



Charles Darwin University

Yolŋu with Machado–Joseph disease

Exploring communication strengths and needs

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Views of Yolŋu with Machado-Joseph Disease

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Yolŋu with Machado-Joseph Disease: Exploring communication strengths and needs

Abstract

Purpose: Yolŋu are Aboriginal Australians from northeast Arnhem Land in the Northern Territory (NT). Machado-Joseph Disease (MJD) prevalence in the NT Aboriginal population is the highest in the world. Yolŋu living with progressive dysarthria associated with MJD could benefit from augmentative and alternative communication (AAC). However, there are no aided AAC systems in Yolŋu languages. This research aimed to explore the views of Yolŋu with MJD about communication, speech-language pathology (SLP) services and AAC.

Method: A collaborative, culturally-responsive research design was informed by Indigenist Research methodology and Constructivist Grounded Theory. Yolŋu with MJD (n = 10) and their interested family members (n = 4) participated in interviews and created visual representations of their social networks. Data was analysed through an oral interpretive process with Yolŋu researchers.

Result: A Yolŋu metaphor, *Gonḏhu* ‘Building understanding by hand’, emerged as a culturally-meaningful way to represent the core understandings required for SLPs to work effectively with Yolŋu with MJD. Elements of this metaphor include seeking to understand the complex lived experiences of Yolŋu with MJD, and working with families to explore the potential benefits of SLP services and AAC.

Conclusion: Yolŋu with MJD and their families want to work collaboratively with SLPs to develop bilingual AAC systems and culturally-responsive SLP services that build on strengths of Yolŋu culture and kinship to improve communication opportunities and participation.

Introduction

Machado-Joseph Disease (MJD), also known as Spinocerebellar Ataxia Type 3 (SCA3), is an autosomal dominant neurodegenerative disorder. MJD involves progressive damage to the cerebellum, resulting in progressive ataxia (Paulson, 2015). Significantly, cognition is not affected. MJD is an expansion repeat disease showing an inheritance pattern known as Anticipation, in which younger generations commonly inherit the same or a longer disordered gene sequence (Paulson, 2015). Generally, the longer the disordered gene sequence the earlier and more severe the onset (Bettencourt et al., 2012). People with MJD can live for 6-29 years after the first onset of symptoms (Paulson, 2015).

Dysarthria, an early symptom of MJD, is a speech impairment resulting from progressive impairment of coordination and control of the muscles required for breathing and speaking. The speech disturbance is characterised by impairment of respiratory-phonatory function including reduced rate, phrase length, loudness, breath support and imprecise consonants (Theodoros & Ward, 2011). In severe stages of the disease, people with MJD can experience anarthria, a complete loss of speech. The impact of dysarthria and anarthria on communication, among other symptoms, negatively impact the socio-emotional wellbeing and quality of life for people living with MJD (Lo et al., 2016).

People with MJD could benefit from speech-language pathology (SLP) services, including voice therapy and augmentative and alternative communication (AAC) (Theodoros & Ward, 2011). As people with MJD can live for many years with limited to no functional speech, they are likely to benefit greatly from use of AAC systems once their voice alone is insufficient in everyday communication interactions.

MJD has a high prevalence amongst Yolŋu, Aboriginal Australian peoples of northeast Arnhem Land, Northern Territory (NT), Australia. Approximately 12,000 Yolŋu live in the NT (Australian Bureau of Statistics, 2008), predominantly in remote townships along the northern coast of Arnhem Land and their surrounding homelands. Many Yolŋu live with poor health, housing, education and employment opportunities and outcomes (Massey, Jane, Lindop, & Christian, 2013). Over time, there has been an increase in the number of Yolŋu living in the NT's capital, Darwin, accessing healthcare, respite care, education and work opportunities. However, most Yolŋu regularly travel back to remote communities to visit family and participate in ceremonies, sometimes staying for months. In 2018, 14 Yolŋu had a diagnosis of MJD, and more than 230 Yolŋu were at risk of developing MJD (Massey, 2018). MJD prevalence in the NT Aboriginal population is thought to be the highest in the world and is certain to increase as a result of population isolation, consanguinity, polygamy, and large families (LaGrappe, Massey, Couchman, Rantell, & Rungan, 2017).

Aboriginal people with a communication disability have reduced access to SLP services in the NT owing to factors such as insufficient workforce, high staff turnover, difficulties in recruitment, geographical, financial, language and cultural barriers (Lowell, 2013). Funding for SLP services for most Yolŋu with MJD has recently improved with a new National Disability Insurance Scheme (NDIS) introduced by the Australian government. However, at the time of data collection most Yolŋu with MJD were eligible to access infrequent fly-in fly-out SLP services in their remote communities, and short blocks of SLP services in Darwin by referral. In addition, a fortnightly AAC Communication Group was established in Darwin in 2016 and jointly funded by the MJD Foundation and NT Department of Health. This group was established for individuals with MJD and their family members living or staying in Darwin to learn and practice using AAC. Most other SLP services for Yolŋu with MJD are individual assessment sessions, with a limited number of therapy sessions. Services are

provided by SLPs who do not share the cultural or linguistic background of the Yolŋu people with MJD and who are infrequently supported by a Yolŋu interpreter.

Despite ongoing cultural change, Yolŋu languages and culture remain strong. Yolŋu culture is based on the interconnectedness of all things through *gurrutu*, a collectivist kinship system that governs all fundamental aspects of Yolŋu life. In Yolŋu culture, all people, plants, animals and natural phenomena are divided into two moieties or groups: *Dhuwa* and *Yirritja*. A moiety is a form of social organisation which describes relationships and guides behaviour. Of the more than 12,000 speakers of Yolŋu languages (Christie, 2004), most are multilingual, understanding and speaking several related Yolŋu languages and dialects. English has little relevance in everyday interactions, unless interacting with *Balanda* (non-Aboriginal people). Use of written language is predominantly restricted to Western education, health, social service and church contexts. Many Yolŋu also know and use Yolŋu Sign Language (YSL) (Maypilama & Adone, 2013).

There are currently no aided AAC systems in Yolŋu languages. There are limited AAC systems and resources in most languages other than English, particularly evidence-based systems and resources (Soto & Yu, 2014). However, there is increasing interest globally around multilingual and culturally appropriate AAC systems and services, including for minority and indigenous languages (Tönsing, van Niekerk, Schlünz, & Wilken, 2018). Individuals and families from culturally and linguistically diverse backgrounds can have diverse views and perspectives about AAC (McCord & Soto, 2004; Parette, Chuang, & Huer, 2004). More research is needed to explore perceptions and experiences of AAC, particularly for people who do not speak English as a first language to inform the development of AAC systems in other languages.

The aim of this study was to work collaboratively with Yolŋu researchers to explore the communication capacities, needs and barriers for Yolŋu with MJD and their family. An

additional aim was to explore the views of Yolŋu with MJD about existing SLP services, AAC and other ideas to support communication participation.

The three main research questions were: For Yolŋu living with MJD and their family members: What are their communication experiences and participation patterns? What are their views about existing SLP services and AAC? What ideas do they have to support communication participation?

Methods

Ethics approval. This project was approved by the Menzies School of Health Research Human Research Ethics Committee (HREC 2017-2832) with reciprocal approval from Charles Darwin University Human Research Ethics Committee (H17072).

Research Design. A collaborative and culturally-responsive approach using primarily qualitative methods was considered appropriate for this exploratory research. This study was informed by Indigenist Research methodology - research undertaken by Aboriginal people, for Aboriginal people in their struggle for recognition of self-determination (Rigney, 1999). The study was also informed by principles of 'Doing research with Yolŋu' (Yalu Marŋgithinyaraw, 2012) to ensure the research was culturally-responsive and of benefit to Yolŋu living with MJD. Cultural-responsiveness is reflected below in the construction of the research team, processes of data collection, and analysis. This study drew on methods of Constructivist Grounded Theory for the purposes of developing shared understanding about communication experiences and views of Yolŋu with MJD, rather than to develop theory (Charmaz, 2014). Semi-structured, in-depth, conversational interviews were carried out in small groups, supplemented by construction of social network data to obtain additional information about the communication context.

Research Team. The research team included a Balanda (non-Indigenous) researcher (first author), and five Yolŋu researchers with culturally-appropriate kin relationships to

Yolŋu with MJD, appropriate experience and capacity. The lead Yolŋu researcher, together with Yolŋu research advisors and Yalu Marŋgithinyaraw (a Yolŋu-run research team using traditional clan structures of governance and management) determined whether researchers were appropriate for this study (Yalu Marŋgithinyaraw, 2012). Yolŋu researchers were all registered interpreters with the Aboriginal Interpreter Service or were highly experienced in Yolŋu-English interpreting. Yolŋu researchers were familiar with the speech patterns of most participants. The lead Yolŋu researcher was also a participant living with MJD, and another Yolŋu researcher was a family participant. All Yolŋu researchers were paid for their work in this study. The research team worked collaboratively through all research stages, using English and Yolŋu languages enabling researchers to communicate in their preferred language and to incorporate ways of knowing from both cultures.

Setting. Small group interviews were conducted in Darwin and in Galiwin'ku, Elcho Island, usually at the beach, or in the shade outside a participant's home.

Participants. All participants were Yolŋu. Ten were participants with MJD, referred to as participants, and four were family members, referred to as family participants. Inclusion criteria for participants were: Yolŋu, 18 years of age and over, with a confirmed diagnosis of MJD (through a molecular blood test or neurological assessment and 'at risk' status).

Participants were recruited purposefully through the Yolŋu researchers.

The MJD Foundation, a charitable organisation which supports people with MJD and their families, uses a functional, four-stage clinical classification of MJD: mild (little or no assistance required for mobility), moderate (requires a mobility aid), severe (ambulant, sometimes uses a wheelchair) and severe (wheelchair dependent). This classification is informed by neurological and functional assessment and roughly reflects stages of progression for all degenerative ataxias (Klockgether et al., 1998). Accordingly, three

participants had mild stage MJD, four had moderate stage MJD, two had severe (ambulant) stage MJD and one participant had severe (wheelchair dependent) stage MJD, see Table I.

Dysathria was not formally assessed in this study, however all participants self-reported changes to their speech. Throughout the interviews, nine out of the ten participants with MJD were intelligible while one participant was unintelligible and used multi-modal strategies to participate, including vocalisations/speech attempts, facial expressions, gesture and some Yolŋu Sign Language. Their close communication partner who was also a family participant interpreted their conversational turns as best as they were able for the researchers.

Participants with MJD were invited to suggest family members who might be interested in participating to enable more effective conversations and diverse perspectives. Inclusion criteria for family participants were: 18 years or over and living or staying with participants with MJD; and related through Yolŋu kinship. Family participants had a close kin relationship to at least one participant with MJD, and a more distant kin relationship to others.

Other family members were interested in the research participated in an informal and flexible manner, for example, by sitting nearby and listening to parts of the conversation. Participants gave consent for other family members to participate as they felt comfortable - either as formal family participants, or informally, i.e. just by listening. All participants and other family members were aware of the research project.

The total number of people involved in small group interviews (participants, researchers and family members who participated informally) ranged from two to 11, with an average of five people involved in each interview. Participant characteristics are presented in Table I.

Data collection. A total of 17 semi-structured, in-depth, conversational interviews were conducted with small family groups in participants' preferred language over a four-month period. Participants were asked about their experiences of learning about and living with MJD, and their current communication, daily activity and participation. During the

interviews, participant views about SLP services, AAC and their own ideas to support communication as dysarthria becomes more severe were explored. The researchers asked open-ended questions and responded to participant stories, using a flexible discussion guide to stimulate further discussion as required. Closed questions were asked to gather background information about participants.

Participants were asked to visually map their social network based on the 'Circles of Communication Partners' (Blackstone & Hunt Berg, 2003) to explore their communication context. Participants were asked to name the people and services that they talk to and characteristics of those interactions and relationships. All participants chose to talk about their social network orally while a researcher recorded this information visually by writing names, drawing lines and symbols to note characteristics of relationships.

Oral and written consent was provided by participants to video or audio record the interviews and social network discussions, with the exception of one participant who requested written notes be recorded from the conversation. All conversations were carried out by the Balanda researcher and one to three Yolŋu researchers. Interviews with two participants were in English while all other interviews were conducted in Djambarrpuyŋu. Parts of the conversation were interpreted orally in real-time for the benefit of the Balanda researcher. A number of additional interactions were conducted with participants over the following eight months to check their data with them, and to reach theoretical saturation by elaborating on and refining core understandings and elements of the emerging metaphor (Charmaz, 2014).

Data analysis. Descriptive statistics were used to describe participant characteristics, and their social networks. All recordings of interviews were interpreted orally by Yolŋu researchers using meaning-based rather than form-based or word-for-word interpreting.

Meaning-based interpreting is the norm and generally preferred by interpreters, because not

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all concepts are universal, and languages express concepts differently (Esposito, 2001). Oral interpretations of Yolŋu researchers were transcribed in English by the Balanda researcher.

All dysarthric speech, family participant interpretations and unintelligible speech attempts were recorded in the transcript. Participants' facial expressions, gesture and productions of Yolŋu Sign Language were also transcribed. When the recording was inaudible due to environmental factors, participants speech was checked with others who were present for the interview or marked as inaudible in the transcript.

The research team analysed and interpreted interview data collaboratively through bilingual oral discussions. The Balanda researcher audio recorded these conversations. Sometimes visual representations were generated during the conversations to capture key words in two languages, concepts and stories, thereby contributing another layer of data. After discussions, the Balanda researcher wrote notes, analytical memos and kept a research journal to record the research process and other reflections.

Data from all sources were coded using QSR International's NVivo 10 qualitative data analysis software (QSR International Pty Ltd., 2014). First cycle codes were generated collaboratively with two Yolŋu researchers to ascribe labels to the data, line-by-line, using simultaneous coding to capture multiple possible meanings of stories shared by participants (Charmaz, 2014; Saldaña, 2016). Participants' phrases and gerunds (verbs ending in '-ing') were used when coding to stay close to the data, detect processes, actions and sequence, and maintain a stronger sense of the participant's perspective and voice.

The researchers grouped like-codes together and core elements began to emerge. Theoretical sampling was carried out through follow-up conversations and interpretive, analytical discussions with participants and researchers to check and re-categorise data (Charmaz, 2014). Core elements were continually tested against new information from memos, discussions and journals until theoretical saturation was reached (Charmaz, 2014).

Some participants chose to be identified by their Balanda name or one of their Yolŋu names in this article. Identification in research is important to some Yolŋu to share their story through educational resources for future generations, and to ensure that the storyteller is an appropriate person to share that information (Amery & Gondarra, 2018; Lowell, Maypilama, Biritjalawuy, & CRC for Aboriginal and Tropical Health, 2003). One participant from this study outlined her reasons for wanting to be identified:

“The story I’ve given... put it in a book or some kind of research paper... that other people can use. I want something like... a photo of me, and I want it to say my story in it. ...Because when my descendants grow up, when I die, they might read that book”.

– Alison Bandayŋa (Participant)

Trustworthiness and Credibility. Strategies were used to enhance the trustworthiness and credibility of this research. From an Aboriginal research perspective, strong relationships of mutual trust and respect were developed and maintained (Drawson, Toombs, & Mushquash, 2017). Appropriate Yolŋu kin relationships, respecting Yolŋu social rules, and spending time together, prior to and throughout this research were key to building and maintaining trust. Use of English and Djambarrpuyŋu languages also demonstrated respect, and enabled clear communication in participants’ and researchers’ preferred language. Yolŋu researchers were invited to lead interviews and oral analysis to ensure that the research privileged Yolŋu perspectives. Co-developing the project and conducting member checking with participants also helped to ensure authenticity, credibility and accountability in relationships and data (Shenton, 2004; Yalu Marŋgithinyaraw, 2012).

From a non-Aboriginal research perspective, triangulation of research methods, data sources, and the coding practices of Constructivist Grounded Theory were used. A clear audit trail of memos and journals exists to document the development of categories or elements (Charmaz, 2014; Shenton, 2004). Writing a research journal and reflexive oral discussions

enabled the researchers to consider the influence of culture, worldview and life experiences on each aspect of the research process.

Result

Participants' social networks showed that Yolŋu with MJD predominantly communicate with Yolŋu family in Yolŋu languages. Communication partners were 79% Yolŋu family and 21% Balanda (predominantly service providers). Thirty-four of the total 178 communication partners (19%) were identified as close kin by three or more participants. A number of communication partners are therefore, likely to experience high care responsibilities, owing to the high number of close family members living with MJD. These factors are likely to impact their experiences of living with MJD, views of communication difficulties, SLP services and AAC. Further exploration of Yolŋu social networks will be presented in a separate publication. The views and experiences of participants and family participants about progressive dysarthria, SLP services, AAC and ideas for supporting communication are presented in the following section.

Gon̄dhu, 'Building understanding by hand', is a Yolŋu metaphor that emerged as a culturally-meaningful way to represent the core understandings required for SLPs to work effectively with Yolŋu with MJD to improve communication. 'By hand' suggests manual labour, a time-intensive task. Building by hand requires patience, commitment, creativity and craftship. There are also rewards from working by hand. In Yolŋu culture, when you collect pandanus and weave a basket, you produce sweat, and sweat represents *miŋjurr* 'value'. Objects have more value when you know first-hand the work that was involved. 'Building understanding by hand' requires engagement with the following five elements: *Dayatham* 'having and holding', *Märram* 'getting what we need', *Mala-djarr'yun* 'working out what suits', *Dayaŋu-waŋganydhirr* 'coming to consensus' and *Djämamirriyam* 'getting on with it'.

These core elements and their components are described below.

Dayatham - ‘having and holding’. The communication experiences and participation patterns of Yolŋu with MJD are described as ‘having and holding’. ‘Holding’ represents ‘living a Yolŋu life’ and maintaining a strong Yolŋu identity. ‘Having’ represents the increasing need for ‘interacting with Balanda’ and ‘living with MJD’. ‘Having and holding’ shares experiences of communication and participation - all of the things that you interact with, past and present, who you are and everything that has happened to you.

Living a Yolŋu life. Whether Yolŋu live in an urban context or remote community (or travel between them), they all hold a strong Yolŋu identity, evident through speaking Yolŋu languages, using Yolŋu Sign Language, and doing activities that are important to Yolŋu life. Most participants reported speaking Djambarrpuyŋu - the lingua franca of northeast Arnhem Land. Older participants reported understanding and speaking multiple Yolŋu languages, as presented in Table I. Some participants also reported using Yolŋu Sign Language, with those who have had more contact with a family member who relies on sign language demonstrating a higher level of competence.

Most of the time, Yolŋu with MJD interact with their family as they participate in activities that are important in Yolŋu life, including: raising their children, spending time with family around the house or camp, hunting, making art and participating in cultural ceremonies. Following Yolŋu *rom* ‘culture/law’, including caring for family, sharing food and resources, having sympathy for close and distantly related family, and having respect are central to living a Yolŋu way of life.

Interacting with Balanda. ‘Interacting with Balanda’ relates to learning and speaking English, engaging with service providers and organisations, realising the impact this has on Yolŋu interactions, and the emergence of ‘new’ contemporary activities that participants engage in. When Yolŋu communicate with Balanda, it is usually in the context of service provision. Communicating with Balanda services and professionals involves talking to

Balanda who have minimal understanding of Yolŋu language and culture, with the onus placed on Yolŋu to switch from their preferred language to speak in English. Speaking about foreign concepts and words that do not exist in Yolŋu languages is often involved. Increasing experience communicating with Balanda in English is changing communication between and amongst Yolŋu family. Many participants code-switch between Yolŋu languages and English, commonly by using a few English words when there is no Yolŋu equivalent. All participants use mobile phones, though they do not necessarily own one, and some also use social media. Participants reported that younger people generally have a better understanding and use communication technology more often.

All participants reported engaging in other relatively ‘new’, contemporary activities not part of traditional life, related to being entertained, playing sport, shopping, practicing a Christian faith, accessing health services, attending school, travelling, working and managing money. Participants each take part in a range of these contemporary activities, and experience both positive and negative aspects of them. One negative aspect of taking part in contemporary activities is missing out on aspects of traditional Yolŋu life:

“The city life is way different from community life. ...You don’t see chests painted, secret mens’ business ...not in the city life. So (kids) miss out on the essential Yolŋu cultural learning ...Now we talk about ‘what’s the next movie on’...I know that we are adapting ...but we’ve still got to keep our culture strong”.

– Elah (Yolŋu Researcher and Family Participant)

Living with MJD. Participants shared many of their experiences of living with MJD, including memories of their parents who had passed away from MJD, their experiences of having tests, and first learning about MJD. Living with MJD involves dealing with many symptoms, including poor balance and walking, weakness in the legs, hands and arms, difficulties with sleeping, incontinence, swallowing and changes to communication.

All participants reported changes to their speech over time: losing their breath, losing volume, speech fading, not speaking clearly, slurring speech, ‘like my tongue is twisting’, feeling tired, not sounding right, tightness in their throat and slowing of their speech. Communication changes led participants to worry and feel sorry for themselves and their close family members. Having dysarthria made participants feel frustrated, angry and sad. Some family participants reported feeling helpless as they did not know what to do to help their family members with severe dysarthria.

“If I don’t do anything for her, she throws herself on the ground. If I don’t understand, she scratches me, like I’m not listening to her. I feel sorry for her but I can’t help her”.

– (Family Participant)

Dysarthria impacts on communication opportunities and the way that participants interact with others. One participant reported that she regularly apologises for her speech. Another reported that she is speaking less and sometimes just sits back and listens:

“Sometimes I can talk, sometimes never talking to anyone, I just sit quietly and say nothing. Because I just want to talk short. I don’t want to talk too much”.

– Alison Bandayya (Participant)

Participants consider these aspects of *Dayatham* ‘having and holding’ to be core components of their communication experiences and participation patterns. ‘Living a Yolŋu life’, ‘Interacting with Balanda’ and ‘Living with MJD’ are all part of what Yolŋu with MJD and their families experience with regards to communication and participation.

Märram - ‘Getting what we need’. The views and experiences of participants about accessing existing supports are shared in ‘Getting help from family’, ‘Getting help from Balanda services and supports’ and ‘Wanting to learn more’.

Getting help from family. Yolŋu with MJD help their family members and receive help from their family in acquiring and preparing food, teaching and looking after children,

cleaning around the house or camp, helping with mobile phones, filling out forms, attending appointments, emotional and spiritual support through use of humour, sharing stories and prayer. The level of support provided by family to meet increasing needs that come with more progressive stages of MJD can be challenging:

“I have a heart problem, so I don’t want to push myself to work too hard, or else I might end up hurting myself... Lifting her, pushing her in the wheelchair, changing her clothes...”. – (Family Participant)

Some Yolŋu have close kin relationships to multiple family members with MJD and as a result provide substantial care and support to many people. The level of supports and responsibility is also impacted by their communication skills and experience, such as their ability to speak English, their level of literacy and/or their understanding of information and communication technology.

Getting help from Balanda services and supports. SLP services for communication support were not accessed by most participants. While many participants had attended swallowing assessments by an SLP, many were not aware of communication assessment or therapy options, including voice therapy. One participant with MJD had attended a session of voice therapy but had not continued.

“Gurrulma was doing that exercise ‘ahh’ and his voice was a bit soft, he said ‘oh no, my battery’s flat’. He said, ‘I might swallow a fly!’ ...It’s just too, you know, it’s too hard”. – Julie (Yolŋu Researcher and Participant)

Almost all participants had never seen or even heard about aided AAC systems. One participant, Wamuttjan, had recently been prescribed an AAC app for her tablet with some support from a SLP while she was still attending school. She was in the process of moving to the city with her parents to access increased support, so was transitioning between services.

The screen of her tablet was broken, the battery usually flat, and she didn’t often carry it with

her. Minimal vocabulary was programmed into the app and all vocabulary was in English. She was not able to use it to communicate with her parents who speak Djambarrpuyŋu.

Wanting to learn more. Yolŋu with MJD expressed interest in working with SLPs to learn more about options for supporting communication impacted by dysarthria in moderate and severe stages of MJD. All participants expressed interest in trying AAC systems in Yolŋu languages, and most said that they would use bilingual AAC systems in Yolŋu and English. Most participants expressed a preference to have systems with picture symbol support due to limited literacy in both English and Yolŋu languages. Most participants were also interested in learning about both high and low-tech devices, especially the possibility of high-tech devices in Yolŋu languages.

“I’d probably start from the low (paper AAC system), and then right up to here (referring to a high tech AAC device)”. – Alison Bandayŋa (Participant)

The potential use of voice exercises to maintain a strong voice was also of interest to some. Others were interested in teaching their family members more Yolŋu Sign Language.

‘Getting what we need’ reflects the views and experiences of Yolŋu with MJD about SLP services and AAC. Currently, Yolŋu with MJD predominantly access communication and participation supports from family, with limited access to Balanda services to support communication. Yolŋu with MJD and their families are interested to learn more about communication resources that could help them, including developing bilingual Yolŋu-English AAC systems. The following three elements of the metaphor integrate Yolŋu responses and suggestions for working together to support communication for Yolŋu with MJD.

Mala-djarr’yun – ‘working out what suits’. Three aspects to collaboratively modify and develop communication services and supports to be responsive to Yolŋu culture, and enable Yolŋu increased participation and control, are ‘Learning with family, for family’, ‘Focusing on Yolŋu strengths’, and ‘Waiting for your inner-spirit’.

Learning with family, for family. Yolŋu with MJD want their family to be with them, sitting close by, listening and learning and sharing stories with them. When a research meeting or activity related to the family as a whole, participants were more interested and engaged. Participants encouraged each other to overcome their worry and fear by framing activity as helping others in the family, and through working and learning together.

“I want granddaughter to come with me, and start learning... Learning for me and also for her, so she knows how to look after me. Yeah, that’s the best, you know”.

– Alison Bandayŋa (Participant)

Focusing on Yolŋu strengths. Therapy processes and activities must be integrated with Yolŋu ways of knowing, being and doing to be relevant and effective. Participants expressed interest in trying new things, though some participants expressed hesitation and fear. They thought that learning new things would be too hard. A senior Yolŋu research adviser shared that when Yolŋu with MJD can connect to their inner-strength and culture, they will be able to try new solutions and decide for themselves what suits them:

“You can have all this stuff, and money and do things the Balanda way, but you have to tap into Yolŋu strength, to connect from there, the beginning story and who they are”.

– L̄awurrpa Maypilama (Senior Yolŋu Research Adviser)

Waiting for your inner-spirit. Providing ongoing opportunities for Yolŋu family to observe and listen, encourages them to think for themselves and take action when they are ready. Group interviews involved Yolŋu family sharing their own stories. This indirectly encourages family to start thinking and come to their own opinions. Yolŋu researchers shared about how it is important to wait for someone’s *ŋayaŋu* ‘inner-spirit’ to be ready for work:

“Don’t force or pressure that person, otherwise they get tired. Maybe that person is sick. When that person feels better inside, in their inner-self ...then they will feel good and get up and work” – Julie (Yolŋu Researcher and Participant).

This element of the metaphor, ‘Working out what suits’, illuminates some of the important ways that Yolŋu engage in services to ensure that they align with their culture and way of life: together with their Yolŋu family, relating through kinship, sharing stories, encouraging each other and waiting for people to be ready in their ‘inner-spirit’. Modifying and collaboratively developing communication supports with consideration for these principles enables Yolŋu with MJD and their family to explore solutions to challenges in their own ways, having greater input and control over what tools, processes and services may be of value for them.

Dayaŋu-waŋganydhirr – ‘Coming to consensus’. Literally meaning ‘inner-spirit becomes one’, the process of everyone agreeing about the way forward, with a common goal is described by ‘Coming to consensus’. It is important for everyone in the family to understand, agree, and work collectively for a common goal:

“The family have to be happy, and they all have to be helping each other –one mind, one heart, one spirit. Strong, to put it to work”.

– Elah (Yolŋu Researcher and Family Participant)

The two areas that Yolŋu have reached consensus about, to support communication opportunities and participation for Yolŋu with MJD are ‘*Learning together as a group*’ and ‘*Learning outside at the beach*’.

Learning together as a group. Yolŋu with MJD want to learn together as a family, rather than in individual SLP sessions. Learning together and spending time as a group helps participants to feel connected, able to support each other and be supported by their family.

“When Balanda try to provide individual services, it doesn’t make Yolŋu strong. It divides them”. – Julie (Yolŋu Researcher and Participant)

Yolŋu with MJD can benefit from therapy, whilst their motivation comes from being with, helping, and caring for their family.

“Sometimes I take all my kids out and do an activity outside, being a family. To share, share family. To help me out, to make me in the middle. To be surrounded with love and joy and happiness with their presence. So I’m not going to think ‘I’ve got MJD’. I’ve got family all around”. – Barbara (Participant)

Learning together as a group allows for more holistic and interconnected learning. Family members can catch up with each other, discuss other issues and achieve multiple goals, or focus on whatever is their priority at the time.

Learning outside at the beach. When possible, participants expressed a preference for communication therapy to be carried out at the beach, or somewhere else outside. Being at the beach connects Yolŋu with MJD to their land, kin and ancestry and helps to uplift their spirit.

“Its good for your head, for your body, for Yolŋu when we sit at the beach. This sea, and breeze, and land, it connects us Yolŋu. They all speak to us and we think back. We’re sitting and it makes me think about my homeland”.

– Joanne (Yolŋu Researcher)

Djämamirriyam – ‘Getting on with it’. All of the elements come to a head in ‘Getting on with it’, a call to put it all into action. ‘Starting now’ and ‘Staying active, staying positive’ are some of the ways that Yolŋu with MJD are ready to start working together to support communication opportunities for Yolŋu with MJD, now and for future generations.

Starting now. Some Yolŋu with MJD are ready to develop and learn about AAC systems now, while their speech is still strong, and before they experience severe dysarthria.

“Give it to us. Not when they’re ready, before it’s too late...because I’m losing my voice and I can’t wait until it’s too late”. – Mary Galipiyawuy (Participant)

Since most participants were still using their speech to meet their communication needs, some didn’t know when would be a good time to start learning about AAC systems. They indicated that they would be open to trying AAC sometime in the near future.

Researchers observed increased engagement and readiness from some participants as the research progressed. By continuing to have opportunities to spend time with their family and learn together, Yolŋu family engaged when they were ready and how it suited them.

Staying active, staying positive. Participants wanted to continue engaging in culturally-meaningful activities, like spending time with family, being outside at the beach and going hunting to feel strong and stay positive. Their view was that staying active helps Yolŋu to not spend too much time worrying or thinking negative thoughts.

“Doing work to make you strong, digging and using all your muscles to get strong. You feel the blood running through and your knees get stronger. Not just sitting down, thinking MJD will make me weak. Thinking about ending up in a wheelchair”.

– Barbara (Participant)

In summary, the metaphor *Gonḏhu* ‘Building understanding by hand’ encapsulates the elements that SLPs must understand to work effectively to support communication for Yolŋu with MJD. *Dayatham* ‘Having and holding’ involves seeking to understand and consider the complexity of Yolŋu communication strengths and needs living between ‘two worlds’.

Märram ‘Getting what we need’ explores participants’ experiences of getting support from family, with limited communication supports from SLP services, but wanting to learn more.

Mala-djarr’yun ‘Working out what suits’ focuses on Yolŋu principles to collaboratively modify and design culturally-responsive supports and services. *Dayaŋu-waŋganydhirr*

‘Coming to consensus’ is about Yolŋu agreeing to work together as a family, outside when possible. Finally, *Djämamirriyam* ‘Getting on with it’, is a call to action to start now while speech is strong to work together to develop bilingual AAC systems and prepare for the future of Yolŋu living with progressive dysarthria associated with MJD.

Discussion

The aim of this study was to explore the communication experiences of Yolŋu and their families living with MJD, their views about current SLP services, AAC and other ideas to support communication. Through meaning-based translation and collaborative interpretation, the research team and participants were able to build shared understanding about Yolŋu experiences and ideas to work together with their families and SLPs to support communication. *Gonḏhu* ‘Building understanding by hand’ is a Yolŋu metaphor that encompasses the elements that SLPs need to understand to work together with Yolŋu living with MJD. Understanding of these elements was developed in collaboration with Yolŋu researchers and families, grounded in relationship and experiences of working together.

Through this study, a new way of doing research about AAC evolved that was designed to suit Yolŋu participants, and guided by Yolŋu researchers. Family group interview conversations and social network mapping were carried out by a Balanda researcher with Yolŋu researchers. The data was collected, analysed and interpreted through collaborative oral discussions, in two languages over a 12-month period to generate a bilingual, bicultural metaphor that represents key findings of the research.

Communication in a Yolŋu context involves finding opportunities to explore narratives, bringing old and new meanings together, to build new practices and ways forward (Christie, 2006). Building shared understanding in this study was a collaboration across cultures and between Yolŋu with MJD and their family members. This collaboration requires positive, authentic relationships, patience, respect and value of diversity (Christie, 2006).

The Yolŋu metaphor *Gonḏhu* ‘Building understanding by hand’ illustrates that there is no fast, easy way to understand the communication and participation experiences of Yolŋu with MJD. Building understanding about ‘Having and holding’, the complexity of lived experience for Yolŋu with MJD, and ‘Getting what we need’, their experiences of accessing

supports from family and Balanda services, and their interest to learn more – involves building relationships and entering into dialogue to listen and learn from each other. Building understanding about ‘Working out what suits’, Yolŋu processes of working collectively with their family, ‘Coming to consensus’, exploring ways to learn together that everyone agrees are culturally-responsive, and ‘Getting on with it’, putting shared understanding into practice – involves the hard work of ‘being’ and ‘doing’ across two languages and cultures.

‘Working out what suits’ and ‘Coming to consensus’, draw attention to Yolŋu with MJD wanting to have greater involvement and participation in the process of modifying and developing tools and services to be culturally-responsive and relevant. ‘Working out what suits’ is a process of ensuring that any new communication resources and support services integrate with Yolŋu culture, values and way of life. Working together with linguists and families is essential to developing AAC systems or other therapy resources that are designed for Yolŋu languages and grammar (Christie, 2006).

‘Working out what suits’ shows that it is also the systems, structures and processes by which SLPs work that determine whether services are culturally-responsive. Informal and flexible practice, observation, and emphasis on developing rapport with individuals and their families have been identified as facilitators of effective SLP practice with Aboriginal adults (Cochrane, Siyambalapitiya, & Cornwell, 2018). *Gonḏhu* ‘by hand’ is a complex and dynamic Yolŋu metaphor that correlates to many of these facilitators of working effectively and responsively with Indigenous people in research and practice.

The metaphor *Gonḏhu* ‘By hand’ expands on these facilitators, identifying the following specific strategies for research and practice with Yolŋu adults: (1) enable Yolŋu to work together as a family group with appropriate kin; (2) work in outside environments that help Yolŋu to feel relaxed and connected to their family; (3) wait for individuals to be ready to participate in their own way and time; (4) build on strengths of Yolŋu language, culture,

and identity; (5) foster ongoing opportunities for Yolŋu family to share stories, and try new therapy resources and strategies to gain collective experience; and (6) enable Yolŋu to make decisions about therapy resources and services as a family collective. The importance of working through the existing Yolŋu system of kinship, reinforcing the inherent strengths of Yolŋu culture by adopting a '*Gurrutu*-centred approach' and promoting Yolŋu-led conversation in Yolŋu languages has also been emphasised in other projects (ARDS Aboriginal Corporation, 2018). A strengths-based approach can counter the 'deficit discourse' prevalent in Aboriginal health research and policy (Fogarty, Lovell, Langenberg, & Heron, 2018) through focusing on communication assets, including cultural knowledge and identity.

'Getting on with it', starting before Yolŋu experience severe dysarthria and speech loss, enables time for SLPs and Yolŋu with MJD to build relationships and work strategically. Working strategically involves working flexibly, incorporating facilitators for culturally-responsive practice with Yolŋu with MJD, and consideration for the complexity of Yolŋu lives and the priorities raised in 'Having and holding'. The earlier families engage with AAC, the greater understanding, skills, choice and control they can develop before speech loss (Costello & O'Brien, 2018).

A key strength of this study was the culturally-responsive and collaborative research process implemented through all stages of the research. A generative process of oral interpretation and analysis in two languages enabled researchers to communicate in the language of their choice, through oral story telling rather than reading or writing. Generating a Yolŋu metaphor to encompass the elements for building understanding enabled the research team to communicate findings with Yolŋu and Balanda audiences, sharing perspectives from a Yolŋu worldview about engaging with SLP services. It was essential to have a research team that included Yolŋu with MJD, and other researchers with appropriate kin relationships

to participants. This enabled the researchers to share the work-load, and build and maintain trust between researchers and participants (Lowell et al., 2003; Yalu Marṅgithinyaraw, 2012).

Limitations. Working collaboratively across cultures and languages is complex and challenging. Using meaning-based interpreting and coding English ‘translations’ of conversations meant that some cultural meaning and perspective was potentially lost. Finding synergy between different ways of being, knowing and doing, and expressing this in a way that is authentic to both cultures and worldviews was challenging. This ‘messiness’ in intercultural research needs to be accepted and examined through continuing to share examples and learn from different ways of working together (Christie, 2006).

There were periods of time when Yolḡu researchers were not available due to personal and family commitments. Few men participated because most Yolḡu living with a diagnosis of MJD at the time of this study were women. Only one participant had severe (wheelchair dependent) stage MJD. All other participants had mild or moderate (ambulant) stage MJD, and reported changes to their speech. That most participants were still able to use their speech likely influenced their views. The scope of this study meant that the perspectives of only a small number of Yolḡu family participants was explored.

Implications for Practice and Future Research. The findings of this study indicate a need for SLPs, linguists, Yolḡu families and relevant organisations to develop strong and collaborative research and practice partnerships. This is essential to develop more culturally-responsive communication resources and services. These partnerships need to be established early, making the most of lead time while Yolḡu with MJD have strong speech to prepare for more severe stages of MJD and associated changes to communication. Further research is needed to explore the collaborative development of bilingual AAC systems so that Yolḡu have increased communication and participation opportunities in their preferred languages, those used with the majority of their communication partners. There is a need to modify

services for Yolŋu with MJD across all areas of SLP to incorporate the facilitators of working together with Yolŋu identified in this study. Research into the accessibility and efficacy of family group therapy models, in outdoor locations and use of telehealth to remote locations could be further explored to respond to the communication needs and goals of Yolŋu families living with MJD. Developments in technology and infrastructure make alternative models of therapy possible, and SLPs aspire to provide more culturally-responsive services. However, existing SLP services predominantly remain infrequent, face-to-face, and for individuals, with limited interpreting support. Alternative models of practice have the potential to build on both the communication and cultural strengths of Yolŋu families, and to develop an evidence base for SLP practice with Aboriginal Australians.

Conclusion

Collaborative and culturally-responsive research methods have enabled the research team to discover the core elements that SLPs need to understand in order to work effectively with Yolŋu with MJD, and support communication opportunities and participation. The research approach used in this study has relevance to SLP research and practice with Aboriginal Australians and other Indigenous peoples internationally, as well as to SLPs practicing and conducting research related to AAC in intercultural contexts. *Gon̄dhu* 'Building understanding by hand' is a Yolŋu metaphor that encompasses these core elements and emphasises the importance of developing relationships, having patience, respect and commitment for working with complexity across cultural and linguistic differences. Further collaborative research partnerships between SLPs, linguists and Yolŋu families are required to develop bilingual AAC systems and culturally-responsive SLP services to meet the unique and changing communication needs of Yolŋu living with MJD.

Declaration of Interest

The authors report no declarations of interest.

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Tables

Table I *Participant Characteristics*

Participant	Sex	Age range	Years since MJD diagnosis	Stae of MJD	Preferred Language	Other Languages Spoken
1	F	20-30	8	Mild	English	Djambarrpuyŋu
2	F	40-50	5	Mild	Djambarrpuyŋu	English
3	F	30-40	1	Mild	Djambarrpuyŋu	Gälpu, English
4	F	50-60	6	Moderate	Djambarrpuyŋu	Gumatj, Warramirri, Gälpu, Dätiwuy, Gupapuyŋu, Ritharrŋu, Wagilak, English
5	F	50-60	8	Moderate	Djambarrpuyŋu	Gälpu, Warramirri, Wangurri, Gupapuyŋu, Golumala, Dätiwuy, English
6	F	40-50		Moderate	Djambarrpuyŋu	Gumatj, Raminginiŋ dialect, Milingimbi dialect, English
7	M	40-50		Moderate	Djambarrpuyŋu	
8	F	40-50	7	Severe (ambulant)	Djambarrpuyŋu	Gumatj, Wangurri, Warramirri, English
9	F	50-60	8	Severe (ambulant)	Gumatj	Djambarrpuyŋu, English
10	F	18-20	5	Severe (wheelchair dependent)	Djambarrpuyŋu	Gumatj, Gupapuyŋu, Dhałwaŋu, English

Supplementary Online Material

Table 2: Flexible Discussion Guide

<p>Talking about MJD and Communication</p>	<p>Can you share some of your story about MJD?</p> <p>When did you find out?</p> <p>What was that like for you?</p> <p>Have you noticed any changes in communication?</p> <p>How do you feel about that?</p> <p>What is changing?</p> <p>What languages do you speak and understand?</p> <p>What do you like to do with your time?</p> <p>What makes you feel happy and strong?</p> <p>What's really important to you?</p> <p>Who do you talk to?</p> <p>Who helps you? (Social network map)</p>
<p>Opinions about AAC and Voice Therapy</p>	<p>What do you think about sign language, using paper systems or high-tech systems?</p> <p>Can you see any problems with using these sorts of tools?</p> <p>What would you be interested to try?</p> <p>Are some better than others?</p> <p>What languages do you think systems should be in?</p> <p>What do you think about doing voice exercises to keep your voice strong?</p>
<p>Ideas for next year</p>	<p>If we could try some therapy sessions or groups next year, what sorts of activities would you be interested to try?</p>

Who needs to learn?

What would you like the MJD Foundation to do to help your communication?

What would you like Speech Pathologists to do to help your communication?

Figure 1: Localities of participants in the Northern Territory: Darwin and Galiwin'ku, Elcho Island in East Arnhem Land. Released under the CC-BY-SA-3.0-DE license, a derivative work of NordNordWest/Wikipedia.



Figure 2: *Gon̄dhu* ‘Building understanding by hand’: Core elements and components

