

Game on With Motor Neruone Disease (MND): Challenges and Opportunities

Ben O'Mara

MND Australia
Unit 3/113 Canberra Ave,
Griffith ACT 2603
beno@mndaust.asn.au

Matthew Harrison

The University of Melbourne Faculty of Education
100 Leicester St,
Carlton VIC 3053
matthew.harrison@unimelb.edu.au

Natasha Dwyer

Victoria University College of Arts, Business, Law, Education & IT
70–104 Ballarat Road,
Footscray VIC 3011
natasha.dwyer@vu.edu.au

Kirsten Harley

The University of Sydney Faculty of Health Sciences
Science Rd,
Camperdown NSW 2050
kirsten.harley@sydney.edu.au

Keywords

Motor Neurone Disease, videogames, inclusion, inclusie gaming, barriers, wellbeing; disability

INTRODUCTION

Evidence suggests that people living with Motor Neurone Disease (MND), a terminal illness with no cure that often leads to muscle weakness and significant physical disability (Lau, Brennan, and Gardiner 2018), enjoy playing video games purely for enjoyment, alone and/or as a social experience (O'Mara et al. 2021). Playing videogames can also help reduce the boredom, stress, isolation and lack of choice in daily life that have been shown to reduce quality of life with MND (Holz et al. 2013; Lancioni et al. 2015; Van Groenestijn et al. 2017; Villani et al. 2018). Quality of life refers to what a person and/or group values for overall health and wellbeing, including having a say in decision making and the ability to participate in cultural and recreational activities (Warren and Manderson 2013).

However, significant challenges associated with MND can make playing videogames much harder and risk worsening quality of life with the disease for those who enjoy videogames (O'Mara et al. 2021). MND can cause weakened muscles and fatigue which tends to get worse over time and may make it difficult to press buttons, hold

Proceedings of DiGRA Australia 2024

© 2024 Authors & Digital Games Research Association DiGRA. Personal and educational classroom use of this paper is allowed, commercial use requires specific permission from the author.

smartphones and controllers and operate keyboards (Mackenzie et al. 2016; Able Gamers 2021). Moreover, selecting in game menus and screens becomes harder, there is a major gap in customized games for players with MND and limited opportunities to play, learn socially and “game on with MND” (MND Australia 2021). In addition to the difficulties playing games, the lack of support for carers and loved ones may limit their ability to help players with MND. Furthermore, few and poor quality opportunities to videogame players with MND reduces their ability to exercise fundamental human rights (United Nations 2006).

In our presentation, we share some of the insights and learning from a “scoping” of relevant research and practice for what may help reduce barriers to playing videogames with the MND community (O’Mara et al. 2021). Scoping reviews are a kind of “mapping” that helps create a picture of available evidence (Baranowski and Lyons 2020; Zonneveld et al. 2020). We reviewed studies from across the world published between 2010 and 2021. After screening for eligibility, 82 studies were included in review analysis. Studies explored ways of making it easier to play videogames and/or use communication technology with people with MND. We also reviewed work involving people with similar health and disability issues (e.g. spinal injuries, muscular dystrophy and cerebral palsy).

Our analysis found technological, physical, social and economic barriers. Common themes in barriers for video games were game playability, the physical requirements for interacting with games and their software and hardware, and issues with games industry protocols and processes. For example, game playability (e.g. speed of play, difficulty levels and screen navigation) was a common issue (Gaddes 2018). Limitations in the ability to hold and control devices and use accessibility tools were problems (Klassen 2018). There were challenges with games industry processes for developing more inclusive games with people with disability (Neil Squire 2022). Lack of public awareness about what helps play videogames with MND was an issue, and so too the affordability and availability of technology that suits the changing abilities from progression of the disease (Mackenzie et al. 2016; Ablegamers 2021). Research found that some forms of BCIs, robotics, VR and eye tracking devices may not be easy to access due to their relatively high cost.

Despite the challenges, we found that barriers can be reduced. Videogames can be made more inclusive by: greater involvement of people with MND in research and development; and, customizing software and hardware (Nuyujukian et al. 2018; Barrett Centre for Technology Innovation 2020; Ablegamers 2021) and relevant policies and guidelines to better meet the needs of people with MND (Compañ-Rosique et al. 2019; Versalovic et al 2022). Customizable interfaces included technology like brain computer interfaces (BCI), eye gaze technology, hands free mouse and wearable sensors (Mackenzie et al. 2016; Castillo et al. 2016; Scherer et al. 2016).

Specifically, it may help to learn from people with MND about developing: multiple options for interfaces and interactions (e.g. sensitive to movement and mobility difficulties); use of sliders and circular metres and devices that don’t need hands; and/or, configurable speed and/or remappable controls. Videogames such as Master of Orion (SimTex, Inc. 1993), Sid Meier's Civilization VI (Firaxis Games 2016), Monument Valley (ustwo Games 2014), Diablo 4 (Blizzard Entertainment 2023), Return to Monkey Island (Terrible Toybox and Bada Games 2022), Hyper Dot (Tribe Games 2020) and others featured options for easier play for those with physical movement and fine motor control issues. Involving people with MND may support greater representation of diverse abilities in videogames (Ellis, Leaver and Kent 2022). Artificial intelligence could support customized programming for more inclusive options for gamers with MND. Government supported, community-based work could

reduce issues with affordability and availability of customized videogames and interface technology with the MND community.

Videogame development can address opportunities for reducing barriers to playing videogames with MND by encouraging collaborations in research and practical work. Beneficial collaborations in Australia and globally are likely to be those between videogames researchers from a range of fields, games and technology developers, people with MND and their loved ones and carers and allied health professionals (including social workers and occupational and speech therapists). Collaborations need to increase qualitative research focused on gameplay and pleasure, improved participant engagement and user oriented games design.

BIBLIOGRAPHY

Able Gamers. 2021. "Gaming with a Progressive Disease". *Knowledge Base*. Online Information Resource. <https://ablegamers.org/knowledge-base/gaming-with-a-progressive-disease/>

Baranowski, T. and Lyons, E. J. 2020. Scoping Review of Pokémon Go: Comprehensive Assessment of Augmented Reality for Physical Activity Change. *Games for Health Journal* 9 (2): 71–84. <https://doi.org/10.1089/g4h.2019.0034>

Barrett Centre for Technology Innovation. 2020. "Specially-Designed Controller Enables Individuals with Parkinson's Disease and ALS to Play Video Games." Humber College. September 14: <https://humber.ca/barrett-centre-for-technology-innovation/media/news-and-events/news/specially-designed-controller-enables-individuals-with-parkinsons-disease-and-als-to-play-video-games.html>

Blizzard Entertainment. 2023. *Diablo IV*. Online Game. Blizzard Entertainment.

Castillo, A., Cortez, G., Diaz, D., Espiritu, R., Ilisastigui, K., O'Bard, B. and George, K. 2016. "Hands Free Mouse". *The Institute of Electrical and Electronics Engineers, Inc. (IEEE) Conference Proceedings*, 109–14.

Compañ-Rosique, P., Molina-Carmona, R., Gallego-Durán, F., Satorre-Cuerda, R., Villagrà-Arnedo, C. and Llorens-Largo, F. 2019. A Guide for Making Video Games Accessible to Users with Cerebral Palsy. *Universal Access in the Information Society*, July, 1–17. <https://doi.org/10.1007/s10209-019-00679-6>

Ellis, K., Leaver, T. and Kent, M. 2023. *Gaming Disability: Disability Perspectives on Contemporary Video Games*. Routledge Research in Disability and Media Studies. New York, NY: Routledge. <https://doi.org/10.4324/9780367357153>

Firaxis Games. 2016. *Sid Meier's Civilization VI*. Online Game. 2K Games and Aspyr Media.

Gaddes, M. 2018. "Accessibility and Games Design - Interview with Ian Hamilton, Video Game Accessibility Specialist and Advocate". *Blogs*. AbilityNet. June 14: <https://abilitynet.org.uk/news-blogs/accessibility-and-games-design-interview-ian-hamilton-video-game-accessibility-specialist>

Holz, E. M., Höhne, J. Staiger-Sälzer, P., Tangermann, M. and Kübler, A. 2013. Brain-Computer Interface Controlled Gaming: Evaluation of Usability by Severely Motor Restricted End-Users. *Artificial Intelligence in Medicine* 59 (2): 111–20. <https://doi.org/10.1016/j.artmed.2013.08.001>

- Klassen, M. 2018. “How I Access Games”. *Can I Play That?* December 1: <https://caniplaythat.com/2018/12/01/how-i-access-games/>
- Lancioni, G. E., Simone, I. L., De Caro, M. F., Singh, N. N., O’Reilly, M. F. Sigafoos, J., Ferlisi, G. et al. 2015. Assisting Persons with Advanced Amyotrophic Lateral Sclerosis in Their Leisure Engagement and Communication Needs with a Basic Technology-Aided Program. *NeuroRehabilitation* 36 (3): 355–65. <https://doi.org/10.3233/NRE-151224>
- Lau, F. S., Brennan, F. P., and Gardiner, M. D. 2018. Multidisciplinary Management of Motor Neurone Disease. *Australian Journal of General Practice* 47 (9): 593–97. <https://doi.org/10.31128/AJGP-02-18-4495>
- Mackenzie, L., Bhuta, P., Rusten, K., Devine, J., Love, A. and Waterson, P. 2016. Communications Technology and Motor Neuron Disease: An Australian Survey of People With Motor Neuron Disease. *JMIR Rehabilitation and Assistive Technologies* 3 (1): e2–e2. <https://doi.org/10.2196/rehab.4017>
- MND Australia. 2021. “Why Videogames Matter for MND These Holidays”. *Spotlight on MND*. Canberra: MND Australia. December 16: <https://www.mndaustralia.org.au/articles/why-videogames-matter-for-mnd-these-holidays>
- Neil Squire. 2022. “From Co-Op Student to Change Maker: Milad Celebrates 10 Years With Neil Squire”. Neil Squire. June 2: <https://www.neilsquire.ca/from-co-op-student-to-change-maker-milad-celebrates-10-years-with-neil-squire/>
- Nuyujukian, P., Sanabria, J. A., Saab, J., Pandarinath, C., Jarosiewicz, B., Blabe, C. H., Franco, B. et al. 2018. Cortical Control of a Tablet Computer by People with Paralysis. *PLoS One* 13 (11): e0204566. <https://doi.org/10.1371/journal.pone.0204566>
- O’Mara, B. Harrison, M., Harley, K. and Dwyer, N. 2021. Making Videogames More Inclusive for People Living with MND: Protocol for a Scoping Review. *Games for Change Asia Pacific Journal* 1 (1): 127–46.
- Scherer, R., Schwarz, A., Muller-Putz, G. R., Pammer-Schindler, V., and Garcia, M. L. 2016. “Lets Play Tic-Tac-Toe: A Brain-Computer Interface Case Study in Cerebral Palsy.” The Institute of Electrical and Electronics Engineers, Inc. (IEEE) Conference Proceedings, 003736–41.
- SimTex 1993. *Master of Orion*. Online Game. MicroProse Software and GameTek.
- Terrible Toybox and Bada Games. 2022. *Return to Monkey Island*. Online Game. Devolver Digital.
- Tribe Games. 2020. *HyperDot*. Online Game. GLITCH.
- United Nations. 2006. *Convention on the Rights of Persons with Disabilities*. <https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-persons-disabilities>
- ustwo Games. 2014. *Monument Valley*. Online Game. ustwo Games.
- Van Groenestijn, A. C., Schröder, C. D., Kruitwagen-Van Reenen, E. T., Van Den Berg, L. H., and Visser-Meily, J. M. A. 2017. Participation Restrictions in Ambulatory

Amyotrophic Lateral Sclerosis Patients: Physical and Psychological Factors. *Muscle & Nerve* 56 (5): 912–18. <https://doi.org/10.1002/mus.25574>

Versalovic, E., Diamond, M. and Klein, E. 2020. ‘Re-Identifying Yourself’: A Qualitative Study of Veteran Views on Implantable BCI for Mobility and Communication in ALS. *Disability and Rehabilitation*. Assistive Technology, September, 1–8. <https://doi.org/10.1080/17483107.2020.1817991>

Villani, D., Carissoli, C., Triberti, S. Marchetti, A., Gilli, G. and Riva, G. 2018. Videogames for Emotion Regulation: A Systematic Review. *Games for Health Journal* 7 (2): 85–99. <https://doi.org/10.1089/g4h.2017.0108>

Warren, N. and Manderson, L. 2013. *Reframing Disability and Quality of Life: A Global Perspective*. Dordrecht: Dordrecht.

Zonneveld, M., Patomella, A., Asaba, E. and Guidetti, S. 2020. The Use of Information and Communication Technology in Healthcare to Improve Participation in Everyday Life: A Scoping Review. *Disability and Rehabilitation* 42 (23): 3416–23. <https://doi.org/10.1080/09638288.2019.1592246>

BIO

Dr. Ben O’Mara has worked in health promotion practice and research for over 15 years, including with people living with Motor Neurone Disease (MND), people experiencing homelessness and communities of refugee and migrant backgrounds. Ben is currently the Project Manager for Game On With MND at MND Australia. Ben also works in research to find ways of making digital health more inclusive, and on creative writing projects, as an Adjunct Fellow at University of New South Wales and Swinburne University. He writes for a variety of academic, news media and literary publications.

Dr. Matthew Harrison is an experienced teacher, researcher and digital creator with a passion for utilising technology to enhance social capacity building, belonging and inclusion in education. He has taught in Australia, South Korea and the United Kingdom at primary, secondary and tertiary levels. Matthew is currently a member of the Learning Intervention team and is the Director of Professional and Continuing Education at the University of Melbourne Faculty of Education. He was awarded the Dyason Fellowship in 2020, and the GEM Scott Teaching Fellowship and the International Society for Technology in Education 'Making IT Happen' award in 2023.

Dr Kirsten Harley is a sociologist who lives with MND and writes regularly about her experience and use of communication technology. Kirsten is an Honorary Lecturer at the Centre for Disability Research and Policy, The University of Sydney, and is also a Board member of MND NSW. Her research interests include health care choice, health experience, the history of sociology and disciplinarity. She co-authored (with Gary Wickham) *Australian Sociology: Fragility, Survival, Rivalry* (2014, Palgrave Macmillan), has co-edited collections on healthcare choice (*Current Sociology* 63:5) and teaching sociology (*Journal of Sociology* 49:4), and blogs at kirstenharleymnd.home.blog

ACKNOWLEDGMENTS

We would like to acknowledge funding from FightMND through a 2023 IMPACT Philanthropy Grant for the ‘Game On for MND’ project (administered through Perpetual Limited) and the ongoing support of MND Australia.