

Introduction

Neuromuscular conditions are a prominent cause of bilateral upper limb weakness resulting in inability to raise the arm. The combined prevalence of the four most common neuromuscular conditions, Duchenne, Becker, facioscapulohumeral and limb girdle muscular dystrophies, that cause arm weakness has been estimated to be 21.8/100,000 (Norwood et al 2009). Other conditions such as cerebral palsy, Parkinson's disease, Friedrich's ataxia, multiple sclerosis (MS) and acquired brain injury can also result in uncontrolled tremor, creating challenges with raising the arm and self-feeding.

The feeding, eating, and swallowing performance of individuals across the life span is an important role for occupational therapists (AOTA, 2014). This role requires consideration of diverse factors, such as psychological, functional, social, biological, financial and care giver role. Gustafsson (1995) evaluated the psychological effects of self-feeding and found that disabled individuals who attained their goals of self-nourishment had a heightened sense of control, security, and hope for the future. The inability to self-feed has been linked to shame, incompetence, decreased self-esteem, and feelings of panic or fear. This is highly significant for this group of people, for whom undertaking everyday activities such as self-feeding becomes difficult and can result in having to rely on carers which may have financial implications. Mealtimes can become time consuming and frustrating when the food is unsuccessfully raised to the mouth, falls off the spoon, and becomes cold (Atkins et al 2008). Mealtimes cease to be a pleasurable social activity, can become stressful and nutrition and health can be compromised (Fung et al 2002). Eating is reduced to an activity that only meets a functional and biological need. Absolom & Roberts' (2011) study of adolescent eating habits found that eating with others positively improved family relationships, social connectedness, friendship and routine. Therefore it is important to maintain, or restore, the occupation of self-feeding to one that offers consumption of food, pleasure, autonomy and social engagement

(Hasselkus & Murray 2007). Recognising that the occupation of eating has biological, social and psychological importance, coheres with the ICF (World Health Organisation, WHO, 2001) biopsychosocial view of disability.

Assistive technology (AT) can restore the occupation of self-feeding, The AT must be fit for purpose and should increase the positive experience of self-feeding (Lindborg and Lindén 2015). Louie et al. (2009) reported a case study of an AT prescription process, for a client with upper limb deficiency, using the Human Activity Assistive Technology (HAAT) model (Cook and Hussey 2002). The client reported reduced social anxiety and increased independence when using the device. This highlights important potential impacts of self-feeding devices, although the findings from a single client case study, have limitation. Gaedt (2012), using mixed methodology, explored the financial savings afforded by AT and the impact of self-feeding on independence. The findings suggested that the use of a feeding device reduced the need for assistance during meals and increased feelings of autonomy. Al-Halimi and Moussa (2016), recently reported that users of the JACO robotic arm also identified independent self -feeding to be important. This provides evidence that self-feeding devices are beneficial to users, however, there is a dearth of literature exploring the experiences of users whilst interacting with such devices.

The aim of this exploratory inquiry was to illuminate the views and experiences of people with upper limb neurodisability and provide an in-depth understanding of their use and interaction with a self-feeding device.

Method

Ethical approval for the study was obtained from the Faculty of Health Research Ethics and Governance Committee of the University of Brighton (09/24).

Procedure

Neater Solutions, supplier of the Neater Eater (NE) was contacted and provided details of the proposed study. Following consideration of the full documentation (informed consent, participant information sheet, interview schedule and ethical approval document) they agreed to participate in the study. In order to maintain anonymity and confidentiality of Neater Solutions' clients, the University of Brighton was **not** permitted to have direct access to their clients' details. Instead, Neater Solutions sent information including a participant information sheet, two consent forms, an explanation of the study and a stamped addressed envelope on University headed paper **directly** to all their NE users. Users were invited to sign both consent forms, retain one and return the other one to the principal investigator with a contact email address or telephone number. The details of the Neater Solutions' clients, who did not want to participate, remained confidential and only retained by Neater Solutions. In addition the users who wished to participate were able to directly engage with the University thus retaining their anonymity from Neater Solutions.

Inclusion Criteria

Neater solutions database only contained the names of users that had been assessed and referred by external independent occupational therapists and equipment technician trained in the provision of eating and feeding devices. Those users that were deemed suitable for self-feeding equipment were supplied with the equipment following satisfactory induction into safe use.

All 200 users from the Neater Solutions database, who had been provided with NE's in the UK in the period 2011 to 2014 were invited to participate.

Participants were required to have a minimum of 3 months experience with the equipment to be eligible to participate in the study. All participants were required to be currently using the NE. Respondents were contacted via their preferred method, as detailed on the consent form,

and either interviewed by telephone or completed the interview schedule via an online questionnaire.

The semi-structured interviews used the same interview schedule as Kumar & Phillips (2013) and followed an iterative process. Each user participated in one interview which consisted of two parts. Part 1 explored personal factors, reasons for wanting the Neater Eater (NE), psychological impact following initial use and current feelings about use and value. Part 2 explored usage, changes to quality of life, benefits and limitations, impact on carers, evaluation of the initial support provided and advice the user would give to others.

Analysis

The interviews were analysed, following the method of thematic analysis described by Braun & Clarke (2006). Codes were inductively and deductively derived and checked to ensure congruence with the context of the interview statements. Initial coding commenced with notes being written on the text and highlighted. Data extracts that demonstrated the code were collated. Codes and extracts were organised into themes. Developing themes were discussed and refined with the research team to increase credibility, confirmability and trustworthiness.

Participant Characteristics

Thirty nine users (19.5%) responded to the letter and consented to participate in the study. Of these, six returned the consent form then failed to respond to follow up email/phone calls to undertake the interviews and 10 partners of deceased users returned the questionnaires uncompleted. The remaining 23 went on to participate in either a telephone or online interview. In some cases participants were assisted by the carer. Some carers also provided their own personal comments and observations about the equipment.

Table 1: The type and distribution of neuromuscular conditions of study participants.

Condition	Males	Female
Motor Neurone Disease	6	0
Dystonic Cerebral Palsy	6	5
Multiple Sclerosis	3	1
Spinal Muscular Atrophy	1	0
Guillain-Barré Syndrome	0	1
Total	16	7

The age range of participants was 11-75 yrs. The range of time of use of the equipment was 3-36 months. The reasons given for initially acquiring the NE were largely as a result of difficulty in self-feeding due to loss of fine motor control, poor arm control, intention tremors, lack of strength and recommendation by their occupational therapist or through social services staff.

Findings

Five themes were identified.

1. Independence and Positivity

The majority of the users expressed positive feelings of being liberated when provided with the NE initially.

“I am so lucky to have the chance to use it, to gain back dignity and independence”

The younger users described a sense of relief and independence:

'I like not having to be fed at school any more'.

Other children reported that the equipment made them feel 'cool' and enjoyed having "full control over eating".

There was also a sense of optimism and happiness about the prospect of a better life.

"I was happy to try something new and hoped it would be useful to my life. I was excited to regain independence and be able to feed myself again'.

Another stated:

"Anything would be better than being helpless".

The majority endorsed the improved quality of life that it afforded including "being in control, independence, positivity, confidence and dignity".

2. Emotions

One user expressed a sense of anxious anticipation.

"I felt apprehensive about whether it would work or not and hoped that it would realise its capabilities".

A few indicated they were embarrassed using assistive equipment whilst familiarising themselves with it.

'It felt awkward'.

Only one user expressed initial frustration which was tempered with an improved technique.

"Quite frankly I was extremely frustrated! The food kept rolling off the spoon into my lap, although I have now improved my technique."

Three users reported that they were unable to continue with the NE because their medical conditions had deteriorated. The rest reported ‘*pride*’ in being able to use it including one young user who enjoyed “*showing off with it*” because it showed his independence. In addition one user was so impressed with it that he reported “*Not liking having to leave it at home when I go into respite care*”.

3. Impact on family and social life

Both carers and users commented on increased social inclusion. Users liked being able to eat with the family, and didn’t feel embarrassed by feeding or eating in front of people:

“I was very excited to be able to feed myself and not be fed, especially at school when it can be embarrassing”.

For others, being in control of the rate at which they ate was important:

“I felt relief when I started using it and was able to feed at my own speed. It felt different and required some alterations to personalise it to make it comfortable”.

For some the NE gave privacy. It provided:

‘Independence away from carers’. ‘It is just one thing that I can do myself’.

Carers/partners liked participating in mealtimes and having their own independence.

“It enables the carer to prepare and leave a cold meal for me in the morning to have at lunch time without the carer”

Some users reported that it was not suitable for ‘wet foods’ such as soups. Foods that needed ‘stabbing’ (sausages) were also problematical.

4. Equipment Functionality

Some users suggested changes to the equipment design to improve usability.

“the bowl needs more space to scoop the food to avoid spills” or “the plate needs a bigger lip to prevent spills”.

For the carers the main functional issue was spillage. Several reported that:

“Food is always being spilt, down himself and on the floor”

One carer reported that his user who was over enthusiastic in his self-feeding action:

*“It is time consuming as D***** needs to be supervised to make sure he doesn't put too much food in his mouth, and needs help when he has nearly finished to clear his plate”.*

A few also commented that for some users with deteriorating conditions the system was expensive if only being used for a short period of time.

5. Motivation

Reflexive comments indicated that the users had to be amenable to using the equipment for it to be successful and that some users might resist adopting the equipment.

“I don't think it will be for everyone as you need the mind set for it to make a difference”.

And

‘You must be prepared to persevere’

There was also user insight into some carers' agendas:

“Support staff have mixed views; some think it is great because of the independence it affords, others feel that I make a mess”.

Mostly the users wanted to recommend it and share their experiences:

“I am now in control of my mealtimes”

Discussion

Achieving independence in self-feeding, was an important outcome of using the NE. This in turn increased self-confidence and enhanced quality of life. Users’ attitude towards AT and their desire to eat independently were also crucial for a successful outcome. Saving time and resources for family, carers and staff were also important. Reducing such pressures resulted in greater satisfaction, less stress amongst carers, and a more equal relationship between user and carer.

The findings further support the importance of appropriately matching technology to the individual which endorses the client-centred Matching Person and Technology (MPT) model (Scherer 1998) and the HAAT model (Cook and Hussey 2009). These models highlight the complex milieu, of the person, their preferences, the technology and their physical and social environment. This concurs with the ICF model (WHO 2001) which is central to occupational therapy practice.

The findings also highlighted that initial use of the equipment could result in feelings of frustration. However, with perseverance and practice in self-feeding techniques, supported by adequate training of users, carers and families, the equipment can fulfil its potential for each individual (Cook 2009).

There are important implications for occupational therapists, including being aware of the positive impacts that self-feeding equipment can have on self-esteem, and increased independence. The NE can improve enjoyment and performance of self-feeding, reduce demand on carers, and potentially reduced care costs. Appropriate AT can reduce anxiety, and

result in a more equal relationship between user and carer. Recommendation of AT, must be fully client-centred and aligned with the revised ICF (WHO 2001). This requires consideration of the importance of the device in aiding the occupation of eating from a biological, social and psychological standpoint. It is important to thoroughly understand clients' motivations for use of equipment, their ability to deal with frustrations and the contexts in which they wish to use the equipment. In this approach clients' opinions and expectations regarding treatment outcomes are considered crucial.

Conclusion

This small exploratory inquiry provides new qualitative evidence, to a limited literature, that assistive eating devices reduce the need for personal assistance, improve life quality, independence and freedom. Time and resource savings for family, carers and staff appear to result in a more equal relationship between user and carer. Limitations of the study include the use of only one type of self-feeding device and also that the participants were not representative of the four most common neuromuscular conditions. Further studies should address these limitations.

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