

Final submission prior to acceptance (pre-proofed)

Abstract

Background: More than 80% of people living with MND (plwMND) develop difficulties with their speech, affecting communication, self-identity and quality of life. Most plwMND eventually use an augmentative and alternative communication device (AAC) to communicate. Some AAC devices provide a synthesised voice for speech, however these voices are often viewed as impersonal and a factor in AAC acceptance. Voice banking creates an approximation of the person's own voice that can be used in AAC and is argued to go some way to preserve a person's identity when natural voice is lost, but there has been little supporting research.

Aims: To understand what plwMND consider when deciding whether or not to bank their voice, what their expectations are, and the expectations of significant communication partners.

Methods: Semi-structured interviews were undertaken with plwMND who had either decided to bank their voice or had decided not to. Thematic analysis was used to provide a qualitative analysis of the data.

Procedures: Participants were an opportunistic sample of plwMND within England recruited via an open advert distributed by the MND Association (MNDA).

Outcomes and Results: Twelve plwMND were interviewed with nine significant others. Nine participants had decided to bank their voice and three decided not to. The data suggests 'preserving identity' is the overarching theme in decision making for voice

banking. Participants who decided to voice bank considered it would help to maintain their identity and preserve their social and work networks. Participants deciding not to voice bank highlighted it could not replace their natural voice or preserve their identity. However, few in either group showed an awareness of how a voice bank is used in AAC, and how communication using AAC is significantly different to natural speech.

Conclusions and Implications: This research is the first study of its kind to examine the considerations for decision making around voice banking for plwMND. Preserving identity is central to decision making when considering whether or not to voice bank. However, the reality of using AAC and voice banking for communication is poorly understood. Professionals have a role to provide plwMND with more information about voice banking in the wider context of using AAC for communication. It may be that the process of voice banking itself is seen as a positive act for plwMND, independent of how it is used later. Further research with associated professionals and stakeholders is indicated.

Introduction

Motor neurone disease (MND), also known in the USA as Amyotrophic Lateral Sclerosis (ALS) or Lou Gehrig's disease is a progressive, ultimately fatal disease causing progressive muscular weakness resulting in loss of function of limbs, weakness of muscles of the trunk and neck. An average life expectancy of two to three years after symptom onset is common, with approximately 25% of people surviving for five years and 10% surviving ten years (Oliver, Radunovic, Allen, & McDermott, 2017). It is reported that 80-95% of people living with MND (plwMND) will become unable to communicate their daily needs using natural speech (Beukelman, Fager, & Nordness, 2011), and in time most will be unable to speak at all (Beukelman, Garrett, & Yorkston, 2007). Up to 90% of plwMND were identified as eventually relying on augmentative and alternative communication (AAC) systems to support daily communication (Ball, Beukelman, & Pattee, 2004).

Speech and identity

When it becomes difficult to talk to communicate, individual and social identity can be negatively affected, increasing the risk of social withdrawal (Yamagishi, Veaux, King, & Renals, 2012). There is evidence of a correlation between the increase in speech difficulties experienced by plwMND and a reduction in their quality of life (QoL) (Leite Neto & Constantini, 2017).

AAC provision for speech loss

The UK National Institute of Health Care and Excellence (NICE) guidelines for the assessment and management of MND, recommend that if appropriate, AAC equipment is provided without delay to meet the needs of a plwMND (NICE, 2016). The priority is that AAC should maximise participation in activities of daily living and maintain quality of life.

A speech generating device (SGD) is often provided to plwMND (Makkonen, Ruottinen, Korpijaakko-Huuhka, & Palmio, 2017). The SGD speaks-out selected letters, words, symbols or sentences using a synthetic representation of a generic human voice. The SGD could be accessed through a keyboard, switch or eye-tracking technology.

For many plwMND, there is nothing that could replace the ease or speed of natural speech, citing the extended time it takes to spell a message with AAC (Murphy, 2004). AAC devices are not well equipped to facilitate talk during conversation due to the rapid timing demands of such interactions, and AAC users often use vocalisations and gesture to try to speed up communication (Higginbotham, Fulcher, & Seale, 2016). Delays that extend beyond a few seconds increase the likelihood for partner inattention, frustration, and misunderstanding, presumptions of incompetence, stigma, and social isolation (Robillard, 1999). Because of these difficulties, some plwMND decide to restrict their interactions using AAC to a limited range of people (McNaughton, Light, & Groszyk, 2001). Psychosocial factors are also argued to play an important role in successful use of AAC, including the confidence, motivation and attitude to communicate using AAC, and resilience in the face of difficulties or setbacks when using AAC (Light & McNaughton, 2014).

As motor skills deteriorate due to the progression of MND different access methods may be needed, and the effort required to learn to operate AAC in new ways may mean fewer plwMND choose to use SGDs (Felgoise, Zaccheo, Duff, & Simmons, 2016); (Linse, Aust, Joos, & Hermann, 2018).

In summary, high tech AAC like SGDs are argued to improve quality of life, however there are factors that need to be considered to support their successful use, including the time to generate a message, the voice of the device and other people's responses (Baxter, Enderby, Judge, & Evans, 2012).

Voice banking for plwMND

Voice banking is a process for creating a 'personalised synthetic voice' (PSV), a synthetic approximation of a person's natural voice (Costello, 2016). A PSV can be used as the 'voice' of a SGD, and aims to provide the SGD user with a personal voice that is unique to them and an alternative to generic synthesised voices (Bunnell, Pennington, Yarrington, & Gray, 2005). A varying number of individual phrases need to be recorded to create a PSV, depending on the type of voice banking software.

However, a PSV does not replicate natural speech: the timing and intonation of sentences "spoken" by a PSV sound 'robotic' (Modeltalker, 2017), and it cannot reflect how a person controls tone of voice to convey meaning – for example the tone of a PSV cannot be dynamically adjusted to indicate happiness, anger, sadness, irony or sarcasm (Pullin & Hennig, 2015).

Several commercial suppliers offer software applications to create a PSV. Acapela™ ‘my-own-voice’ is currently the most used voice banking service for plwMND in England, Wales and Northern Ireland (MND Association, 2019). It requires 350 phrases to be recorded and a PSV can be created in variety of languages (Acapela, 2019). ModelTalker™ is also a popular choice for plwMND, and usually requires 1600 phrases to be recorded (Modeltalker, 2017). The choice available for voice banking suppliers is growing.

PlwMND are an important consumer group for voice banking suppliers. Acapela™ and ModelTalker report that approximately 80% and 95% respectively of all the PSV files they create are for plwMND (Acapela by email, 2020) (ModelTalker by email, 2018).

For a person used to speaking naturally, communicating using the synthesised voice of a SGD can seem impersonal and unfriendly (Mckelvey, Evans, Kawai, & Beukelman, 2012) and is one of a number of factors linked to AAC acceptance/rejection and use (Linse et al., 2018).

Suppliers make various claims about the realism of a PSV recorded using their technology, but few clearly link that a PSV is used in a SGD, and that communicating through a SGD is different to using natural speech for everyday conversation. VocaliD™ says on their website “Whether you are suffering from throat cancer, losing your voice to ALS, or perhaps you would just love to preserve your voice for personal tech uses such as virtual avatars, your Vocal Legacy allows you to speak as yourself” (VocaliD, 2019). CereProc™ also emphasises the accuracy of their PSV: “with a CereVoice Me voice, a speech generating device can later be used to talk with your own voice” (CereProc, 2019). Acapela claim to “create a digital copy of your voice, to keep this essential part of your identity” (Acapela, 2019).

In a study where listeners compared the short sentences recorded by the same person using their natural voice and PSV, the natural voice recording was preferable perceptually to listeners even though the sentences were equally intelligible (Overton, 2017). However, it might be that a PSV does not have to be more than an approximation of natural voice to deliver some benefit to people losing natural speech - subjective feedback from patients undergoing laryngectomy report that voice banking prior to surgery improves their quality of life after surgery (Jůzová, Romportl, & Tihelka, 2015).

The value of voice banking in everyday communication

This research did not identify any studies that investigate the value of voice banking, a similar finding to Linse et al., 2018. Nathanson argues that there is a moral case for providing a PSV for people who are likely to lose natural voice, however she acknowledges that there are no quantitative data showing the difference between use of a PSV and a standard synthetic human voice available in many VOCAs (Nathanson, 2016).

Jůzová reports that a significant improvement to quality of life was achieved by creating PSVs for several patients prior to laryngectomy. However, there is no indication of how they measured the change in quality of life or how the study could be replicated. Jůzová acknowledged that further research is required to show empirical evidence of any change in quality of life (Jůzová et al., 2015).

Despite the lack of evidence for the claimed benefits of a PSV and what appears to be a lack of awareness for how a PSV is used in AAC, there is significant and growing interest in voice banking from the MND community. In 2018 the MNDA

directly helped over 100 plwMND to voice bank through the 'Voice Banking Volunteer' (VBV) scheme (this scheme trains volunteers to provide practical support for plwMND wishing to voice bank). In 2019, 386 people registered with the MND Association to record their voice using Acapela' my-own-voice. More than 600 registrations are forecast for 2020 (MND Association, 2020).

The views of significant others

The behaviour and attitudes of communication partners towards AAC have been shown to influence how and where AAC is used and ultimately how successful the provision of AAC may be (Scherer, Jutai, Fuhrer, Demers, & Deruyter, 2007). The views of significant others may also play a part in the decision-making process for plwMND considering voice banking. Videoed interviews of two plwMND who were already using their banked voices (used for training of speech and language therapists) indicated significant others may value a PSV more than plwMND themselves (Cave & Gleave, 2016). Additionally, a PSV has been reported as saving the distress of significant others being unable to remember what their loved one sounded like, a kind of 'vocal insurance' in case voice is lost (Benson, 2015). However, the evidence referred to here is drawn from a very small sample, and a more robust, larger scale investigation is required to investigate the views of significant others.

To date, there is no identified research on what plwMND consider when deciding whether or not to voice bank, what expectations their communication partners have of

voice banking, or what the difference communicating with a PSV makes when compared to using a generic synthesised human voice. This study focuses on the first two of these questions:

- What do plwMND consider when deciding whether or not to bank their voice?
- What are the expectations of significant communication partners of voice banking?

The outcomes will be used to make recommendations relating to provision of information and training about voice banking to SLTs and other professionals, plwMND and significant others.

Methods

Semi-structured interviews were undertaken with plwMND who had either decided to bank their voice or had decided not to. The interview recordings were orthographically transcribed and inductive thematic analysis (TA) (Braun & Clarke, 2006) was used to provide a qualitative analysis of the data. Ethical approval for this study was granted by the sponsoring University's Research Ethics Committee.

Recruitment

Opportunistic sampling was employed in order to recruit sufficient numbers of participants. Participants were recruited through either an advertisement placed in the UK MND Association branches or through MNDA Regional Care Development Advisors (RCDAs) in England. The RCDAs were contacted by phone and email and

provided with inclusion criteria by the researcher. Contact details for the plwMND and significant communication partner were only provided to the researcher when potential participants requested additional project information. The researcher followed up to request verbal consent and obtained formal consent at interview. If potential participants were not able to sign a consent form because of the nature of their disability, they were asked to indicate consent on an audio recording.

Participants were included who had a diagnosis of MND or were a communication partner of a person with MND, were over 18 years of age and resident in England. Potential participants were excluded if there were concerns about capacity to consent. Participants with English as an additional language (EAL) were accepted if they were able to understand English to a sufficient level as part of the interview process, as judged by the researcher at the information briefing prior to consent.

Participants

Twenty-one participants were recruited comprising plwMND ($n = 12$) and their significant communication partners ($n = 9$). The participants' characteristics are displayed on Table 1 below.

Twelve plwMND participated ($n = 6$ females and $n = 6$ males). The average age of the participants was 57 years and most were not currently working ($n = 9$). Participants' were on average five months after diagnosis at the time of the interview. Nine had decided to bank their voice (five males and four females), three had decided not to (two females and one male). All used natural speech and did not require AAC.

Nine communication partners participated, the majority (n=8) were the spouse of interviewed plwMND and one was a child of the plwMND. The average age of the communication partners was 54 years.

Table 1: Sample Participants' Characteristics

Code	Participant	Months since diagnosis	Gender	Role	Chose to voice bank?	Primary communication method	Age
plwMND1	PlwMND	4	M	Retired	Yes	Speech	50-60
plwMND2	PlwMND	12	M	Retired	Yes	Speech	50-60
CP2	Communication Partner (wife)		F	Carer for the plwMND	n/a	Speech	50-60
plwMND3	PlwMND	6	F	Retired	No	Speech	60-70
plwMND4	PlwMND	8	M	Retired	Yes	Speech	50-60
CP4	Communication Partner (wife)		F	Carer for the plwMND	n/a	Speech	50-60
plwMND5	PlwMND	4	F	Retired	Yes	Speech	60-70
CP5	Communication Partner (husband)		M	Carer for the plwMND	n/a	Speech	60-70
plwMND6	PlwMND	6	M	Professional	Yes	Speech	50-60
CP6	Communication Partner (wife)		F	Carer for the plwMND	n/a	Speech	50-60
plwMND7	PlwMND	3	F	Retired	Yes	Speech	60-70
CP7	Communication Partner (husband)		M	Carer for the plwMND	n/a	Speech	60-70
plwMND8	PlwMND	10	F	Retired	Yes	Speech	60-70
CP8	Communication Partner (husband)		M	Carer for the plwMND	n/a	Speech	60-70
plwMND9	PlwMND	2	F	Retired	No	Speech	30-40
CP9	Communication Partner (husband)		M	Carer for the plwMND	n/a	Speech	30-40
plwMND10	PlwMND	5	M	Professional	No	Speech	40-50
CP10	Communication Partner (wife)		F	Carer for the plwMND	n/a	Speech	40-50
plwMND11	PlwMND	1	M	Professional	Yes	Speech	40-50
plwMND12	PlwMND	4	F	Retired	Yes	Speech	80-90
CP12	Communication Partner (daughter)		F	Carer for the plwMND	n/a	Speech	40-50

Interview format

Interviews were undertaken with plwMND who had decided to bank their voice or had decided not to. The interviews were designed to explore in depth their perception and expectations of voice banking.

Interviews took place in the participant's home or an alternative location of their choice (for example the local MNDA branch) and were conducted by the researcher. All interviews were audio-recorded, each lasting between 20–45 minutes. The interviews were conducted over a period of six months between September 2018 and March 2019.

A semi-structured interview approach was used. This allowed for the flexibility of covering key areas the researcher had planned for and enabled participants to discuss issues important to them that the researcher had not anticipated (Braun & Clarke, 2013). The interview question schedule (see appendix) was created around a set of questions informed by the clinical experience of the first author, who is a senior specialist SLT working with plwMND, corresponding to the overall aims of the study.

The proposed interview schedule was reviewed by a volunteer plwMND and his significant communication partner. Neither were participants in the research. The plwMND had previously chosen to bank his voice and had been supported by the first author. Their review helped to ensure the questions were meaningful to the participants, answered the research question and minimised problematic assumptions embedded the way questions were asked (Braun & Clarke, 2013). Their feedback resulted in minor wording changes for clarity.

Interview Analysis

The interview recordings were orthographically transcribed and pseudonymised with the participants represented as numbers. Reflexive thematic analysis (TA) in the form described by Braun and Clarke (Braun & Clarke, 2006) was used for qualitative analysis of the interview transcripts. TA is a recognised, widely used and accessible inductive method of identifying themes to analyse concepts and ideas in qualitative data (Braun & Clarke, 2013).

The research process followed Braun and Clarke's (2006) 15-point checklist of criteria for reflexive thematic analysis. The interviews were transcribed and checked against the recordings for accuracy. The transcripts were read repeatedly to increase familiarization with the data, and full and equal attention was given to each data item. NVivo 12 software was used to structure the coding process and group individual responses from the transcripts. Further review of the coding using 'mind mapping' for visualization enabled sub-themes to be identified and eventually a hierarchy of distinctive main themes and sub-themes was created.

The lead author acknowledges his familiarity with the topic and that he has not coded in isolation. As such he has played an active part in searching and identifying patterns and themes in the data. He has nearly 12 years of experience of working with adults with acquired and progressive neurological conditions, including MND. The most recent two years have been working specifically with plwMND as national project lead for voice banking on behalf of the MND Association.

Results

Identity was central to decision making for plwMND who chose to or not to bank their voices as well as to their significant communication partners. The process of deciding about voice banking or not included keeping control and fighting back, maintaining social networks, concerns about using AAC and the support of professionals.

Following initial coding, the initial 36 sub-themes identified were further refined into four main themes with an overarching theme of “preserving identity”. The process of voice banking decision making included: keeping control and fighting back, maintaining social networks, concerns about using AAC and the support of professionals.

Table 2: Overarching Theme: preserving identity

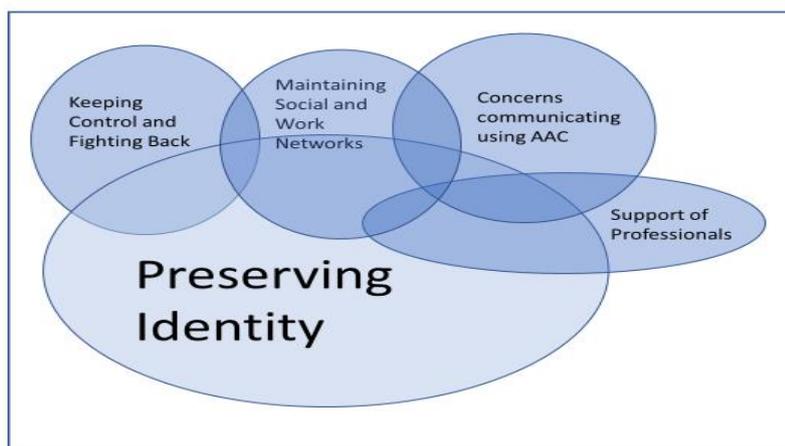


Table 3: Sub-themes categorised by plwMND choosing and significant others

<i>PRESERVING IDENTITY</i>	<i>CONTROL</i>	<i>MAINTAINING SOCIAL NETWORKS</i>	<i>FIGHTING BACK</i>	<i>USING AAC</i>	<i>SUPPORT OF PROFESSIONALS</i>
A banked voice will preserve personal identity	Keeping control for as long as possible	Maintenance of social and work network	Fighting Back against MND	Concerns of using AAC to communicate with their banked voice	Frustration about a lack of timely information about voice banking
Other people are more likely to treat them as an individual	Support the wishes of plwMND	Maintenance of social network			SLT attitudes to voice banking vary widely
A banked voice has psychological benefits		Maintenance of relationship with plwMND			Little support available for technically and emotionally difficulties of voice banking
Voice bank may be used for identity theft					SLT attitudes to voice banking vary widely
A banked voice will not preserve their identity					Little support available for technical and emotional difficulties of voice banking
Do not wish to consider voice banking while natural voice is unaffected					
Other ways would be more useful for preserving identity than banking a voice					
A banked voice can preserve personal identity					

Legend		
Views of plwMND choosing to voice bank	Views of plwMND choosing not to voice bank	Views of significant others

Overarching theme: preserving Identity

Identity was core to decision making for plwMND. On one end of the spectrum participants identified their voice as integral to their sense of who they are in the context of new losses with their disease, whilst on the other end participants were clear that MND was moving quickly in their life and maintaining the things that mattered to them was more important to their sense of self than spending extended time saving a record of their already altering voice. For communication partners, identity was also a key consideration. They embraced the plwMND's right to decide this as part of their autonomy and identity, but also shared the view that a banked voice was helpful in preserving identity and would add something supportive to a relationship that was under significant pressure.

plwMND who chose to bank their voice

PlwMND who chose to bank their voice, saw it as a way of preserving a part of their identity when other parts are disappearing: ***“This disease is so so so dreadful it takes away everything, everything it takes away from you. The voice helps me retain something of me. I'm surprised there aren't more things to help”*** [plwMND8]. PlwMND felt that being able to communicate with a synthesised voice that approximated to their own would be beneficial to mood: ***“It keeps part of you as you as opposed to someone else for longer and I think psychologically the fact that your voice is coming out of a machine as an individual it makes you feel better that you are not just a synthesized voice“*** [plwMND4]. Using their own unique voice instead of the generic voice was seen as a way to protect a unique sense of self: ***“It would retain my personality people would recognise it was me as opposed to being like a SatNav or something like that so I think it's very important with what I***

have I'm going to be fairly disabled so it's good that I can still be me and people will know that it's me" [plwMND11] as well as believing that it would change the way others saw them and interacted with them: ***"An individual voice rather than a generic one is part of your identity and maybe that will make you treated more as more of an individual rather than the generic voice generated by machine"*** [plwMND6].

One participant commented that in their view the standard synthesised voice actually reflected the identity of someone else entirely and it was important to sound different: ***"It is better than having the Steven Hawking voice"*** [plwMND12].

One plwMND was aware that voice was entwined intimately with identity in the wider world and highlighted concerns that a synthetic voice may be used for identity theft and felt he would have to change access to his bank account because of it: ***"There could be risks of misuse for example my bank now uses voice recognition when I call and so they no longer ask me security questions and obviously in future we may have to switch back to answering security questions"*** [plwMND6].

plwMND who chose not to bank their voice

The plwMND who chose not to voice bank also related their decision to identity – how a banked voice cannot bring the natural voice they once had, only an approximation of the dysarthric voice they have now: ***"I don't really want my voice to come out synthetically and I don't really want it to come out as it is now"*** [plwMND3]. A banked voice was perceived not to be able to replicate natural inflection or stress: ***"It would not sound like me or have my inflection or my meaning ... I mean a computer can't assume how the sentence is structured"*** [plwMND10]. One plwMND

did not want to consider voice banking as their natural voice was unaffected: ***“I didn’t want to think about that yet”*** [plwMND9].

A plwMND thought the perceived amount of time and effort needed to voice bank would not be worth it: ***“when it comes to the stage when I can no longer speak properly I would need this software and how long would I live for and is it worth that amount of time would I care certainly I don’t think so I don’t care enough I don’t think it’s worth it for the amount of time that I will live for”*** [plwMND10].

One plwMND said that making videos for her loved ones, rather than hours banking her voice would be time better spent: ***“I would prefer to do something different...recording a video for people to see is better than just voice”*** [plwMND9].

Significant Others

Significant others said they wanted to support the wishes of the plwMND whether they decided to bank a voice or not, and respected this as central to the person’s identity and self-autonomy in living with MND: ***“I support my wife and her decisions, so if voice banking is important to her, it’s important to me. Whilst I stress over my wife’s diagnosis and how we’ll cope in the future, I follow my wife’s lead on how she wants to cope and live with MND”*** [CP7] and ***“For me we’ve had a bit of a detailed chat with our son who’s fifteen telling him about it that we both accept and completely understand and support his position on it*** [CP10]. This was recognised by one plwMND ***“She didn’t say oh you’ve got to go and get that done or no you don’t have to get it done she’s very good she said whatever I want I’m going to be able to do it”*** [plwMND10]. For others, their preference was to hold on to parts of the person they love and this was important in considering their voice: ***“We’ve spoken***

to family and friends, and they have all said the same thing. They would prefer my wife's banked voice, compared to a synthetic voice" [CP7].

Most significant others thought that a banked voice would help preserve identity: ***"The voice is really the only thing I see a noticeable deterioration and has affected us so yes it is hugely important and as it would be for our children we want as much of you left as possible and this is a way of doing that"*** [CP6]. The voice was seen as embodying the person's core: ***"It helps people like my wife save a piece of themselves. If I heard a synthetic voice speaking on behalf of my wife, I think it would take a lot of getting used to. I've listened to several synthetic voices, and they don't seem to have any soul"*** [CP8]. Participants felt a banked voice could support their social network: ***"that's the most important thing the remaining being connected to other people and being a part of what's going on. it takes away that isolation if you can't communicate it's such a natural thing to do"*** [CP2].

Significant communication partners also related the decision to the possible mood related benefits: ***"to me the most important thing is how he felt it doesn't matter how I feel I think if he feels part of it and could communicate with us and that makes him feel better then that's the most important thing for me"*** [CP2] and highlighted concerns about quality of life and social isolation and exclusion as communication losses occur: ***"She would have been more self-conscious, reluctant to put herself out there without a banked voice"*** [CP12].

They thought a banked voice could help support their personal relationship during a difficult time: ***"it's retaining a bit more of her...and it helps maintain my own enthusiasm my drive just to keep plugging on helping her you know it's just one day at a time whatever the challenges are we just have to adapt to move on so***

that for me is good compared to the other needling things just have to get things into perspective” [CP8].

However, one significant other was uncertain about how much benefit a banked voice would actually have in daily life: ***“we’re making this commitment without knowing anything about what benefits it will have really”*** [CP6].

Keeping control and fighting back

Many participants were less than six months post diagnosis and at the early stages of learning about their condition and the prognosis. For some, trying to maximise control over what happens now and in the future was frequently brought up by plwMND choosing the bank their voice: ***“I think a lot of people in my situation it is about control if you read about it the word control comes up a lot so as I said earlier I will lose my voice so what am I going to do about it?”*** [plwMND1].

Choosing to voice bank was seen as a positive way to fight back against the relentless progression of MND: ***“as much as I know I’ll lose my voice through MND, this I can fight back on. And try to preserve a part of me”*** [plwMND7].

Maintaining networks

Some plwMND felt family and social relationships would be supported using a banked voice: ***“I think kids and family and friends will feel will feel more comfortable that it’s me not someone else that speaking out of the voice box”*** [plwMND4].

PlwMND felt that a banked voice would support ongoing work relationships better than using another synthesised voice: ***“in a work environment I have a guess that people if I was dealing with somebody who was using a banked voice I think I***

prefer to hear their voice so in that work environment when you see people certain people you interact with only once every two or three months and have a discussion with I think it would be a bit of a shock if they turned up and they suddenly sounded like Queen Elizabeth or George Clooney or whatever and it would actually be reassuring that so I guess when the communication is a bit more formal it would be reassuring professionally” [plwMND1].

Using AAC

However, some participants were concerned that using AAC may slow down the speed of communication so much that they won't be able to participate in conversations easily (a banked voice can only be used within AAC devices): ***“it's inevitable that communication's going to be hugely compromised anyway and you can't answer the same speed which is a key thing you can't become part of conversation discussion and banter the way I would be normally so ... the person that was there basically is there but is now semi-detached”*** [plwMND4].

Two plwMND were concerned about how much slower communication would be using AAC and had suggestions for increasing the speed – being trained in touch-typing, sign language or inventing a device solely designed to make speed of communication faster when using a banked voice: ***“you are using a machine to speak it's only as quick as you can type now I've been giving it some thought and..the guy I deal with he went on a Pitman's typing course and he can type faster than he can speak so it got me thinking that I should be doing the same...logically to me the quicker you type the better you can communicate”*** [plwMND4].

“Is there something that's just purpose built I'm talking hardware here where literally you have some way to put around your neck or maybe not some way simple and dedicated to being your speaker with the right keypad no logging in no other apps on the machine maybe something a bit more discrete” [plwMND4]

Support of Professionals

Three subthemes were identified within the support of professionals around the support available to inform and help with voice banking.

Some felt that health professionals should have provided support for voice banking much sooner after diagnosis: ***“The hospital told me about voice banking but they couldn't provide that facility. Neuro health professionals were ready to tell me that this wonderful thing called voice banking existed but there was no practical follow up” [plwMND5].***

There was frustration about the variation in advice that SLTs offer about voice banking – some encouraged plwMND to voice bank if it was their preference, while other SLTs advised the same plwMND against – arguing their natural voice was too dysarthric for a banked voice to provide benefit: ***“At my local hospital two of the SLTs made it clear that they thought me doing voice banking would not work... then I met Roxanne part of the SLT she listened to me and encouraged me to do voice banking... Why is there such a difference in professional views regarding voice banking, even within the same hospital team? Is there any form of training for hospital staff regarding voice banking?” [plwMND7].***

Both plwMND and communication partners felt that voice banking was a difficult process to go through – citing the technical skills required and the time it took to

complete, barriers that could stop people attempting to voice bank: ***“At present, the IT skills needed to bank your voice are considerable and there are no trained professionals with the time to help individuals who, like me, find it challenging to bank their voices”*** [plwMND5].

Discussion

This research is the first study of its kind to examine decision making surrounding voice banking for plwMND. It shows how preserving identity is critically important in how people deal with a diagnosis of MND. For those choosing to voice bank, this is seen as an effective way of preserving their identity, a way of 'fighting back' against MND, helping to maintain social networks and giving a positive psychological benefit. Those deciding against voice banking do not believe it could maintain their identity and cannot bring back the natural voice they once had. Timing was important and some plwMND may not be ready to consider voice banking while their natural voice is unaffected and believe other ways of maintaining social networks to be more effective. Significant others want to support the wishes of the plwMND, believe a voice bank will help maintain their relationship with the plwMND and support the wider social network.

Preserving Identity

Many plwMND deciding to voice banking felt it would help maintain identity when their natural voice was lost which is consistent with other research (Nathanson, 2016). However, the group that decided to voice bank made little reference to how a PSV sounds different to natural voice. In contrast, the group that decided not to voice bank often referred to the likely unnaturalness of a PSV as overriding any of the potential positives. In both cases, if a plwMND has not heard a PSV, there is a risk that some may have unrealistic expectations about how it sounds and how it is used.

Given the focus on preserving identity, one interviewee was concerned that his PSV could be used for identity theft. Although he decided to proceed with voice banking, he subsequently changed the security settings for his bank account to disable voice access. This is an important area where very limited research has been conducted. One

AAC supplier has demonstrated that a standard synthesised voice, that comes with its AAC software, can be used to successfully send commands to Alexa, a virtual assistant developed by Amazon (Smartbox, 2019). As biometric identification, including voice recognition, is predicted to become the norm in financial services (Nasonov, 2017), considerations of the ramifications of a person using their PSV to set voice security when they are using that voice in daily communication is an important future area of research, clinical consideration and ethics. Particularly as security of access to their bank account may be dependent on ease or difficulty of accessing the PSV file or operating the AAC.

Keeping control and fighting back

Voice banking is seen by some plwMND as a way of 'fighting back': exerting some control over the future to delay or minimise the effect of voice deterioration. The process of voice banking itself may feel beneficial as a positive and hopeful act, in addition to the perceived benefits of a PSV. Focusing on the possible is a more pragmatic approach than attempting to get rid of distressing or difficult experiences (Gould, 2017). It may be that the process of voice banking itself is seen as a positive, proactive act for plwMND, regardless of how it is used later in AAC.

As MND is a degenerative chronic condition, plwMND may see voice banking as a hopeful and achievable activity that could help them live their lives as best they can, of preserving as far as possible and engaging in hopeful activities (Brown & Addington-Hall, 2008). Hope has been identified as a central need of people with medical conditions and their significant others (Kylmä & Juvakka, 2007) and as a coping strategy for plwMND (Hirano, Yamazaki, Shimizu, Togari, & Bryce, 2006). Voice banking could be perceived by plwMND as both attainable and a way to

maintain a sense of control in one's life – these are key factors contributing to patient hope (Duggleby & Wright, 2014). An activity such as voice banking may provide an opportunity to focus on something other than potentially distressing thoughts relating to MND (Duggleby & Wright, 2014).

Maintaining social networks

Leite Neto & Constantini (2017) reported that a reduction in natural speech increases the risk of social withdrawal and reduced QoL with other researchers showing the changes in relationships that occur between plwMND and significant others is devastating (Gauthier et al., 2007). Some participants described communicating using a PSV may help mitigate these risks and maintain social, work and family relationships and provide positive psychological benefits. Significant others were all supportive of their partner's decision regarding voice banking and some felt a PSV could support their relationship as they try to manage the difficult times ahead. Nathanson (2016) argues a similar point that a PSV promotes human interaction and social participation, enabling plwMND to function more effectively within their own families and social circles and allow them to contribute to wider society for longer through continued employment.

Using AAC

Only a few plwMND raised concerns about how different communication is likely to be using AAC when compared to using natural speech. As a PSV can only be used in AAC, the well documented barriers with using AAC in everyday communication are likely to apply whether a PSV is used or not

Support of professionals

Some plwMND and significant others were frustrated about the inconsistency in advice SLTs offered about voice banking. This could be reflective of how many SLTs may not have had training or practical experience of the process. Provision of advice to people about voice banking is considered part of the SLT role, however it may not always fit easily within the 'traditional' SLT areas of dysphagia or voice therapy, and it may not be fully understood that a discussion about voice banking should be in the context of using AAC for communication. It may also be the case that a plwMND may not have been referred for SLT while voice and communication remain unaffected and there are no difficulties with eating and drinking.

Clearly, banking a voice with dysarthria will generate a PSV with dysarthria. Some participants expressed that they not wish to consider voice banking while their natural voice was unaffected, while others reported frustration that they had not been told early enough to be able to complete the process with their unaffected voice. Professionals working with plwMND may therefore find themselves in a delicate and difficult position of bringing up the subject of voice banking well before the person has developed an understanding of the prognosis and course of MND.

Many participants felt voice banking software is technically difficult to use and required help to get through the process. One interviewee said that others that had not started voice banking because the software was perceived too difficult to understand. The perceived or actual technical barriers for voice banking are a significant concern given that some plwMND may experience speech decline as soon as six months from diagnosis (Makkonen et al., 2017). Time is of the essence: the longer it takes to voice bank, the bigger the risk of a poorer quality PSV due to voice deterioration or that voice banking cannot be completed at all. The MNDA VBV project provided volunteer support

to around 100 plwMND wishing to voice bank in 2018. The process took an average of three months to complete even with volunteer support (MND Association, 2019).

One plwMND said that recording videos for loved ones would be more useful than banking a voice, raising the possibility that she may have been considering legacy video messaging - for example, the service provided by RecordMeNow (RecordMeNow.org, 2012). The MND Association reports voice banking and legacy messaging can be easily confused, but both should be considered (MND Association, 2019). It may have been that the purpose and role of voice banking and legacy messaging were not fully explained.

Summary

There is much interest in the plwMND community for voice banking and this study indicates that maintenance of personal identity, relationships and a desire to fight back may be some reasons why. Significant others support plwMND in their decision making and have expectations that personal identity can be maintained in part by voice banking too. However, in both groups there appear to be less awareness of how a voice bank is used in AAC, and how different communication using AAC is when compared to natural speech. The moral responsibility discussed by Nathanson (2016) to develop more accurate personalized voice technology perhaps could be extended to ensuring that plwMND considering voice banking are given the information to understand how it is used in practice.

Limitations

MND is a relatively rare condition and for plwMND there are many things pressing on their ever-decreasing time. Recruitment expectations were not met. Despite an attempt to recruit nationally, the participants were recruited mainly from one regional area. It was very difficult to recruit plwMND that had decided not to voice bank and as a result were significantly outnumbered by interviews of plwMND that did.

The interviews were conducted for 20-45 minutes, a long time for people who find communication effortful and who may have cognitive challenges, but a brief time to explore in depth personal issues such as identity. Fatigue from the effort of communication was observed in some of the interviews and is one of the most commonly reported symptoms of MND (Gibbons, Thornton, & Young, 2013). On reflection, returning to continue the interview over multiple visits may offer both a deepening of rapport with the interviewer and thus a willingness to disclose potentially more personal content and manage the challenges associated with the MND.

Although qualitative research is unlikely to be representative for a population, as it reflects the experiences of a small sample, this study has highlighted the need to widen the scope of future research to include professionals such as SLTs and associated stakeholders, which would enhance the strength of any recommendations.

Recommendations for clinical practice

One goal of this research was to inform provision of information and training about voice banking to plwMND, significant others, SLTs and other professionals. The following recommendations are made in the context of the limitations of this research already described.

Education and information provision to aid informed choice making: It would be helpful for professionals working with plwMND to provide information about the progression of the condition and the range of options for communication if and when natural voice deteriorates. It is important that this includes the opportunity to listen to a PSV when considering voice banking to assist in helping plwMND understand the differences between natural voice and a PSV.

Demonstration of the practical aspects of voice banking: When considering whether to voice bank, professionals could provide information about how voice banking is used through AAC - that a PSV is really an element of AAC. The availability of professionals to advise and support people regarding AAC has been shown to improve AAC device uptake (Baxter et al., 2012). One option is for SLTs or other professionals to demonstrate voice banking and how AAC is used at the same time.

Timing of discussions: The development of guidelines for professionals for how and when to discuss voice banking would be helpful. Some plwMND did not wish to consider voice banking while their natural voice was unaffected, while others reported frustration that they had not been told early enough to be able to complete the process with their unaffected voice. Considering how to provide skills for SLT's to have confidence in managing these difficult discussions and judging the timing of them is critical for plwMND. Development of a training workshop may be considered.

Development of an online video education tool: Some plwMND expressed frustration at the lack of clear information from professionals. Other research has indicated the anxieties within professionals with having discussions with plwMND about the sensitive nature of voice loss. The MND association has a website that provides information and support to plwMND and a brief online educational tool that would enable the wider family of a plwMND to understand the critical points for decision making (as they may not be at appointments with professionals) and to enable the plwMND to understand the points in their own time.

Recommendations for future research

Future research to include professionals such as SLTs and associated stakeholders, would enhance the strength of any recommendations.

An area for future research could be to explore the vulnerabilities of plwMND in relation to data protection and security risks posed by both authorised and unauthorised use of a PSV, particularly as the quality of PSVs is likely to improve over time as technology changes. Research could also be considered to understand the potential for a PSV to control devices in the local environment, perhaps by activating a virtual assistant or another method. Environment control (EC) can enhance independence and improve quality of life by enabling control of frequently used devices such as a television, computer, lighting and 'plug-in' electrical appliances, as well as door entry intercom and access (DH Long-term Conditions NSF Team, 2005; Regional Environmental Control Equipment Service, 2018).

Given that plwMND are a significant consumer group for voice banking, further research may be helpful to understand how accessible and inclusive the process of

voice banking is for plwMND and potentially to support suppliers to make their products easier for plwMND to use. Even if a service is accessible it is also important that the system can be understood and navigated easily, effectively and efficiently (Combe, Harrison, & Dong, 2013).

Finally, some plwMND and significant others felt that communicating using a PSV may help to maintain social and family relationships and give positive psychological benefits, this would also an area for future research.

This study has made a novel contribution to understanding the reasons why plwMND decide whether or not to voice bank. The research data indicate that preservation of identity is of primary importance to plwMND who decided to voice bank as well as to those who decided against this and their significant communication partners. SLTs already have a professional role to educate and support plwMND when deciding whether to voice bank and development of guidelines for professionals working with plwMND when considering voice banking may be useful.

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Question Sheet for Semi-Structured interview with people living with MND and significant communication partners

XXX Research Ethics Committee Approval ID Number: **12607/001**

Voice Banking: Yes or No? What people living with motor neurone disease consider when deciding to voice bank, and what their expectations are

Introduction

Voice banking is a method of creating a synthetic approximation of a person's own natural voice. It can be used in a communication device if natural speech becomes unclear or cannot be understood.

We would like to learn more about what people living with Motor Neurone Disease consider when deciding whether or not to bank their voice, and what they and their significant communication partner's expectations are from it. This interview will help us understand your views on voice banking. The results will be used to understand how to improve the information provided to people living with MND about voice banking and the training of professionals working in this area.

There are no right or wrong answers, we just want to understand your views.

- 1. What do you think about voice banking?**
- 2. What would you say the benefits of banking a voice are?**
- 3. What would you say the drawbacks of banking a voice are?**
- 4. If a person found it difficult to use natural speech, how much would a banked voice make up for it?**
- 5. What do you think would be the same or different if a person used their banked voice compared to a 'standard' synthetic voice?**
- 6. How do you think family or friends may respond to a banked voice compared to a standard voice?**
- 7. How do you think professionals may respond to a banked voice compared to a standard voice?**
- 8. How important is banking a voice compared to everything else a person living with MND needs to consider?**
- 9. How important is banking a voice compared to everything else a significant other to a person with MND needs to consider?**
- 10. Do you have any further comments or views?**