

Manual Feeding Device Experiences of People With a Neurodisability

Anne Mandy, Tara Sims, Graham Stew, Dominic Onions

OBJECTIVE. Neurological bilateral upper limb weakness can result in self-feeding difficulties and reliance on care providers. Mealtimes become time consuming and frustrating. In this exploratory inquiry, we examined the experiences of users of a feeding device.

METHOD. Semistructured interviews were either conducted by telephone or administered via email to explore quality of life, changes to independence, benefits and limitations, and psychological impact of the equipment.

RESULTS. Thematic analysis gave rise to five themes: independence and positivity, emotions, impact on family and social life, equipment functionality, and motivation.

CONCLUSION. This exploratory inquiry has contributed new qualitative evidence to the knowledge and understanding of users' experiences of a manual feeding device. Users reported that the need for assistance was reduced and that their quality of life, independence, and freedom improved. Time and resources savings for the family, care providers, and staff appeared to result in a more equal relationship between user and care provider.

Mandy, A., Sims, T., Stew, G., & Onions, D. (2018). Brief Report—Manual feeding device experiences of people with a neurodisability. *American Journal of Occupational Therapy*, 72, 1–5. <https://doi.org/10.5014/ajot.2018.025353>

Anne Mandy, PhD, MSc, BSc(Hons), is Associate Professor, Centre for Health Research, University of Brighton, Eastbourne Campus, Sussex, England; am86@brighton.ac.uk

Tara Sims, PhD, MSc, BA, is Senior Lecturer, School of Health Professions, University of Brighton, Eastbourne Campus, Sussex, England.

Graham Stew, DPhil, MA(Ed), is Principal Lecturer, School of Health Professions, University of Brighton, Eastbourne Campus, Sussex, England.

Dominic Onions, BSc(Hons), is Research Officer, Centre for Health Research, University of Brighton, Eastbourne Campus, Sussex, England.

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 per 100,000 population (Norwood et al., 2009). Other conditions, such as cerebral palsy, Parkinson's disease, Friedrich's ataxia, multiple sclerosis, and acquired brain injury, can also result in uncontrolled tremors, creating challenges with raising the arm and self-feeding.

As specialists in activities of daily living, the feeding, eating, and swallowing performance of people across the life course is an important role for occupational therapists (American Occupational Therapy Association, 2014). This role requires consideration of diverse factors, including psychological, functional, social, biological, financial, and caregiver role factors.

Gustafsson (1995) evaluated the psychological effects of self-feeding and found that people with disabilities who attained their goals of self-nourishment had a heightened sense of control, security, and hope for the future. The inability to feed oneself has been linked to shame, incompetence, decreased self-esteem, and feelings of panic or fear. This finding is highly relevant for this group of people, for whom undertaking everyday activities such as self-feeding becomes difficult and often impossible and can result in having to rely on care providers, which may have financial implications.

Mealtimes can become extremely 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 and can become stressful with dependency on others, and nutrition and health can be compromised (Fung et al., 2002). Eating is reduced to an activity that meets only functional and biological needs.

While studying adolescent eating habits, Absolom and Roberts (2011) found that eating with others positively improved family relationships, social connectedness, friendship, and routine. Therefore, it is important to maintain and, when necessary, restore the occupation of eating and self-feeding to one that offers consumption of food, pleasure, autonomy, and social engagement (Hasselkus & Murray, 2007). Recognizing that the occupation of eating has biological, social, and psychological importance coheres with the biopsychosocial view of disability represented by the revised *International Classification of Functioning, Disability and Health (ICF)*; World Health Organization [WHO], 2001).

One way to restore the occupation of self-feeding is with assistive technology (AT). The assistive devices must be fit for purpose and should increase the positive experience of self-feeding (Lindborg & Lindén, 2015). Louie, Lai, Poon, and Wong (2009) reported a case study of a client who was prescribed a custom-made, self-feeding device based on Cook and Hussey's (2002) Human Activity Assistive Technology model. The client reported a reduction in social anxiety and increased independence through use of the device. This finding highlights some of the important potential impacts of self-feeding devices, although as a single client case study, this area requires further exploration. Using mixed methodology, Gaedt (2012) explored the financial savings afforded by AT and the impact that self-feeding had on independence. It was found that using a feeding device reduced the assistance required during meals and increased feelings of autonomy among users. Additionally, Al-Halimi and Moussa (2017) reported that independent eating was identified as the most important activity for users of the JACO robotic arm.

Findings such as these provide promising evidence that self-feeding devices are beneficial to users; however, there is a dearth of literature exploring the experiences of users while interacting with such devices. The reality of how disability and technology affect a person can only be explored with participants and reported through their own voices. The aim of this exploratory inquiry was to illuminate the views and experiences of people with an upper limb neurodisability

and to provide an in-depth understanding of their use and interaction with the 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.

Procedure

Neater Solutions (<http://www.neater.co.uk>), supplier of the Neater Eater (NE) feeding device, was contacted and provided details of the proposed study. After consideration of the full documentation (informed consent, participant information sheet, interview schedule, and ethical approval document), they agreed to participate in the study. To maintain anonymity and confidentiality of clients, Neater Solutions did not permit the University of Brighton 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. The users were invited to sign both consent forms, to retain one, and to return the other one to the principal investigator at the University of Brighton with a contact email address or telephone number. This process ensured that the details of Neater Solutions' clients who did not want to participate remained confidential and retained by Neater Solutions. In addition, the users who wished to participate were able to directly engage with the University of Brighton, thus retaining their anonymity from Neater Solutions.

Inclusion Criteria

Referral for self-feeding equipment was undertaken by suitably qualified medical practitioners. Each user who was referred was then individually assessed for suitability by an independent occupational therapist. Those users who were deemed suitable for the equipment were supplied with the equipment and were inducted into its use by the occupational therapist who had been trained in the provision of

eating and feeding devices and also by an equipment technician. This procedure was to ensure correct provision of the equipment and correct setup of the equipment to meet the users' needs.

All 200 users from the Neater Solutions database, who met the inclusion criteria and who had been provided with NEs in the United Kingdom in the period from 2011 to 2014, were invited to participate. Participants were required to have a minimum of 3 mo 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 they were either interviewed by telephone or completed the interview schedule via an online questionnaire.

The semistructured interviews used the same interview schedule as Kumar and Phillips (2013) and followed an iterative process. The interview schedule was compiled in two parts. Part 1 explored personal factors, reasons for wanting the NE, psychological impact after initial use, and current feelings about use and value. Part 2 explored usage, changes to quality of life, benefits and limitations, impact on care providers, evaluation of the initial support provided, and advice the user would give to others. Both parts were completed during the interview.

The interviews were transcribed and analyzed by the research officer following the method of thematic analysis described by Braun and Clarke (2006). Codes were inductively and deductively derived and checked to ensure congruence with the context of the interview statements. Codes were grouped into clusters and categorized 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, 6 returned the consent form and then failed to respond to follow-up email and phone calls to undertake the interviews, and 10 partners of deceased

users returned the questionnaires uncompleted. The remaining 23 users went on to participate in either a telephone or online interview. In some cases, participants were assisted by the care provider (see Table 1). Some care providers also provided their own personal comments and observations about the equipment. The age range of participants was 11–75 yr.

The range of time of use of the equipment was 3–36 mo. The reasons given for initially acquiring the NE were largely because 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.

Results

We completed thematic analysis of data using Braun and Clarke’s (2006) model. This undertaking comprised familiarization with the data, generation of initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the final report. Five themes were identified.

Independence and Positivity

Most 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 anymore.” Other children reported that the equipment made them feel “cool,” and they 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 user 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.”

Emotions

One user expressed a sense of anxious anticipation: “I felt apprehensive about whether it would work or not and hoped that it would realize its capabilities.” A few users indicated that they were embarrassed using assistive equipment while familiarizing themselves with it: “It felt awkward.” One user expressed initial frustration that 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 1 young user who enjoyed “showing off with it” because it showed his independence. In addition, 1 user was so impressed with it that he reported “not liking having to leave it at home when I go into respite care.”

Impact on Family and Social Life

Most users used the NE for lunches and dinners but reported that it was not suitable for “wet foods,” such as soups or pasta. Foods that needed “stabbing” (e.g., sausages) were also problematical. The social impact that the device afforded was noted for both users and care providers. Users liked being able to eat with the family, and they did not 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 personalize it to make it comfortable.” For some, the NE gave privacy by providing “independence away from carers. It is just one thing that I can do myself.” Care providers and part-

ners also articulated that they were free to participate in mealtimes, which in turn afforded them their own increased independence and inclusion at mealtimes: “It enables the carer to prepare and leave a cold meal for me in the morning to have at lunch time without the carer.”

Equipment Functionality

The functionality issues highlighted by users mostly referred to a desire for improvements in the design of the equipment: “The bowl needs more space to scoop the food to avoid spills,” or “The plate needs a bigger lip to prevent spills.” For the care providers, the main functional issue was spillage. Several care providers reported that “food is always being spilt, down himself and on the floor.”

One care provider reported that his user was overenthusiastic in his self-feeding action: “It is time consuming as [user’s name] 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.

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 mindset for it to make a difference,” and “You must be prepared to persevere.”

There was also user insight into some care providers’ agendas: “Support staff have mixed views; some think it is great because of the independence it affords, others feel that I make a mess.” The users mostly wanted to recommend it and share their experiences. One user summarized his endorsement as “I am now in control of my mealtimes.”

Discussion

Achieving independence in self-feeding, a fundamental activity of daily living, was an important outcome of using the NE. This outcome in turn increased self-confidence

Table 1. Neuromuscular Conditions of Study Participants

Condition	n	
	Men	Women
Motor neuron 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

and enhanced quality of life. However, an important factor in achieving independence was the user's attitude toward AT and the user's desire to eat independently, which were crucial for a successful outcome. Other important factors were the labor savings in terms of time and resources for family, care providers, and staff. These reduced pressures resulted in greater satisfaction and less stress among care providers in addition to a more equal relationship between user and care provider.

The findings further support the importance of appropriately matching technology to the person. This conclusion endorses the client-centered Matching Person and Technology model (Scherer, 2002) and the Human Activity Assistive Technology model (Cook & Hussey, 2002), which highlight the complex milieu of the person, the technology, and the environment. Aligning technology must encapsulate the users' personal characteristics and preferences in addition to their psychosocial and physical environments. This finding concurs with the *ICF* model (WHO, 2001).

The findings from the inquiry also highlight 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, care providers, and families, the equipment can fulfill its potential for each person (Cook, 2009).

Important implications exist for occupational therapists, including being aware of the potential positive impacts that provision of self-feeding equipment can have on self-esteem and appreciation of independence. The NE can lead to enjoyment of mealtimes as an occupation for both users and care providers, improved self-feeding task performance, reduced demand on care providers, and potentially reduced care costs. Appropriate AT can reduce anxiety and result in a more equal relationship between user and care provider.

Recommendation of AT must be fully client-centered and aligned with the revised *ICF* (WHO, 2001). This approach requires consideration of the importance of the device in aiding the occupation of eating from biological, social, and psychological standpoints. 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.

Implications for Occupational Therapy Practice

The findings of this study have the following implications for occupational therapy practice:

- Positive effects of self-feeding on self-esteem and independence reduced demand on carers.
- Care costs may potentially be reduced.
- Assistive must be fully aligned with the revised *ICF*.

Conclusion

This small exploratory inquiry provides new qualitative evidence, to a limited literature, that assistive eating devices reduce the need for personal assistance and support when feeding, resulting in improved life quality, independence, and freedom. The labor savings in terms of time and resources for family, care providers, and staff appear to result in a more equal relationship between user and care provider. Limitations of the study include that the findings were only captured from one type of self-feeding device and that the participants were not representative of the four most common neuromuscular conditions.

The feedback from this study has already been used to inform changes to the design of the NE devices, including performance with runnier foods. Occupational therapists may not have awareness, experience, or specialized knowledge of AT, and this deficiency should be addressed when it is relevant to current practice (Verdonck, McCormack, & Chard, 2011). Working with AT is a multidisciplinary process, which should involve relatives, care staff, and other professionals who are familiar with it and its ethical, practical, pedagogical, psychological, organizational, and financial implications. ▲

Acknowledgements

I thank all the study participants for their time and invaluable contributions,

References

- Absolom, S., & Roberts, A. (2011). Connecting with others: The meaning of social eating as an everyday occupation for young people. *Journal of Occupational Science*, 18, 339–346. <https://doi.org/10.1080/14427591.2011.586324>
- Al-Halimi, R. K., & Moussa, M. (2017). Performing complex tasks by users with upper-extremity disabilities using a 6-DOF robotic arm: A study. *IEEE Transactions on Neural Systems and Rehabilitation Engineering*, 25, 686–693. <https://doi.org/10.1109/TNSRE.2016.2603472>
- American Occupational Therapy Association. (2014). Occupational therapy practice framework: Domain and process (3rd ed.). *American Journal of Occupational Therapy*, 68(Suppl. 1), S1–S48. <https://doi.org/10.5014/ajot.2014.682006>
- Atkins, M. S., Baumgarten, J. M., Yasuda, Y. L., Adkins, R., Waters, R. L., Leung, P., & Requejo, P. (2008). Mobile arm supports: Evidence-based benefits and criteria for use. *The Journal of Spinal Cord Medicine*, 31, 388–393. <https://doi.org/10.1080/10790268.2008.11760741>
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77–101. <https://doi.org/10.1191/1478088706qp0630a>
- Cook, A. M. (2009). Ethical issues related to the use/non-use of assistive technologies. *Developmental Disabilities Bulletin*, 37, 127–152.
- Cook, A. M., & Hussey, S. M. (2002). *Assistive technologies: Principles and practice* (2nd ed.). St. Louis: Mosby.
- Fung, E. B., Samson-Fang, L., Stallings, V. A., Conaway, M., Liptak, G., Henderson, R. C., . . . Stevenson, R. D. (2002). Feeding dysfunction is associated with poor growth and health status in children with cerebral palsy. *Journal of the American Dietetic Association*, 102, 361–373. [https://doi.org/10.1016/S0002-8223\(02\)90084-2](https://doi.org/10.1016/S0002-8223(02)90084-2)
- Gaedt, L. (2012). *Eating Robot for citizens with a physical handicap* (Report 1). Taarstrup, Denmark: Robotteknologi Teknologisk Institut Press.
- Gustafsson, B. (1995). The experiential meaning of eating, handicap, adaptedness, and confirmation in living with esophageal dysphagia. *Dysphagia*, 10, 68–85. <https://doi.org/10.1007/BF00440076>
- Hasselkus, B. R., & Murray, B. J. (2007). Everyday occupation, well-being, and identity: The

- experience of caregivers in families with dementia. *American Journal of Occupational Therapy*, *61*, 9–20. <https://doi.org/10.5014/ajot.61.1.9>
- Kumar, A., & Phillips, M. F. (2013). Use of powered mobile arm supports by people with neuromuscular conditions. *Journal of Rehabilitation Research and Development*, *50*, 61–70. <https://doi.org/10.1682/JRRD.2012.03.0047>
- Lindborg, A. L., & Lindén, M. (2015). Development of an eating aid—From the user needs to a product. *Studies in Health Technology and Informatics*, *211*, 191–198.
- Louie, S. W. S., Lai, F. H. Y., Poon, C. M. Y., & Wong, S. K. M. (2009). Use of a tailor-made feeding device to improve the self-feeding skills of a woman with congenital upper limb deficiency. *British Journal of Occupational Therapy*, *72*, 401–404. <https://doi.org/10.1177/030802260907200906>
- Norwood, F. L. M., Harling, C., Chinnery, P. F., Eagle, M., Bushby, K., & Straub, V. (2009). Prevalence of genetic muscle disease in Northern England: In-depth analysis of a muscle clinic population. *Brain*, *132*, 3175–3186. <https://doi.org/10.1093/brain/awp236>
- Scherer, M. J. (Ed.). (2002). *Assistive technology: Matching device and consumer for successful rehabilitation*. Washington, DC: American Psychological Association. <https://doi.org/10.1037/10420-000>
- Verdonck, M., McCormack, C., & Chard, G. (2011). Irish occupational therapists' views of electronic assistive technology. *British Journal of Occupational Therapy*, *74*, 185–190. <https://doi.org/10.4276/030802211X13021048723291>
- World Health Organization. (2001). *International classification of functioning, disability and health*. Geneva: Author.

AUTHOR QUERIES

AUTHOR PLEASE ANSWER ALL QUERIES

Note that these are uncorrected page proofs that do not reflect proofreader corrections or corrections submitted after the article went to typesetting. If you submitted corrections and do not see them reflected in the document, please indicate what needs to be corrected.

AQ: In Acknowledgments, change “I” to “We”? Not clear who “I” is because there are four authors.
