrogryposis.

A main role of occupational therapists at MontroseAccess is the prescription of aids and equipment for the home, including hoists and slings for children who are non-ambulatory and require lifting for transfers (eg, moving from a wheelchair to a bed). Using a hoist to transfer children who are over a certain weight is an important aid to ensure the safety of the client. Importantly, using a hoist helps to prevent carer strain and back injury, particularly in adult females who are often the primary care giver.

Children with physical disabilities, especially those who are non-ambulatory, present caregivers with many additional challenges. Carers often complete daily, repetitive physical assistance with transferring their child throughout the child’s life. As they grow, the children frequently do not develop independence in mobility, resulting in long-term risk of stress and strain on carers (J, Thomas 2007 et al). Non-ambulatory children often use wheelchairs or other mobility devices that also require transferring into and out of vehicles and homes (J, Thomas 2007 et al).

Carers who perform manual handling tasks for children with disabilities may cause tissue damage to their back due to the forces on the lumbar spine and this can be attributed to musculo-skeletal injury (A, Shepherd 2007 et al).
Thomas J et al reported that studies of caregivers of children with physical disabilities have reported a high rate of self-identified musculoskeletal problems including high incidence of neck and back pain. Manually lifting children with physical disabilities between differing levelled surfaces and lifting children under stressful circumstances such as handling a wet child, together with use of poor body mechanics cause significant challenges for maintaining back and neck health (J, Thomas 2007 et al).

A study was completed at Novita Children’s Services by Shepherd et al 2007, titled *Mother’s perceptions of the introduction of a hoist into the family home of children with physical disabilities*.

This study highlighted an overall positive impact of hoist introduction on the parent. This was found to be important with regards to hoist acceptance and subsequent use, which may take up to two years after attaining the hoist (A, Shepherd 2007 et al).

There are limited studies in hoist use for parents/carers with children who have physical disabilities. Therefore, the following pilot study was conducted at MontroseAccess in March 2011.

**Aims**

There are two main reasons as to why this pilot study was conducted. The first is that occupational therapists have anecdotally reported hoists are often left unused. Secondly, there are concerns regarding the risks associated with the heavy manual handling tasks performed by carers on a daily basis. The study aimed to investigate the following issues:

- Back pain/carer strain as a result of manual handling tasks related to their children
- Psychosocial factors
- Time constraints
- Environmental factors
- Equipment overload
- Equipment design

**Method**

A Combination of qualitative and quantitative methodologies was used for this study. The study involved parents of children with physical disabilities who were clients of MontroseAccess. The sample size involved twelve clients with Duchenne Muscular Dystrophy (DMD) and one client with Spinal Muscular Atrophy.

Carers signed a consent form that had been pre-approved by management before undergoing an interview with two occupational therapists and filling in a survey.

In addition to carer’s perspectives, seven Occupational Therapists at MontroseAccess also participated in a qualitative survey in relation to their clinical reasoning and decision making.

**Results**

A wide-ranging variation of topics arose from the interview data. Results can be summarised under two categories. The first is the survey that seven families returned and the second are the interviews with families and surveys from occupational therapists.

**OF 7 SURVEYS RETURNED:**

- All seven were satisfied with the design of hoist
- Three felt very skilled using a hoist, four felt average
- Five felt that grief and loss does not impact on whether they use the hoist or not
- Five feel that the hoist was issued at right stage of child’s life
- Four felt that time constraints do not stop them from using the hoist
- Four felt their child’s attitude was positive towards hoist
- Four felt that their attitude was positive towards hoist
- Four felt that lifting (instead of using hoist) was an opportunity to demonstrate care

The results of the interviews of carers with a child with a physical disability and the survey from the occupational therapists working with these children can be categorised under the following six headings:

**General hoist use**

Twelve of the thirteen families that were interviewed were using an electric hoist and only one family was using a ceiling hoist. Due to the population (i.e. neuromuscular clients),
the majority of families were using a hoist with a pivot frame.

In terms of length of time that the families had had the hoist, six families had only been using the hoist for under two years. The other seven families had the hoist for between three and over five years.

Frequency of use of the hoist varied. Six out of the thirteen families used their hoist more than five times per day, four used it three-four times per day, and one family used it twice per day. Surprisingly, only one family reported that they never or very rarely used their hoist.

Families stated their reasons for hoist use as: their child came off their feet and started using a power-chair; child became too heavy or too tall; workplace health and safety necessities (respite worker coming in to the home).

Back pain and back care

When primary carers and parents were asked about back pain, seven out of the thirteen reported that they do suffer from back pain in varying degrees. The majority were reluctant to attribute this pain to lifting their children, reporting other causes such as previous motor vehicle accidents or gardening. It is perhaps worthwhile to speculate about the cumulative effects of manual handling even with younger children.

Four out of the thirteen parents/carers reported that they had had no back care or lifting education from therapists and many reported that they felt this would be worthwhile.

Barriers to or challenges with hoist use

Barriers to or challenges regarding regular hoist use were found to come under a number of different headings:

CONDITION FACTORS
Specifically relating to the boys with DMD were challenges around sling placement and manual handling in bed. Due to their increasingly limited movement, carers reported difficulty getting the “sling on right” when the boys were sitting in their power chairs and difficulty rolling the boys in bed to get the sling on from a lying position.

EMOTIONAL FACTORS
One family spoke about how their child encouraged his dad to lift, saying “come on Dad, just lift me”. Lots of families spoke about both the child and the carer being scared or nervous about the hoist initially. One family referred to the hoist as “impersonal”.

ENVIRONMENTAL FACTORS
Lots of families spoke about the difficulty they have with storage of the hoist in small bedrooms and bathrooms. A couple of families who were not living in disability specific housing spoke about difficulties with narrow doorways.

HOIST DESIGN FACTORS
Almost every family spoke of difficulty pushing the hoist, particularly over carpet. Some families also discussed difficulty getting the sling on their son when he is wet and managing clothing during toileting. Some families reported that having a hoist is a major barrier to travel. Many families expressed desire for a ceiling hoist with cost being the major prohibitor.

OTHER FACTORS
In addition to those described above, one family talked about the time it takes to hoist being a major barrier and many families discussed the fact that they had limited training from therapists at initial hoist prescription and delivery.

Perceptions of hoist use

We asked carers about their perception of the hoist and also about their child’s perception of the hoist. There were a range of responses, but surprisingly largely positive replies.

Caregivers generally reported that they perceived the hoist as helpful and easy to use. Many stated that it was hard or that they were nervous in the beginning, but as one carer said, “now it’s great!” Parents reported the hoist as much better than trying to lift and one carer stated “it is quicker not to use the hoist but my body suffers”. Only one family reported that it takes too long to use the hoist.

Clients were not directly questioned but carers gave their impression of the children’s perception of the hoist. Almost all carers reported that the children were nervous and uncomfortable in the beginning but that this
passed with experience and exposure. “He was scared at first but now he is very confident”.

Prescription and follow-up training

Parents and carers made a number of comments and made a number of suggestions about prescription and follow-up.

PRESCRIPTION

Parents and carers felt that they would like to be aware of the need for a hoist sooner rather than later. One mother reported “When the hoist is first mentioned to parents, it is like another kick in the face that your child is deteriorating and the disease is progressing so of course they are hesitant to accept another piece of medical equipment into their home. But if the parents have a chance to talk to another parent that has already experienced the hoist, it might help ease the anxiety and back problems [caused by delaying use of a hoist for lifting].”

Another carer shared this thought: “Perhaps the hoist could be delivered at the same time as the power-chair to help parents accept the changes that are happening to their child at the ONE time rather than on two different occasions”.

FOLLOW-UP FROM MASS

Parents reported little or no follow-up from MASS however this is fairly standard procedure as the prescriber is required to do this.

FOLLOW UP FROM THERAPISTS

Carers felt there could be more prescriber training and follow up and that some practical help would be worthwhile. One carer stated: “practising putting on sling, charging battery, where is the battery/emergency switch button?” Carers also thought a print out of a step by step procedure would be useful.

Carers stated it would be beneficial to receive further back care training and therapists at MontroseAccess feel it could be worthwhile to establish an exercise program for parents and caregivers to build core stability and teach correct lifting techniques. This program could perhaps also be adjacent with social work family support.

Suggestions for other parents

HOIST USAGE

Carers reported a few suggestions for other parents, for example; “don’t leave your child in the hoist e.g. to answer the phone”. Carers tended to describe how they needed to allow for more time in their morning and afternoon routines. One carer reported, “be calm and slow. Don’t panic. Allow thirty minutes to get him up in the morning”. On numerous occasions carers discussed that hoist usage becomes easier over time with increased practice.

ENVIRONMENTAL

It was very apparent that the biggest environmental factor that inhibited hoist usage was having carpet. Carers discussed that it was exceedingly difficult pushing the hoist over carpet, particularly with the DMD population as they are often on steroid medication which can cause weight gain and consequently the boys are of a significant weight.

IN THE BEGINNING

Many carers talked about the things they learnt "in the beginning". This emerging theme outlines the difficulty clients and carers had when they first started using the hoist.

Some suggestions from carers included; “give boys a little swing for fun”, “use it as soon as possible, it doesn’t take much to ruin your back, save your body”. It is notable that carers highlighted the importance of continual instruction due to the degenerative nature of the condition and the subsequent changes in function.

One carer stated; “using a hoist is difficult at first but with practice it will become second nature” another suggestion from carers is to give the child the controller to allow more control and decision making to enable ownership of hoisting.

Discussion and Recommendations

This study sought to identify and understand the factors that influence hoist usage. The findings from this pilot study suggest that numerous factors associated with the carer, the child, the home environment, and hoist design itself, impact on hoist usage.

Recommendations can be categorised into five headings:
DESIGN
In an ideal world, ceiling hoists are recommended. Ceiling hoists are easier to use and take up much less space. With regards to floor hoists, a better ability to push hoists over different surfaces, particularly carpet, would be ideal. It also advised that therapists consider and trial a variety of different options to ensure the design of hoist best suits the family’s needs.

HOIST INTRODUCTION
From our surveys and current literature it is important to introduce the concept of the hoist earlier, either through play or discussions.

Providing early hoist introduction was seen by the carers as an opportunity to allow both carer and child transition time prior to hoist acceptance and subsequent use. Perhaps introducing the hoist early, when it’s not pertinent, will allow carers control and choice over when they use the hoist. This has been identified as an important factor in acceptance of assistive technology (Wielandt & Strong, 2000).

FOLLOW UP
Appropriate follow up should be instigated by therapists. Some therapists suggested that perhaps there needs to be a standardised protocol that all occupational therapists must do with families when getting their new hoist.

It is also recommended to provide continual support and instruction due to the degenerative conditions and therefore ever-changing functioning of the child.

BACK CARE EDUCATION
An important outcome of this study is the identified need for enhanced back care and correct lifting education and training for carers. This could be done in a group format in conjunction with other disciplines such as family support and physiotherapy or one on one instruction and guidance by occupational therapists.

The group format training has the potential to provide other benefits such as peer support, socialisation, improved fitness and an opportunity for parents/primary carers to meet with other parents of children with a disability who use a hoist.

This study highlighted the need for therapists to consistently provide a handout to compliment practical hoist training. This may include: step by step procedures, common hoisting issues, what to do when something goes wrong and picture prompts if necessary.

FURTHER STUDY
Due to the limitations identified in regards to this study, a further more rigorous study is recommended to be completed at MontroseAccess.

Limitations
The small sample size limits the generalizability of the findings and should be interpreted with caution. One other limiting factor is that there was no ethics committee involved in this study. Another limitation was insufficient time available. The therapists who compiled this study only had a short time frame to complete it.

Due to the small sample size, only two types of conditions were interviewed (DMD and SMA). In future it would be ideal to include a wider range client group.

Conclusion
Contrary to what was expected, the findings from this study found that the hoist had an overall positive impact on the family. However, it is known from literature and from anecdotal evidence that use of the hoist may take up to two years after acquisition (A, Shepherd 2007 et al).

Prescription of hoists is part of an ongoing dialogue which requires continual discussion as the child’s function changes, along with changes in the family and home environment.

The discrepancy of anecdotal evidence in comparison to outcomes of this study is important to consider. It may be that parents/carers do not wish to be stigmatised or singled out by providing a negative response, in fear that they may not receive equipment in the future. Parents often do not want to complain of a relatively ‘free’ service such as that provided by MontroseAccess.

Perhaps a more thorough study may tease out these differences. At present this study may not be an accurate reflection. Nonetheless, the study has provided recommendations which aim to help improve
quality of life for the both parents/carers and the child with a physical disability.

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References


