Communication Technology for People with Motor Neurone Disease

Current picture and future directions

Anna Love
10 September, 2012

ANNA LOVE, KIM RUSTEN, PRARTHNA BHUTA, JANET DEVINE
& Associate Professor LYNETTE MACKENZIE

DISCIPLINE OF OCCUPATIONAL THERAPY, UNIVERSITY OF SYDNEY
“The biggest thing for me is that MND stops a person from being independent but with the computer, my sister was able to communicate, interact and be very much a part of our life – we’re so grateful that she had this equipment.”

- Survey respondent (carer, anonymous)
“The difference technology has made to my life is unbelievable. It has brought such joy and given me back my independence. I may not be able to speak and swallow but I still keep my sense of humour, love to travel, play bingo and make the most of each day.”

- Personal communication from person with MND
"I have never done that (internet video calls/ VoIP), I have never seen that and don’t think my computer is sophisticated enough to do that. I don’t think the doctors would want me to do that. If they wanted me to then I guess, maybe, but it would have to be them asking me."

- Survey respondent (anonymous)
Snapshot: use of communication technology, needs and aspirations

Current picture + opportunities

Literture Evidence + Survey results
Communication devices
AAC and early intervention
Telehealth
Internet use
Communication devices

- Unprepared for reality of using augmentative and alternative communication (AAC)
  
  (Brownlee & Palovcak, 2007)

- Unique progression complicates equipment planning
  
  (Beukleman & Ball, 2002)

- Short lifespan of equipment – no single device ‘does it all’
  
  (ALS Forum, 2011)
AAC and early intervention

Early intervention and decision-making are crucial

(Brownlee & Palovcak, 2007; Beukleman, Fager, Ball & Dietz, 2007)

Consumer resistance - ‘giving in’, reminder of what is lost

(Brownlee & Palovcak, 2007)

Source: verballyapp.com
Overview of literature

Telehealth

- **Advantages**: service provision at home, low cost

- **Disadvantages**: privacy, security, technological literacy, client preference

  (Yuen & Goetter, 2012; Herbert & Forman, 2012; Frost & Massagli, 2008)

- Can work in practice *after initial visit*

  (Hill, Theodoros, Russell & Ward, 2009; Hordern & Georgiou, 2011)
Overview of literature

Internet use

- 55% of people with MND, 83% of carers research MND on internet
  
  (Chio et al., 2008)

- Unreliable, false hope, potentially harmful

  (Chen & Turner, 2010; Hordern & Georgiou, 2011; Bedlack & Hardiman, 2009)
Survey of MND NSW members

- Literature Evidence
- Survey results
  - Survey design
  - Survey results
- Current picture + opportunities
Survey design

- Consent via MND NSW Member Satisfaction Survey

- Delivery methods:
  - Email / Online (SurveyMonkey)
  - Telephone
  - Post

- Questions:
  - 20 questions
  - Information rich
  - Low respondent burden
  - Non-mandatory
  - Anonymous
## Survey participation and delivery

<table>
<thead>
<tr>
<th>Method of survey delivery</th>
<th>No. members who volunteered to be contacted (from MND NSW Member Satisfaction Survey)</th>
<th>Response rate (to Communication Technology Survey)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Post</td>
<td>9</td>
<td>3</td>
</tr>
<tr>
<td>Email</td>
<td>57</td>
<td>55</td>
</tr>
<tr>
<td>Phone</td>
<td>27</td>
<td>21</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>93</strong></td>
<td><strong>79</strong>*</td>
</tr>
<tr>
<td><strong>Total MND NSW membership</strong></td>
<td><strong>c. 447</strong></td>
<td></td>
</tr>
</tbody>
</table>

* Participation rate represents approximately 20% of MND NSW membership
How do people with MND use technology?

- 85% own desktop or laptop (n=61)

  “It’s a pretty big part of filling my week now. I’d be pulling my hair out with boredom without it.” — Survey respondent

- 48% own tablet computer (e.g., iPad) (n=61)
  - 39% are gifts

- 88% have access to the internet - nearly all broadband (n=66)
  - 50% of survey respondents are regional or rural (n=68)

Internet use (n=54)
- 59% use internet to find out about MND
- 91% use email at least occasionally
- 42% use internet for technology advice
Who are they asking for technology advice?

Respondents (n=64)

- **Family**: 80%
- **Friends**: 70%
- **MND NSW**: 60%
- **ST**: 50%
- **Internet**: 40%
- **OT**: 30%
- **GP**: 20%

"I ask my kids. Our age group is pretty illiterate about this stuff, they’re useless."

"I get the cleaning lady’s 14 year old son to help me out with the iPhone."
What support are they asking for?

› “I am very keen to get some accessibility solutions... I wish there was a one stop shop or some gurus I could easily access... and have an applied consultation.”
  - Survey respondent

› “All the help would have been available had we needed it but he wasn’t keen to use it. He finds it hard to accept his diagnosis.”
  - Survey respondent (carer)

› “I think the thing is it is very early in my diagnosis so I have my head in the sand. I sort of hope they have made a mistake.”
  - Survey respondent
How confident are they with technology?

Respondents (n=64)

- Desktop computer
- Laptop
- Tablet computer
- Text messages
- Internet
- Internet video phone
- Email

Confident

Not at all confident
How willing are they to utilise modes of telehealth?

Confidence mismatch: 75% Willing - 50% Confident
Other findings

Lack of anticipation of need:

“I’d be a great advocate for people to start learning technology immediately, because that’s the only type of communication you’re going to have… One of the things I’d push is for the MND Association to give information from day one.”
- Survey respondent (carer)

Gratitude for technology:

“Without email, typed notes and text messages I would be unable to communicate my thoughts, wishes, and would be unable to take care of my own affairs.”
- Survey respondent
Opportunities for practice

Current picture + opportunities

- Awareness
- Telehealth
- Internet
- Training
What are the opportunities for practice?

- Raise awareness early
  - Client preferences: assistance means ‘giving in’?

- Option to utilise telehealth
  - After initial client visit

- Trustworthy information on the internet

- Training and ongoing support
  - Internet video phone / VoIP
Acknowledgments
“To be disabled without technology is unthinkable”

- Survey respondent


Buchsbaum, R., Kaufmann, P., Barsdorf, A. I., Arbing, R., Montes, J., Thompson, J. L. P., & Group, Q. S. (2009). Web-based data management for a phase II clinical trial in ALS. Amyotrophic Lateral Sclerosis, 10(5-6), 374


