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“Ode to Confidence”: Poetry Groups for Dysarthria in Multiple Sclerosis

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Abstract

Purpose: Approximately 40-50% of people with Multiple sclerosis (MS) have dysarthria impacting confidence in communication. This study explored how people with MS experienced a novel therapeutic approach combining dysarthria therapy with poetry in a group format.

Method: Participants were recruited through MSWA (formerly known as the Multiple Sclerosis Society of Western Australia), a leading service provider for people living with all neurological conditions in Western Australia. They attended eight weekly sessions led by a speech pathologist and a professional poet. The study was co-designed and qualitative, using observational field notes recorded during sessions and semi-structured in-depth interviews with participants after program completion. The results from an informal, unstandardised rating scale of communication confidence, along with standardised voice and speech measures, were used to facilitate discussion about confidence in the interviews.

Result: Nine participants with MS completed the group program. Analysis of the qualitative data revealed participants' positive views regarding the pairing of speech pathology and poetry. Thematic analysis identified four core themes: living with MS and its "series of griefs"; belonging to a group – "meeting with a purpose"; the power of poetry; and poetry as a medium for speech pathology.

Conclusion: Poetry in combination with dysarthria therapy represents a novel, interprofessional approach for improving communication confidence in individuals with MS.

“Ode to Confidence”: Poetry Groups for Dysarthria in Multiple Sclerosis

Multiple sclerosis (MS) is a chronic, progressive autoimmune disease causing inflammation within the central nervous system leading to degradation of the myelin sheaths surrounding neurons (Nylander & Hafler, 2012). This demyelination results in the formation of plaques which disrupt nerve conduction with varying consequences depending on the site of lesions (Nylander & Hafler, 2012).

One of the common consequences of MS is dysarthria, a motor speech disorder resulting from neurological damage to the efferent pathways which innervate the muscles associated with speech production (Duffy, 2013). Dysarthria has been found to affect between 40% and 50% of individuals living with MS (Duffy, 2013; Hartelius, Runmarker, & Andersen, 2000; Ruzs et al., 2018; Yorkston et al., 2003) and presents as a range of auditory-perceptual characteristics, often consistent with lesion locus and with variable impact on intelligibility (Darley, Aronson, & Brown, 1969). Ruzs et al. (2018) found dysarthria secondary to MS to be predominantly of the mild-moderate spastic-ataxic type, characterised by monopitch, slow rate, articulatory delay, excess loudness variation, pitch fluctuation and imprecise consonants. The level of impairment does not necessarily correspond with the perceived impact on quality of life (Hartelius, Elmberg, Holm, Lövberg, & Nikolaidis, 2008; Piacentini et al., 2014; Walshe & Miller, 2011). Therefore, it is not uncommon for individuals with no discernible signs of dysarthria or only subtle changes to their speech and/or voice to experience a restrictive effect on communication (Walshe & Miller, 2011; Yorkston et al., 2007a).

Perceived alteration to an individual’s communicative ability has been found to impact psychosocially in relation to confidence, frustration and reliance on others and often precedes clinically measurable impairment (Walshe & Miller, 2011). Conversely, some

individuals with significant changes to their communication may remain unaware and consequently, minimally impacted with regards to quality of life (Yorkston et al., 2007a). Interestingly, Klugman and Ross (2002) found in their study of 30 individuals with MS that despite 62% of respondents identifying themselves as having communication problems impacting on their quality of life, none had received intervention for these difficulties.

Traditionally, management for dysarthria has focused on promoting strength and precision via oral motor exercises (Hodge, 2002), encouraging effective respiration (Spencer, Yorkston, & Duffy, 2003), managing speech rate and prosody (Yorkston, Hakel, Beukelman, & Fager, 2007b) and increasing intensity (Sapir et al., 2003). More recently, clear speech, which requires that speakers moderate their speech rate whilst enunciating speech sounds purposefully, has been found to be effective (Park, Theodoros, Finch, & Cardell, 2016). Tjaden, Sussman and Wilding (2014) looked at the impact of clear, loud and slow speech on intelligibility in people with mild dysarthria due to both MS and Parkinson's disease. They found that being loud and clear were more effective than slow for both groups. These aspects are commonly reflected in clinicians' approaches to dysarthria therapy generally but there are some variations with aetiology of progressive dysarthria. In their survey of practice completed by 119 speech and language therapists in the UK, Collis and Bloch (2012) found that the three most common interventions with clients with MS were general rate/volume/prosody work; conversation/interaction adaptation; and addressing functional communication. More work on individual speech subsystems was found with Parkinson's disease, a focus on augmentative and alternative communication in motor neurone disease, and more attention to communication partner skills in Huntington's disease. In addition, the authors found less experienced clinicians tended to focus on impairment level work while experienced clinicians more on functional work and holistic approaches.

Dysarthria therapy has conventionally relied on generic therapy tasks such as reciting word lists or tongue twisters which can result in clients feeling self-conscious and even foolish (Brady, Clark, Dickson, Paton, & Barbour, 2011). Interest and motivation are central to learning (Schmidt & Lee, 2011) which attests to the importance of using stimulating therapy materials for practising speech (Park et al., 2016). Additionally, motivation is deemed essential for promoting adherence to therapy (Haneishi, 2001) and Yorkston (2007) has emphasised the importance of salient therapies which include communicative participation for individuals with degenerative dysarthria. In this vein, researchers have explored singing as a vehicle for a range of motor speech disorders (Wan, Rüber, Hohmann, & Schlaug, 2010), including within a group choral format, with measurable improvements in speech production reported (Azekawa & Lagasse, 2018; Fogg-Rogers et al., 2016; Haneishi, 2001; Hurkmans et al., 2012; Tamplin & Baker, 2017).

Interestingly, while singing features as a therapy approach in dysarthria, poetry currently does not. A search of the research databases CINAHL, MEDLINE, PsycINFO and Web of Science conducted in September 2018, using the search terms “dysarthria” AND “poetry” yielded no results. Broader scoping searches of the literature also failed to reveal any research relating to the application of poetry for the treatment of motor speech disorders. This is despite poetry sharing obvious vocal, rhythm and word choice features with singing, and having aspects in common with dysarthria therapy. Figure 1 summarises common elements found in the spoken delivery of poetry which also feature in dysarthria therapy. As noted previously, dysarthria therapy often encourages a slower rate, clear, over-articulated speech, awareness of prosody, particularly intonation and emphasis, and increased volume. Similarly, poetry recital generally emphasises a rhythmic line, stressed words and speech sounds, most obviously with rhyme, but also with alliteration, alongside increased volume. Shafi and Carozza (2011) suggested poetry therapy in the form of reading and reciting may

help clients with impaired articulation to speak more fluently. The regulated pace and rhythm of poetry may encourage people with dysarthria to articulate more deliberately than regular speech (Norton, Zipse, Marchina, & Schlaug, 2009). Fujii and Wan (2014) emphasised rhythm as particularly significant for speech and language rehabilitation. Speech motor control may be improved via rhythmic speech entrainment, the connecting of speech movements to rhythmic auditory stimuli by a model speaker, a promising therapy for people with dysarthria (Späth et al., 2016). Additionally, listener judgements of intelligibility may be assisted by anticipating rhyming words, or by hearing repetition of key words during poetry.

[Insert Figure 1 here]

Whilst there is a lack of evidence for the use of poetry in the treatment of motor speech disorders, poetry therapy has been applied widely in other therapeutic contexts (Heimes, 2011), for example, with schizophrenia, enabling creativity and personal insight through writing poetry (Shafi, 2010). Poetry has been used for dementia (Hagens, Beaman, & Ryan, 2003), depression (Furman, Downey, Jackson, & Bender, 2002), for individuals following attempts at suicide (Stepakoff, 2009), and in palliative care (Gardner, 2006). Poetry intervention delivered through a group format has been found to promote personal wellbeing, social interaction and the formation of supportive networks (Hilse, Griffiths, & Corr, 2007). Group cohesion may be further enhanced in poetry workshops via the inclusion of collaborative poetry writing (Golden, 2000) with poetry improving mood through self-expression (Czernianin, 2016). Within speech pathology, poetry therapy has been implemented for the treatment of aphasia (Shafi & Carozza, 2011). Pinhasi-Vittorio (2007) found in his case study of a young adult with expressive and receptive aphasia that writing poetry enabled the client to express himself despite limited verbal communication. The benefits of using poetry therapeutically are in line with a review of the effects of combining

the arts and health (Tesch & Hansen, 2013) which found elevated self-confidence, increased creativity, improved perceptions of health and reduced social isolation.

This paper describes a project involving the delivery of a series of combined speech pathology and poetry workshops for people with dysarthria due to MS. It builds on the properties of poetry (Figure 1) which present an authentic opportunity for the application of speech therapy techniques and principles of traditional dysarthria therapy (Palmer & Enderby, 2007; Spencer et al., 2003; Yorkston et al., 2007b). In particular, this project sought to use the poetry workshops to explore several innovative approaches to working with people with MS: to be co-designed, strengths-based and authentic; to be relevant and salient, noted as important for motor learning (Ludlow et al., 2008); to incorporate interprofessional practice through the speech pathologist collaborating closely with a professional poet; and to highlight communicative confidence as a goal. Therefore, the purpose was to investigate: the impact of the poetry intervention on communication confidence for people with dysarthria due to MS; how participants reflected on poetry as a medium for dysarthria therapy; and how they viewed poetry within a group workshop format. While pre-post measures of speech and voice were collected, this is was not a treatment study evaluating the impact of the intervention on speech and voice production as there was no control group.

Methods

This study was approved by the Human Research Ethics Committee from Edith Cowan University and from MSWA (formerly known as the Multiple Sclerosis Society of Western Australia), a leading service provider in Western Australia for people with all neurological conditions. The qualitative approach involved interviews and observation during sessions to explore the experiences of participants attending the poetry workshops. The pre-post quantitative measures of speech, voice, and confidence, are presented here to help

describe participants and gauge trends. They also provided useful information to facilitate discussion about the experience of being in the group during interviews.

Features of the co-designed group program

The co-design involved two planning meetings with four individuals with MS to help shape the focus of the program, and ongoing discussion and feedback. The co-designers worked with the research team on the recruitment flyer, chose the name of the group (“Ode to Confidence”), and advised on practicalities about when and how it should run, and the content (Bate & Robert, 2006). For example, they suggested a change to the scheduling of sessions from twice weekly one hour sessions to once weekly two hour sessions to be less disruptive to participants’ other appointments and commitments. Co-designers also requested morning sessions and the provision of a morning tea midway to combat fatigue. Two other important issues raised in this process were that the poetry group should be open to people with MS who wished to come even if not currently receiving dysarthria therapy (considering people with MS themselves may be aware of speech and voice changes which professionals might not consider sufficiently intrusive to warrant speech pathology services), and that the facilitators should not assume a focus on MS or disability in the content of the poetry program. The planned speech pathology and poetry topics for each week are illustrated in Figure 2. The weekly format was that both speech pathologist (third author) and poet (fourth author) were present for the entire session but the first half was spent focusing on speech and voice, and the second on a poetry topic. Morning tea provided a natural break between the two halves, but they remained linked due to regular guidance and prompting from the facilitators to apply speech and voice-related strategies to the poetry sections where relevant. Interestingly, group members also commented and encouraged each other in relation to how the poetry sounded (for example, to slow down, speak louder, include emotion). Each participant was given an individual file with resources added weekly to assist memory of

what had been covered. The final week was only loosely split between the speech pathologist and poet, focusing on summarising the program and providing feedback on performances of poems to each other, including those that participants had written. [Insert Figure 2 here]

Participants and setting

Participants were recruited through MSWA. Participants all had a confirmed diagnosis of MS as assessed by a neurologist working for MSWA and all had at least some self-reported mild changes in speech or voice (and some self-reported in language). These had not necessarily led to offers of therapy (one person had recently completed a block of dysarthria therapy and another was referred) but changes were either noticeable to the participant or to a communicative partner. Participation was open to anyone of any level of severity of MS who wished to enhance communicative confidence, voice and/or speech clarity. Recruitment was via an emailed promotional flyer to members listed on the MSWA database, MSWA social media sites, notice boards and in organisational publications. Eight women and two men initially joined up but one of the men had to withdraw from the study due to personal circumstances following the first session. This meant that all but one of the participants were women. The poetry group ran for eight weeks, once a week for two hours in a leisure centre local to MSWA. Pre and post assessments, and interviews, were conducted in participants' own homes or at the MSWA site according to preference. Pseudonyms were developed for all participants. Table 1 contains participant information.

Data Collection

Semi-structured interviews formed the primary focus of this study. These lasted about an hour, and were framed in line with the following topic guide: introduction by opening with experiences of living with MS; any concerns specifically around speech or communication; experiences of taking part in the poetry group (with prompts to comment on different aspects,

such as the balance of speech pathology and poetry, or feelings about poetry writing or performance; or what elements were considered important); whether anything has changed as a result of attending the group; if attending again, what would be the suggestions for changes; and finally, any other comments. Field notes collected during the “Ode to Confidence” program by the first author (who was not part of the program delivery) were completed to contextualise interview data and allowed observations relating to socialisation, level of engagement and contributions made during sessions. Original works of poetry represented additional qualitative data (Fraser & al Sayah, 2011).

In order to have an understanding of each participant, quantitative measures were selected to complement the qualitative data, with assessments carried out six weeks prior to the group starting by the first author, and then again two weeks after, at the same time as the post-program interviews. With the small sample size in this study, the aim was not to establish the efficacy of the intervention conducted, but to check for any trends in changes to the speech, voices, and particularly confidence, of participants. Assessments and interviews were audio recorded using a digital voice recorder. The measures were: the Frenchay Dysarthria Assessment Second Edition (FDA-2) (Enderby & Palmer, 2008), to get a sense of dysarthria severity; the Consensus Auditory-Perceptual Evaluation of Voice (CAPE-V) (Zraick et al., 2011); The Voice Handicap Index (VHI-10) (Rosen, Lee, Osborne, Zullo, & Murry, 2004) which is compatible with the CAPE-V and provides insights into the perceived daily impact of each participant’s voice; and finally, a simple confidence rating scale. This was devised for this study in the absence of a scale specifically for measuring communication confidence in motor speech disorders and it consisted of a line with points from one (not confident) to ten (very confident). Similar scales have been used for measuring communication confidence (Cameron et al., 2017; Cherney, Babbitt, Semik, & Heinemann, 2011). CAPE-V ratings were also completed by an additional clinician who was blinded to

participants' identity and the timing of recordings (pre or post) to promote internal validity. Inter-rater reliability was evaluated using a two-way mixed effects, consistency, single measurement intra-class correlation coefficient (ICC) to determine the consistency of assessors in scoring overall dysphonia severity. Assessors had a high level of agreement for the rating of dysphonia using the CAPE-V, $ICC = .98$.

Data Analysis

Audio recordings of interviews were transcribed verbatim. Care was taken to include non-verbal aspects, such as facial expression, or shrugs, to help guide interpretation of the exchange. Qualitative analysis of interview transcripts and field notes used thematic analysis (Braun & Clarke, 2006) with data managed through NVivo 11 software (QSR International, 2017). A framework of themes and sub-themes was created following familiarisation, initial coding and reviewing of themes. The research team discussed results in order to reach consensus regarding coding and development of themes and sub-themes.

Regarding rigour, *credibility* and *confirmability* of findings involved member checking (Lincoln & Guba, 1985) both at the time of interview through verification of responses with the participants, and also during a follow-up meeting with participants at MSWA where a brief summary of findings was presented for feedback. This summary also assisted those with memory deficits which are common in MS. Triangulation was achieved via the inclusion of interviews and observational data in a field journal, collected over the eight weeks of the program. In view of the need to avoid researcher bias and maintain researcher reflexivity, this field journal provided an audit trail and increased transparency of the analysis. The prolonged engagement of the researcher (first author) with the group helped with understanding the context and assisted with building trust with participants (Lincoln &

Guba, 1985). Additionally, approximately 30% of transcripts were checked for accuracy by the second author who was not directly involved in running the program.

Results

Nine participants attended the full program and participant attendance was 88% across the eight sessions. This is an important result given the effort required to attend for many participants.

Thematic Analysis

Analysis of participants' interview transcripts and field notes revealed four key themes, each with several sub-themes (See Figure 3). [Insert Figure 3 around here]

Theme 1 – Living with MS and its “series of griefs.”

A step-wise sense of loss was a prevailing theme when discussing living with MS and the consequences of the condition: “I always think of it as a series of griefs as I lose something which I used to be able to do” (Anna). The continually evolving symptoms of the disorder and the need to adapt constantly to coincide with one's current level of ability were evident for many. Jen remarked: “So I guess the thing that characterises that period of my life is having to adapt... It's not being able to participate in things without consideration of my disability.” Participants talked about attempting to make sense of the disease's progression and identify patterns to establish external influences that aggravated their condition. Janet reported: “I feel like I'm a medical encyclopaedia all the time because it tends to trigger off one thing and then another thing and it's all got to do with trying to understand the concept of it all.” Another participant, Caitlyn, also captured the efforts to understand and predict the *muddle* of MS:

You know, you try to eat right and try and do exercises and you try to do all these things to try and prevent it going, progressing but just as I don't know why it started in the first place, I don't know what to do to stop it for sure so you muddle along knowing that.

Three sub-themes were evident: *changes to communicative ability, social impact of MS / lack of communication opportunities* and *relinquishing control*. Participants had a variety of concerns relating to their *communicative ability*, highlighting the multifaceted impact that MS has on communication. These included the changes to volume and not conveying their message clearly: "... I went out with friends to a lovely bar and I could barely make myself understood. People were constantly saying 'what was that?' You know, and that's a huge change for me" (Anna). Reflection on how deterioration of their verbal communication might affect them in the future was apparent and confronting for those that acknowledged it. Trish used humour to highlight her fears regarding the potential decline of her communicative ability. Referring to other residents in the aged care facility in which she resided, she said: "...I thought if I don't learn to speak clearly soon I'll just be like the rest of them and become an inarticulate source of smells (laughs)". Diane described similar deep-seated concerns which linked her communicative ability with her self-identity:

Yeah, I mean that is one thing that I was always fearful of with my MS that my speech be taken from me because that would be the end of me. Because I like talking too much (laughs). I'd be devastated.

Several participants noted difficulties with language and cognition: "I can't find the words, I've got them up here but it's just trying to communicate out, that's the thing and also too I get very confused" (Janet). Although the project was focused on confidence with speech and voice, the group represented an opportunity to address feelings about deterioration of

their communication more broadly. Participants described *lack of communication opportunities* following the diagnosis and progression of their illness. Trish ascribed this to the stigma of disability: “So many of my friends disappeared when I went into a wheelchair... Why does that happen? People get embarrassed and you sort of think ‘it’s not contagious.’ But it happens.” Caitlyn associated her lack of social opportunities with no longer sharing common interests: “Because I can’t keep up with the social things I used to do, I can no longer do and so you fall by the by.” For Anna, her reduced social activity was due to practical constraints: “...I’m finding for example all my friends in this area... I can’t get into their houses. So I’ve had to stop visiting people because I can’t get up the front step (laughs).” In turn, less socialising meant limited opportunities for interacting with others with implications for communication proficiency. Trish described the effect this had on her conversational skills: “... and because I was so hermyty (sic), I would often speak to a visitor and worry about every word I’d chosen...” For Anna, limited participation in discourse made communication more arduous when the opportunity arose: “And now also because I don’t talk a lot I find when I do talk it’s just that much more hard work.”

Relinquishing control and learning to rely on others and accept daily routines and living arrangements with limited control was considered a huge adjustment. This was particularly the case for Suzanne who was dislocated from family because of the need for residential care. She had also performed a caring role previously so the shift was very pertinent:

This is what I used to do for a living, I used to coordinate all the care like this and now I’m one of the people that uses it, even with the MS and stuff but I don’t need to tell anyone what to do anymore so it’s quite good that I can get what I need but I don’t like it because I’m not with my husband. (Suzanne)

Caitlyn also described the difficulty of adapting to a new role in which she received assistance instead of provided it:

...I always feel like I should be up helping other people because there's other people worse off than me and I immediately want to move back into that helper nursing role. I have to pull myself back from that but you know I find it really strange to be looked after.

Theme 2 – Belonging to a group “meeting with a purpose.”

Participants identified a sense of purpose in attending the workshops which provided direction and the opportunity to connect with like-minded individuals over shared interests.

Suzanne stated: “It gave me a reason to go out every day, to go to that every Tuesday...”

Caitlyn described the value of having a specific focus within a group: “...it's good to be socialising with a purpose not just sitting around gawping at each other and going, you know, what do we talk about?”

The social aspect was important for many given that access to social gatherings was often difficult. For some, the poetry group simply represented a break from the norm and the freedom of “getting out of the house” (Dave). For others it was the acceptance associated with belonging to a group: “... everyone's there for the same reason like, yes, everyone's got MS...you can feel like you belong somewhere” (Suzanne).

Sub-themes were: *gaining perspective on one's own condition, importance of a “safe space” and motivating effect of commitment to a group.* Considering the disease progression in MS varies greatly, the workshops enabled participants to compare their level of functioning with that of others with MS, and this provided *perspective on their own condition.* Generally this was constructive and allowed participants to look for the positives in their own situation, as Suzanne said: “Because everyone's different and you get to know

different things about other people and then you think oh you're not that bad, you know?"

Lisa described feeling grateful that MS had not been more detrimental to her:

... I constantly thank God or whoever or whatever that I do not have it as bad as it can be... I have seen how bad it can be, you know. And I mean I complain about my mobility which I've got equipment to help me and whatever but I can walk. You know, I have to see that because otherwise I'll... I'll dement myself.

However, for some of the more able bodied participants these comparisons led to feelings of uncertainty and the fear of decline with no sense of control:

I do find there's a part of me quails and thinks "oh my God, oh my God, my God I'm not going there, I'm not going there!" Because I know very well that part of the disease process that it may, you know something may tip and I never know what for sure to do to prevent that. (Caitlyn)

Integral to the success of the poetry group was the *provision of a safe space*. For participants this meant physically in terms of access and facilities: "... because when you go to the MS society there's rails and the floor's level and the toilets are right" (Anna). However, this also extended to feeling "safe" emotionally in terms of sharing poetry and being open to receiving feedback. Jen described her feelings around sharing poetry within the group:

There's a hint of nervousness about how it's going to be received but there always is when you share something original, I think. But it felt safe; it felt like a safe space to do that. I didn't expect anyone to say 'oh that was horrible' or anything like that really, yes so that was good.

The shared experience of having MS and the appreciation of what this meant contributed to the feeling of safety: “Because, they had MS too... So I wouldn’t be judged” (Caitlyn). There was also a sense of relief in not having to explain oneself constantly:

... I didn’t have to make any excuse, like with some people, with some of my friends I’ll say “oh don’t worry about it I’ve got MS” or whatever but you know I didn’t have to do that. I just was able to be myself. (Lisa)

The environment was considered to be nurturing and supportive which encouraged even initially reticent participants to make contributions within the workshops: “... what I thought was great was no one criticised each other, everyone praised one another and that was beautiful, yeah really beautiful” (Janet).

Despite declaring an interest in writing and having a range of experience relating to the literary arts, participants acknowledged that it was the *commitment to the group* that motivated them to write: “...it’s just something I sort of enjoy but don’t really have the motivation to do on my own” (Diane). Jen also felt that the group acted as a motivator to go back to writing: “I have dabbled in writing off and on over the years, not recently, and that’s probably one of the things I enjoy about the group is that it pushed me, or encouraged me to write.” Participants prioritised their writing over day to day activities because they wanted to share an original piece at an upcoming group:

... the fact that we were given something to achieve for the next week which you know, it’s been a long time since I’ve done (laughs) homework. But that was good because it forced me to sit and concentrate on one thing. (Anna)

Additionally, commitment to the group was enhanced by respect for the group’s professional poet, Maddie Godfrey (fourth author), and the enthusiasm she generated in poetry. Jen spoke of how Maddie inspired her to write:

I think largely Maddie's participation, it was a great incentive. I just thoroughly enjoyed her, listening to her, chatting to her at the break about her experience of writing. And it didn't seem unachievable...

Theme 3 – The power of poetry.

Participants spoke of their personal experience of writing and sharing poetry within the group and the associated benefits. Creative expression had a cathartic effect in alleviating some of the emotional pressure participants had internalised. Suzanne said: "... it just made me able to speak about something that's gone on in my life and I don't speak to anyone about that except my counsellor ... It's just a way to get things that you need to say and get it out there." Sub-themes associated with the power of poetry were: *forgetting about MS*, *receiving feedback* - "*applause*", and *confidence*. Regarding the first sub-theme, the focus on poetry diverted participants' attention, albeit temporarily, from their condition, making them "feel like a normal human being" (Suzanne). Anna observed: "It was something different and something separate from the MS" (Anna). This reflected the directive from the co-design group that the content should not be assumed to be about MS. Poetry was a welcomed distraction which enabled participants to distance themselves from the minutiae of daily life with a disability. Anna exemplified this effect by saying that the poetry was:

...one thing apart from 'What are we going to have for tea tonight?' I spend a lot of time with carers and talking to people I don't particularly want to talk to about stuff I don't really want to talk about...

Receiving feedback, especially from the group's poet, was strongly valued by participants: "It was nice to get a bit of input into what Maddie said and you know with her being a published poet and everything" (Diane). Participants enjoyed the opportunity to discover or reaffirm their flair for composing poetry, an ability that remained relatively intact:

... I didn't realise that I had that ability to write, that sort of thing because I've always been very fearful of it because my grammar's never been that perfect but when I got the feedback from her... I just thought "wow, okay"... (Janet)

Self-esteem was enhanced through writing pieces that were valued by others as measured by the acclaim or *applause* that was received: "Well when you've got somebody saying 'this is really good' and it's something that you did, then that does help" (Lisa). Anna also acknowledged the influence of receiving recognition: "It is uplifting and not everyone responds to it. I'm sure that even... my sister would not like to be recognised whereas I prefer that people have noticed (laughs). In a good way... I need the applause."

The third sub-theme of *confidence* appears closely linked with receiving "applause" as this led to improved self-esteem which elevated confidence. However, confidence was addressed separately by participants and was often commented on in relation to others or the group collectively as opposed to the individual's own level of confidence: "Well I think that confidence is a big thing, I think that people in a group like that do get a chance to you know develop some confidence speaking in front of people" (Jen). Janet linked feeling more confident with receiving feedback but felt it was also due to there being no fear of criticism: "... she wasn't critical with our work or anything, she allowed us to be free and that's where I felt more confident." Lisa noted: "... confidence builds on itself... you go in and you don't feel very good about anything or about life or whatever, and then slowly, slowly..." Other participants noted a change in Lisa in their interviews and identified her specifically as exuding more confidence, for example, with Trish saying: "she blossomed like a flower". Research field notes taken during the workshops further support Lisa's growth in confidence. During an early session, Lisa had said: "I don't have the confidence to read poems to the group." However, in the final three workshops, Lisa shared original poems and made increasing contributions during the course of the program.

Theme 4 – Poetry as a medium for speech therapy.

Overall participants felt that the pairing of poetry with speech therapy made the principles of traditional therapy more salient: "... certainly tying it with speech therapy makes it more relevant" (Anna). However, for some participants, there was some confusion around the aims of the group and where their personal goals fitted: "Look the poetry was very gripping and extremely interesting and delectable to hear her (*Maddie*) doing it but most of us only want to sound good in the supermarket queue" (Trish). Others, like Lisa, found it difficult to pinpoint what was beneficial about the program:

...it's difficult to know whether it's the social aspect or whether it's the speech thing but all of it was really good. So I don't know enough to say "this particular thing is better than that." It was just fantastic. All of it, really, really fantastic.

Sub-themes relating to poetry as a medium for speech therapy were: *avoiding the stigma of therapy, flexibility of poetry as a medium, being reminded of the principles of speech production, intensity of practice and application in daily life*. Participants made reference to the *stigma* that they felt was attached to having speech therapy: "...I thought that's pathetic, speech therapy" (Trish). Part of what made the group attractive to individuals was its lack of association with a "therapy" label: "...it doesn't sound like I'm going anywhere to learn how to talk or anything like that..." (Suzanne). In relation to *flexibility*, poetry satisfied people in different ways. Some participants enjoyed the opportunity for creative expression through writing: "I found the creative side... being able to put together a poem... I found that was very stimulating..." (Anna). Jen outlined her priorities within the group: "First I think the writing... Umm, maybe the sharing but that's secondary I think for me." For others it was all about the opportunity to practise speaking or performing: "She didn't want to learn how to write a poem she wanted to learn how to say it clearly" (Trish, referring to another

participant). Lisa asserted: "...the sharing and speaking for me personally is paramount. I mean it's because my confidence level is... whatever the right word is... disgusting (laughs) and it definitely uplifted me and helped."

In evaluating the speech pathology component of the workshops, participants generally focused on the value of being "*reminded*" of the principles of speech production. For example, Caitlyn commented: "Just touching base again about the breathing, just renewing, refreshing, to remember to relax the shoulders and to breathe..." Anna also acknowledged the benefit of revisions: "...it was just a reminder... it's been such a long time for me..." Participants suggested that consolidating learning with regularly repeated exercises was an important consideration for future programs, especially in light of the cognitive issues that may accompany MS: "I enjoyed the exercises at the time but I found that I tended to forget what they were, you know, over the next few days and not remember to do them" (Jen). Janet suggested: "... if she's ever going to do it again... before you start any class start off with the breathing first and then finish with breathing." The need for *intensity of practice* was noted but varied with participants' different objectives within the group, whether to perform or to write. Those that prioritised improving their speech or the performance aspect of the workshops suggested more time be allocated to participants' poetry readings: "... I spoke to Suzanne and she felt the same... she wanted more speech" (Trish). "...I think it's important to not only hear their wonderful poems but to get on to your own stuff so you can be a performer" (Anna).

Finally, participants commented on how the principles of speech production could be *applicable to their daily lives*. Jen noted: "When you're just having conversation, you think about what you're talking about but not how you're talking." Suzanne said: "It makes me more conscious of what I'm saying and when I'm breathing and things like that so I'm more aware of what I need to do". For Trish: "It was the elocution... and the limbering up".

Caitlyn was impressed by the session that included straw phonation: “...that bit about the straw! I could hear the difference; feel the difference in my voice”.

Finally, Table 2 summarises the individual participant scores for all measures and the means for the pre and post assessments across the four measures. Considering the lack of a control group, statistical analysis of these results is not reported here, although there was a non-significant trend towards improvement following the program. [insert Table 2 here]

Discussion

This small, co-designed study explored how participants reflected on poetry as a medium for dysarthria therapy, and how they viewed receiving the intervention within a group workshop format. The four key themes and their sub-themes, developed through the thematic analysis of interviews and field data, provided insight into the experiences of the participants and demonstrated that the program raised more than comments on speech and voice clarity delivered alongside, and through, poetry. Participants spoke openly of change, loss and grief, fear for the future, coping and adapting. They acknowledged that a group such as this went some way to addressing their needs in terms of socialisation, support and acceptance, as well as providing supports for their speech and voice. They noted the safe space of the group, the chance to be somewhere without needing to explain their MS.

Overall, people spoke favourably about the program, and particularly about the opportunity to use poetry as a medium for therapy, to consider breath support, volume and clarity for the purpose of performance. Poetry was a relief from a focus on MS, and a way to consider speech and voice skills without the work being medicalised as therapy. Poetry worked to people’s strengths and allowed them to showcase their creativity, to receive *applause* in a context of loss, grief and uncertainty. There was a high rate of attendance suggesting that people were engaged and committed to the program and it also enabled an

opportunity for individuals with mild speech and/or voice impairments to receive an intervention not otherwise available or seen as necessary by health professionals (Klugman & Ross, 2002). Even with the diversity of the group, it appeared cohesive, with people commenting on each other in their interviews rather than only on themselves. The approach was useful considering the cognitive issues, such as memory and insight, which were clearly present when it came to the discussion of communication confidence. There was a distinct mismatch between how some people rated communication confidence and what was conveyed during interview. Trish, for instance, made impressive gains in communication confidence according to her pre and post ratings but made no acknowledgement of this during her interview. Trish was unable to recall rating herself in her pre-assessment and it is important to note the impact that cognitive impairment may have on self-report measures in this population.

In evaluating the benefits of amalgamating the arts with healthcare, this study's findings support those of Tesch and Hansen's (2013) review with participants reporting gains in confidence, creativity and social activity. Poetry writing was not originally a focus of the program as it was about poetry as a medium for dysarthria therapy, however for some participants, it proved a valued element of the program. Participants described diminished negative mood as a result of self-expression through poetry which is presented as a useful self-regulating initiative for people with disability (Czernianin, 2016). The creation of poetry went further than purely enabling individual self-expression and was also about helping and motivating others through the sharing of these pieces.

Interestingly, participants viewed their poetry readings as "performances" and avoided terms like "practice". Given the stigma that was associated with receiving speech pathology, avoiding clinical terminology and emphasising the performance aspect of a program such as this may promote its acceptability. Participation in "Ode to Confidence" has

increased the social networks of some individuals by introducing them to others with whom they share things in common, strengthening existing friendships and creating further social opportunities. For example, a small number of participants attended a book signing event held by the poet after the group finished. Additionally, a new writer's group has been established since the program ended following a request by participants. Arguably, MSWA and organisations like it, play a vital role in providing social opportunities that are accessible to people with disability. While these outcomes are somewhat removed from the original focus on dysarthria, they do demonstrate that speech and voice work can be embedded in authentic, social and engaging broader activities which may result in more generalisation and maintenance of communication than in traditional clinic based activity.

A clear limitation of this study was the imbalance of gender. Results may be more representative of women with MS than of both men and women. Numbers were small and all recruited through one organisation. The lack of a control group meant that statistically analysing pre-post differences on the quantitative measures of voice and speech was of limited value. Lack of measurable, significant change was not surprising given the size of the sample, relatively short duration and lack of intensity of the intervention, particularly within the context of degenerative illness. Co-designers did not want the group twice per week even though this was originally offered. Interestingly, there was a small trend towards improvement on all four measures, which was encouraging. However, this study is innovative and important in its focus on confidence in dysarthria, in its co-designed approach, and particularly through its novel inter-professional focus on bringing poetry and dysarthria therapy together as an intervention. Dysarthria techniques within poetry workshops represent an alternative to conventional treatment methods for dysarthria in MS. Such an approach may prove more motivating for clients given the sometimes unpopular nature of traditional dysarthria therapy (Brady et al., 2011) and the perceived stigma attached. The approach

reported here highlighted the joy of performance and self-expression even with dysarthria, and of contextualising speech and voice work in an applicable, social and authentic activity.

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Figure 1: Illustration of overlap between poetry and elements of interest in dysarthria therapy

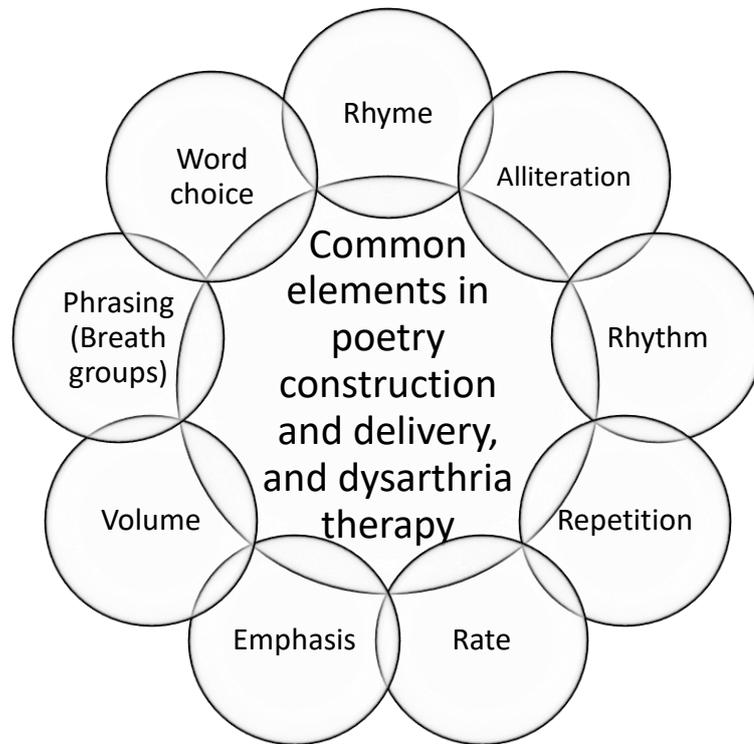


Figure 2: Structure of the Ode to Confidence program

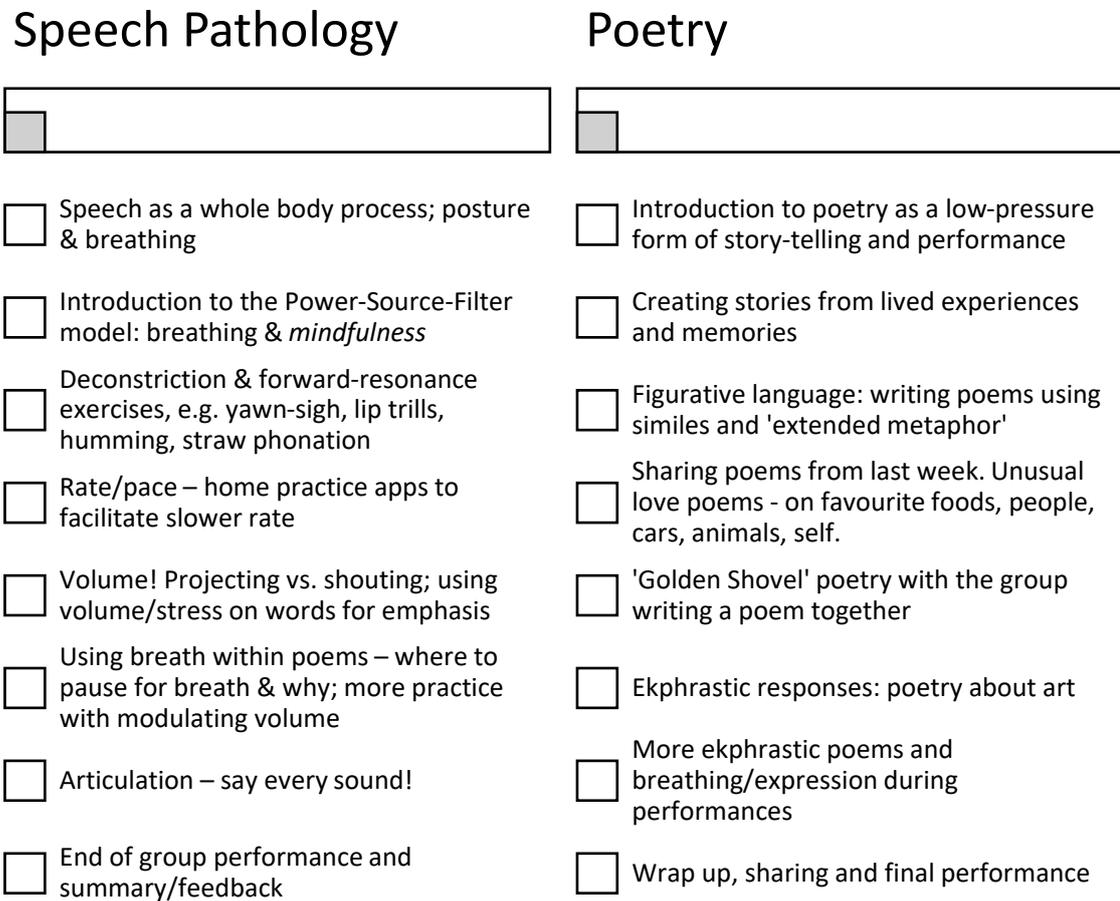


Table 1: Participant information

Person with MS	Gender	Age	Years since diagnosis	Mobility	Residence	Severity and deviant speech/voice characteristics
Caitlyn	F	63	22	Ambulant	Own home	Voice changes noted; low pitch
Suzanne	F	42	23	Wheelchair	Residential care	Moderate dysarthria; Strained voice, Soft volume, Poor breath support
Janet	F	49	14	Ambulant/ mobility aid	Own home	Self-reported changes not evident to listener
Diane	F	60	28	Wheelchair	Own home	Mild; strained voice quality
Trish	F	68	24	Wheelchair	Residential care	Moderate dysarthria; Imprecise articulation; slow rate; low pitch
Dave	M	61	23	Wheelchair	Own home	Severe dysarthria
Jen	F	56	30	Wheelchair	Own home	Very mild. Soft volume, reduced breath support
Lisa	F	52	17	Ambulant/ mobility aid	Own home	Mild dysarthria; more evident with fatigue / prolonged talking. Dysfluency
Anna	F	58	26	Wheelchair	Own home	Moderate dysarthria

Table 2: Measures of speech, voice and confidence before and after the program

Person with MS	Frenchay Dysarthria Assessment (FDA-2)* (Enderby & Palmer, 2008)		Consensus Auditory-Perceptual Evaluation of Voice (CAPE-V)** (Zraik et al., 2011)		Voice Handicap Index (VHI-10)** (Rosen, et al., 2004)		Communication Confidence Rating Scale*	
	Pre	Post	Pre	Post	Pre	Post	Pre	Post
Caitlyn	226	219	0	0	10	6	5	7
Suzanne	174	182	50	55	23	19	8	9
Janet	214	214	2	2	2	4	10	10
Diane	197	202	25	20	5	6	10	10
Trish	166	177	45	55	21	20	3	10
Dave	111	149	80	77	16	5	9	8
Jen	228	221	3	1	0	2	9	9
Lisa	213	227	4	2	13	4	5	7
Anna	188	188	45	40	21	16	4	5
Means across all participants	191.88	197.66	28.22	26.88	12.33	9.11	7.00	8.33

Note: * denotes a measure on which higher scores are favourable. ** denotes a measure on which lower scores are favourable.

The FDA-2 score was the sum of 26 individual items rated on a 9 point scale with 9 denoting normal function. The maximum score was therefore 234 (i.e. 9 x 26 attributes assessed), correspondingly an average score of 5 on each sub-test would result in a score of 130. Table 2 includes participants' pre-intervention FDA-2 scores and illustrates the variation in dysarthria severity amongst the group.

Figure 3: Ode to Confidence themes and sub-themes

