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Chapter 5. Case Report 4: A Better Conversations approach for people living with dysarthria

Abstract

In this chapter we report on the use of Better Conversations with Dysarthria (BCD) therapy featuring a man living with Parkinson's and his communication partner. A Better Conversations approach aims to help people with communication difficulties to have more enjoyable interactions. We outline the pre-post therapy assessment process, the intervention itself and highlight a specific outcome relating to responses to the communication partner's turns. We also present data on the acceptability of BCD. This is the first BCD therapy case to be published and as such provides an important reference point for future work in this field.

Abbreviations

BC – Better Conversations
BCD - Better Conversations with Dysarthria
CP – Conversation partner
LSVT - Lee Silverman Voice Treatment
SLT – Speech and language therapist

Introduction

In this chapter we present the case of Nick and Dorothy (pseudonyms). Nick is a man with Parkinson's and hypokinetic dysarthria characterised by reduced volume and pitch. He also has bradykinesia (slowness of movement). Dorothy is his conversation partner (CP). This case report follows the CARE Guidelines (Riley et al, 2017).

Better Conversations (BC) is an intervention designed for use by speech and language therapists (SLTs) to support people with communication difficulties to have more enjoyable

interactions in their everyday lives. It involves working in collaboration with these people, and their regular communication partners to identify their own priorities, to promote positive conversation strategies (facilitators) and to reduce any barriers that lead to problems. The therapy itself is based on a clear understanding of each couple's existing communication profile: what they find easy in conversation as well as areas that are challenging. The key principle is that conversations are highly individual to particular speakers. One-size-fits-all strategies are not as helpful as those tailored to the conversational style of the partnership. BC also recognises that strategies need to be the focus of therapy and not just add-on suggestions at the end of a session; practice and facilitated reflection are key. The starting point for the approach is an SLT's observation of a dyad's everyday conversations using recordings (audio or video) made in as natural an environment as possible. Such observations are used as a central part of the conversation assessment and as part of feedback in the therapy.

The case presented here is unique given that it is the first published account of the BC approach for people living with Parkinson's and dysarthria. We focus on one specific goal (responses to a CPs turns) and show how the participants' conversation behaviours change in line with the therapy objectives.

Key take-away messages for the reader:

- Conversation involves interaction between two or more people. Enabling conversations to work better means doing therapy with *both* the person with the communication difficulty and a key communication partner
- The Better Conversations approach to therapy starts with understanding how a dyad's conversation works and the dyad's own priorities for communication
- It aims to promote strategies that help conversations flow (facilitators)
- It also aims to reduce behaviours that hinder the flow of conversation (barriers)
- Feedback and facilitated reflection are key to making change

Narrative

Participant Information

Nick, a 72-year-old retired security consultant, living in the South of England, was recruited to a BCD feasibility study. Ethics approval was obtained from a UK National Health Service research ethics committee. Full consent was obtained as part of the recruitment process. Nick had been diagnosed with Parkinson's 10-years prior to the study and, at the time of recruitment, was classified as Stage 2.5 on the Hoehn and Yahr Scale. There were no reported co-morbidities. At the time of this study Dorothy was a 70-year-old woman, neuro-typical, having been married to Nick for 45 years.

Primary symptoms and concerns of the participants

In the previous 4 years Nick's speech had been characterised by hypokinetic dysarthria featuring significantly reduced volume and some slowness of articulation. There was also some loss of facial expression and slowness of movement and initiation. Nick's primary concern was not being understood, particularly in group settings but increasingly at home with Dorothy. Dorothy's primary concern was a perceived lack of response from Nick when she talked to him. She was unsure whether he always understood her or not, or if he was even interested in what she had to say. Hearing and vision were unimpaired based on patient report and observation.

History

There was no reported family history of neurological disorders and no reported mental health issues. Both Nick and Dorothy reported strong local community support through participation in the church and as active followers of a local football team. They had three adult children and four grandchildren.

Relevant past speech and language therapy interventions with outcomes

Within the 3 years prior to the BCD treatment Nick had engaged with one-to-one Lee Silverman Voice Treatment - LSVT® (Ramig et al, 2018) and also more general communication support in a local speech and language therapy group. He reported reasonable satisfaction with LSVT® but found the intensity and regularity of the sessions difficult. He

felt that his voice was louder during therapy but did not feel that this had generalised to everyday life. He found the group work enjoyable but did not feel it made a significant difference to his overall communication. Dorothy reported that the communication support group was helpful for her in terms of meeting other partners/carers. She felt that the LSVT® had been a considerable amount of work for Nick and had led to some fatigue.

Clinical findings

Parkinson's confirmed by the local neurologist following a neurological examination and a trial of levodopa.

Assessment

Pre-therapy assessment

Nick's speech was classified by the first author as demonstrating moderate to severe hypokinetic dysarthria. He was difficult to understand in conversation. Intelligibility was measured using the Assessment of Intelligibility of Dysarthric Speech (Yorkston & Beukelman, 1981). The results revealed 40% intelligibility for single words, 63% intelligibility for sentences.

A conversation baseline measure was taken: a video recording of the dyad engaged in conversation at home. The dyad was asked to talk about their day-to-day plans and activities with no pre-set conversation topics. The SLT set up a standard digital camera on a tripod, started the recording and then left the room, returning to turn the camera off. The dyad recorded themselves in conversation 30 minutes before therapy, and 30 minutes after therapy.

From the recording a number of barriers and facilitators were identified by the SLT. These are summarised in Figure 5.1.

>Figure 5.1 here<

From a pre-therapy interview Dorothy's primary concern was a perceived lack of response from Nick when she spoke to him. Nick did not show the same level of awareness but was concerned about the potential impact of his communication problems on Dorothy. A review of the pre-therapy video did provide evidence for how Nick was responding to Dorothy. This was particularly apparent for what we call assessments or evaluations initiated by Dorothy (e.g. expressing a positive or negative opinion about someone or something). If Dorothy expressed a view about something in conversation there was often a next turn opportunity for Nick to share his own view or stance (see Pomerantz, 1984) but what followed was often a lengthy silence. It was not the case that Nick never spoke or never gave an opinion but that he did so far less often than might be expected. This absence of responses by Nick is illustrated in Figure 5.2 below (see '→' for specific turns where a next turn response might be expected).

>Figure 5.2 here<

A review of the video recording identified 13 'evaluative' instances. All 13 featured Dorothy making an evaluation or assessment that could be followed by an agreement or further evaluation/assessment by Nick. There was evidence of just 3 such next turns by Nick.

Post-therapy assessment

As with the pre-therapy session, a 30-minute video of the dyad in day-to-day conversation was recorded without the SLT present. This was followed by a semi-structured interview to discuss acceptability and feasibility of the therapy for the participants (see below for further details).

Additional assessments

Nick and Dorothy's perspectives were elicited through weekly written feedback during the BCD intervention and also in a post-therapy interview.

Therapeutic intervention

The BCD programme comprised six direct face-to-face treatment sessions. All sessions were scheduled according to the availability of the dyad and took place in their home to maximise natural interaction. Each therapy session lasted 90-minutes and took place approximately one week apart (+/- 2 days) over a six-week period. Total contact time was nine hours. The therapy sessions were delivered by the first author in the capacity of a research SLT with over 25 years experience of direct clinical and applied research work with people with progressive neurological conditions. Therapy sessions were filmed to provide a record of the delivery and content of therapy and to support programme evaluation.

The therapy itself, summarised in Figure 5.3 below, was designed in collaboration with a specialist SLT advisory group and informed by ongoing applied research work on dysarthria in conversation (Bloch, 2013, Bloch and Wilkinson, 2009 & 2011a and b, Griffiths et al, 2012). It was also informed by Better Conversations with Aphasia (Beeke et al, 2013).

>Figure 5.3 here<

Follow up and outcomes

Here we report two outcomes: changes in conversation behaviour as assessed through the post-therapy video, and participant report outcomes as assessed through the post-therapy interview.

Changes to conversation behaviours

Based on the post-therapy video we saw a marked increase in next turn uptakes from Nick, both for the specific area we targeted but also more generally. As this is based on a feasibility study we cannot be conclusive in reporting our behaviour change outcomes but there are

indications of a clear difference between the pre-post recorded conversations with reference to how Nick responded to Dorothy.

As stated, prior to therapy there were 13 'evaluative' instances. All 13 featured Dorothy making an evaluation or assessment that could be followed by an agreement or further evaluation/assessment by Nick. There was evidence of just 3 such turns by Nick.

Post therapy there were 12 evaluative instances. Six of these were initiated by Dorothy and six by Nick. In all six of those initiated by Dorothy, Nick followed with an agreement or further evaluation/assessment with no silence between turns lasting more than 1-second. See Figure 5.4.

>Figure 5.4 here<

Participant reported outcomes

Both Nick and Dorothy reported the therapy helped them to talk about the effect dysarthria was having on them as individuals and the influence of this on their relationship. Understanding and acknowledging their difficulties together was reported to help reduce barriers for them in their relationship.

***Nick**: It has not only helped us to communicate better it has increased my understanding of the effect my speech problems have on Dorothy.*
[Researcher: what's working well?]
***Nick:** Knowing that Dorothy understands how difficult it is for me to respond immediately to questions.*
***Dorothy**: But it was this feeling that he was disappearing almost. That he was less affectionate. He was inside - but it just wasn't demonstrated which is what he needed to understand - why I was how I was. But I needed to understand that as well and I didn't come to terms with that until we'd spoken to the SLT… I just don't feel that we have any barriers any more… Like all these simple things they mean quite a lot when you get them going. They make a difference.*

Nick and Dorothy explicitly mentioned appreciating feedback on the positive aspects of their communication, describing it as "*encouraging*" and "*needed*".

***Nick**: [The SLT] asked me how I felt and I said I was shocked at my non-reaction to anything, he pointed out that I did in fact react.*
***Dorothy**: And you instigated a change in conversation where you offered a different point of view in the conversation.*
***Nick**: Yes, he said I showed a reaction when people were talking - facially.*
***Dorothy**: You found that really useful didn't you. Not just useful but encouraging which you needed.*

Another outcome was one of self-awareness. With a core focus on feedback and self-reflection we saw an increased confidence in talking about communication in both the abstract and in relation to Dorothy and Nick's own lives. It became clear that they had never had this opportunity before despite having engaged in SLT over a period of years. The impact of this awareness become evident in some unexpected problem solving. Dorothy, for example, realised that Nick didn't necessarily have to be talking to show he was interested. This led to a self-generated solution whereby they would simply sit closer and hold hands whilst watching television. A seemingly small change that had a big impact on their communicative ease and emotional wellbeing.

Challenges to participation in the therapy

Dorothy and Nick noted that occasionally their engagement with the intervention was challenged:

***Nick:** I was extremely tired this week and my voice was week. Communication was difficult.*

***Nick**: I can't write so Dorothy had to go through my diary, which wasn't a problem.*

Adverse and unanticipated events

There was one adverse event to report. The BC approach has been developed with bespoke video feedback reflection as a key feature. This had been explained to the dyad as part of the

consent and pre-therapy introduction process. Despite this Nick's negative reaction to seeing himself on video was unexpected and something that required immediate intervention. This event did not prevent the programme from continuing but did alter the way in which the tasks were delivered. As a result of Nick's reaction, the planned video-reflection task was immediately adapted within the session to focus on the SLTs own analysis of the pre-therapy recording and also extended to enable Nick and Dorothy to reflect on how they were both communicating during the session itself.

Participant Perspectives

Nick and Dorothy reported that after the BCD intervention they were better able to cope with dysarthria. They reported benefiting from time spent on next turn uptakes as well simple strategies which improved intelligibility such as: a non-verbal signal, supporting comprehension with lip reading, slowing down and taking a breath. They also reported benefitting from the suggestion of a set-time in the evening for non-verbal communication - when speech was most difficult.

Dorothy: *The suggestion to sit together on the sofa at times during the day worked very well for us. The opportunity of non-verbal communication (touch, eye contact) was good and resulted in a reduction in the feelings of isolation and separateness.*

Dorothy described how spending time with Nick and the SLT together helped her to talk more openly about issues in their relationship relating to dysarthria, which they hadn't discussed before:

Dorothy*: With other systems you could have somebody just wanting to work on your voice. We've almost took it for granted now that there's nothing that's going to improve your voice now. We've almost got used to that. But being able to cope with it means talking to each other and with dysarthria that tends to get pushed in to the background.*

Dorothy*: It wasn't until we talked about it with [the SLT] that I put it into words and I had no idea about it. We're very good at talking to each other but we didn't manage that did we.*

Dorothy acknowledged that she had been feeling disconnected from Nick, because of his reduced responses. This was described by Nick as *"a revelation"* and led to practical problem solving for the couple. This is particularly interesting as Dorothy and Nick described their relationship as one with lots of positive communication: *"There are times when we've talked in to the night and gone to bed really late because we've just talked and talked and talked… We always have something to talk about don't we."* This, along with the comment from Dorothy above *"we didn't manage that, did we"* suggests that there is a need to explore communication and to problem solve even for couples who rate their own communication as positive and are experiencing speech difficulties which are "mild".

Discussion

A BC approach aims to identify and address areas that will make a difference to the everyday lives of people with communication disorders. It does this by working with participants to identify and promote facilitators that make conversation easier/more enjoyable and to reduce barriers that make conversation problematic.

Nick and Dorothy took part in a feasibility trial of BCD. The therapy approach, session plans and resources were developed to support a six-session programme. The therapy programme was designed to be flexible enough to respond to the overall needs of the participants and the moment by moment responses to the activities and ideas being presented.

The outcomes of this early work have been promising. The participants as well as the SLT found the experience rewarding and interesting. There is also evidence that a targeted approach can change the conversation behaviour of a person with Parkinson's.

A greater openness and knowledge around their own communication supported Nick and Dorothy to take a more reflective approach to their conversations together when faced with barriers. This is a useful outcome as the ability to reflect together on their communication is something they can continue to use to problem solve for themselves. It also suggests the understanding that their communication is a joint responsibility. Interestingly, this dyad also felt that they benefitted from reflecting on the programme in between sessions via the feedback forms. This could suggest that reflection is applied more readily by some couples

and it may be that others require support to reflect or understand how reflection could benefit them.

There were two important issues that had not been expected. The first was Nick's reaction to seeing himself on video. The BC programme had been developed with bespoke video feedback reflection as a key feature. This had been explained to the dyad as part of the consent process and in the early therapy work. Despite this Nick's negative reaction to seeing himself on video was unexpected and something that required specific intervention. The result was positive but it was a clear indication that sensitivity is required when using video feedback. SLTs should certainly not assume this will be unproblematic even if clients agree to its use. One option is to use video clips of *other* people if available and if there is consent. The key here is to ensure there are appropriate examples of specific communication features to share. The second issue relates to the importance of the therapeutic alliance (Elvins and Green, 2008) for the BC approach. For this case there is little doubt that establishing and maintaining an appropriately collaborative relationship was integral to this self-reflective behaviour change programme. The SLT was not just delivering the programme but was part of the therapeutic process itself. To this end the impact and efficacy of a BC approach needs to be understood in the context of the broader interaction between therapist and client(s). This may be more relevant that more structural/physiological interventions.

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