



Show Notes - Episode #23 Relationship-Centered Care to Implementation Science: A Conversation with Dr. Linda Worrall

Today, Katie Strong (Assistant Professor at Central Michigan University) will be presenting another segment on “A-ha!” Moments in Aphasia Care as she speaks with Linda Worrall about relationship-centered care, psychosocial health, and implementation science in aphasia.

Professor Linda Worrall is a Professor of Speech Pathology, Co-Director of the Communication Disability Centre and Postgraduate Coordinator at The University of Queensland, Brisbane, Australia. She completed her undergraduate degree in speech pathology at The University of Queensland but then completed her Ph.D. in the Stroke Research Unit in Nottingham, UK. She has practiced as a speech pathologist both in Australia and the UK and founded the Australian Aphasia Association, the consumer-led organization, in 2000. She has published over 200 peer reviewed journal articles, 26 book chapters, and 6 books; graduated 27 Ph.D. candidates and has had continuous nationally competitive research funding during her academic career. From 2009-2014, she led the NHMRC funded Australia-wide Centre for Clinical Research Excellence in Aphasia Rehabilitation.

In today’s episode you will:

- Learn the complexity of effectiveness trials and how research and clinical practice go together;
- Understand the importance of relationship-centered care and the power of authentic relationships;
- Learn the origins of the living successfully with aphasia movement;
- Appreciate the negative impact mood has on aphasia outcomes and the important role speech-language pathologists have in preventing depression.

Note: These show notes have been edited and condensed.

One of the aspects I appreciate most about your work is how approachable and relevant it is to living successfully with aphasia. You’ve announced your retirement this year and I’m sure you have a number of significant “a-ha!” moments in your career. You had shared a story with me about your experience in the UK with the complexity of aphasia treatment trials and I was hoping you might tell a little bit more about this “a-ha!” moment.

When I was young, I went over to the UK was the one of the treating therapists in one of the large effectiveness trials that was very controversial at the time. It was published by Lincoln et al. in 1984 in the Lancet. As a treating therapist, I had been allocated three patients and two of them had been randomized to the treatment arm of the study and one was randomized to the no-treatment arm of the study.



One of the patients who was randomized to the treatment arm of the study was so globally aphasic that she really wasn't able to understand what I was saying. She was in a nursing home. She was essentially non-responsive. I was able to argue the case that she was not suitable for treatment. The other person who was randomised to the treatment arm was a man who I was going to see, but he also had a heart condition and his heart condition really was a greater priority for him than his speech therapy. He would often miss sessions because he had to go off to the hospital. And I think that other heart condition was really a big factor in his outcomes even though he was achieving some good language outcomes.

The man who was randomized to the no-treatment group - I would have loved for him to have been randomised to the treatment group because he had all of the features that we consider to be successful predictors of a successful outcome. And so I had to leave him and that was hard. However, I met up with him towards the end of the trial and he was very happy with his recovery. He had received no treatment at all. He and his family were very grateful for all the help that they had received and, in fact, he had made a pretty good language recovery all by himself. So the "a-ha!" moment from that is our efficacy and effectiveness trials contain very complex questions and the patients that we are treating have a multitude of problems. Sometimes their aphasia is not their priority. So, when we view the effectiveness trials we need to understand the complexity of not only our intervention, but also the patients that we're treating at the time. Certainly my "a-ha!" moment was, "Well, maybe... *maybe*... I'm not so essential to the recovery of people with aphasia. Maybe there's a lot of other things that they need to recover and not just speech therapy."

That's powerful. It also goes to the importance of clinical practice and research. It really highlights the importance of making sure that clinicians are understanding the nuances of research and that researchers are really understanding the intricacies of clinical practice as well.

Yeah. I think in our field we are seeing more of an emergence of clinical researchers: speech pathologists who have been practicing in the field who then return and do a Ph.D. in a particular area of clinical practice that they're interested in that has great relevance for them. This is different from what we've done in the past with a more science-type of Ph.D. - where a student goes through university and enrolls straight into a Ph.D. and into a lab. It's more of an apprenticeship model which trains researchers who are not so in touch with what happens clinically. While I think that their research can be valuable, I think we also need that strong sense of what are the important questions to ask in research that will help us improve outcomes for people with aphasia.



Absolutely. Spending time in clinical studying helps to become more aware of what those important questions are.

Absolutely. And it's not just about the clinical setting. It's about spending time with people with aphasia over the recovery period. So I think it's important to have that perspective not only for the first three months of their recovery or even the first 12 months - but the first 10 years of their recovery to see what is possible and for them to be viewed as experts on what helped them achieve that recovery.

We talked earlier about this debate that seems to be going on between impairment-based vs. functional-therapy approaches and whether or not one one better than another. I'd love for our listeners to hear your perspective on this and the "a-ha!" moment that contributed to what you believe is really the most important factor in treating aphasia.

This debate has been around since the beginning of aphasia treatment. About 15 years ago, I met a man and he was the head of the English department at my university. He was a professor and I knew his wife who was also a professor. He had a Wernicke's aphasia - so he was quite fluent. After a while, he didn't want to go to any groups. He didn't want any compensatory approaches or anything like that. He wanted to work hard on his language because he wanted his language back. To someone who is a professor of English, I can understand that and he was able to articulate to me why language and the components of language was so important to him.

That led me to the idea and we did a big study where we interviewed 50 people with aphasia, their family members, and their treating speech pathologists about what their goals of rehab were. We were wanting to compare and contrast the goals of the speech-language therapist to the goals of the client and their family member. Through the process of interviewing these people, we found out that the relationship between the therapist and the client and their family member is the crux of it all. If you look at the literature, there is something called relationship-centered care which is all about the relationship between the health professional and the client. It's not person-centered care. It's not family-centered care. It's not patient-centered care. It is definitely not therapists-centered care. This means that the client needs to understand that a therapist brings their own values and constraints into the relationship. That core concept that the relationship is the crux of the therapeutic relationship doesn't seem to have hit home.

If we're still talking about functional and impairment-based therapists, it's not our decision to decide whether it's functional or impairment. It's got to be a negotiated approach. It's got to be an informed approach. It's got to be collaborative decision making. I know a lot of therapists will say, "Well, they just say 'you do it because you're the expert.'" I tell them, "No. Actually, *you* are



the expert in getting them to talk about what they would like to be able to achieve.” It’s about getting a client talking about who they are and what they want to use their communication for before even talking about therapy. It’s about putting those base steps down in order to focus the forthcoming therapy to what the client needs or wants to achieve. This does take time and, in a medical model, this is not a valued concept, that you actually take time to develop a relationship with the client. In some of our current research, we’re trying to work out ways in which we can systematically prepare clients for that discussion and to make them realize that thing called “rehabilitation” is a shared partnership. So, yes - I do think this concept of relationship-centered care is all about the client and the therapist and should be the focus of this discussion. It’s not our decision whether functional- or impairment-based approaches work or not.

I’m curious about the English professor. Do you want to tell us a little bit more about how that turned out?

Sure. He did get a lot of his language back. He did a lot of therapy. He started to become more involved in the Australian Aphasia Association and that was terrific because he was starting to give back to the community. On the tenth anniversary of his stroke. I invited him to be the speaker at the graduation ceremony of all of our students. He prepared for this using scripts. He made a few paraphasic errors, and his wife and I were on edge the entire time, but he got a standing ovation from the students and the audience. He was, of course, over the moon. Because we were able to help him towards his life goals, his wife has donated a substantial amount of money in philanthropy to develop Australia’s first aphasia center. We’re just over the moon about that. She saw the value of what we were doing and we didn’t think that this was something that could even be possible and it just came out of the blue. We’re very grateful for that donation.

You were at the helm of creating the movement “Living Successfully with Aphasia” and “Making the World More Aphasia Friendly”. For those of us working regularly in the aphasia field, these concepts almost seem commonplace now but they really were revolutionary to aphasia rehabilitation. Would you share the “a-ha!” moment of how you linked these concepts to the field of aphasia?

Sure. One of my areas of research was aging. I did a lot of work particularly in successful aging. When you read the literature on successful aging, they often are talking about nuns who lived until age 105 or something in a remote community and they are trying to figure out what it is about that particular population that led them to living so well for so long.

I started to see that this same concept can be applied to aphasia. We started to think that maybe it’s quality of life that is the end goal for what people with aphasia want. However, quality of life measures don’t always take into account communication and certainly don’t take into



account communication disability. Therefore, some people have developed some communication-specific quality of life measures, but again, they can't be compared with other quality of life measures. There was a whole heap of problems around that concept of "quality of life" as being "what we're ultimately aiming for". So, this concept of successfully living with a aphasia seemed to be relevant because I knew people who had overcome aphasia and were living a great life. I also knew people who were still as frustrated with aphasia as the day they had their stroke.

Of course, you wonder what differentiates the two. One of my Ph.D. students, Kyla Brown, interviewed people with chronic aphasia, their family members, and speech pathologists about their understanding of what living successfully with aphasia means. There were three major themes in her results and I've used these themes over and over again in my work. One theme is that it's about people. This gets back to the relationship side of things. It's about having people who support you. It's about having contact with other people with aphasia who are living successfully. And family members who stood by them through their recovery. The second theme was "doing things". It was about getting out. It was doing things that were an achievement to them. Sometimes a bit of a challenge. Sometimes it was doing things that they previously had done and sometimes they were doing things that that didn't tax their language - like photography and art. The third theme was "positivity" - having a positive outlook. These were the three things that these people considered to be essential to living successfully with aphasia.

Then Brooke Grohn, another one of my Ph.D. students and looked at that first year of recovery when most of the therapy occurs in Australia. She saw that there were different trajectories in that first year. Some people whose language would gradually recover and some people who were back participating in their community. People's trajectory was generally up and down - a bit of a zigzag. There was a group whose mood went down and they considered themselves to not be successfully living with aphasia at all. It was those people who had mood problems - they were really struggling to cope with living successfully with aphasia. That realization led us to putting in a grant application where we were able to track about 70 people with aphasia during the first year post-stroke. We looked at the determinants of living well with aphasia. And, through that, we discovered that a depressed mood was a *major* negative impact on successfully living with aphasia.

That led to another "a-ha!" moment. Looking back to some work we did with Madeline Cruice in her Ph.D. and she found the negative impact of mood too. But we had put it aside because we just felt like we couldn't do anything about depressed mood. So this came out other people's work like Katerina Hilari, that mood is the most constant and significant negative predictor of living successfully with aphasia. That led us to where we are at the moment, which is about rather than saying, that's not our problem if they get depressed that is something for a psychologist to address. But looking at the literature, the best approach to depression is to



prevent it in the first place. We, as speech pathologists, have a role in preventing depression and we asked ourselves, “What should we be doing to prevent depression in people with aphasia and their family members?” There are numerous techniques around that help people manage their mood and improve their mood. You've got a lot of positive psychology literature out there and you've got a lot of research in the general psychology literature on depression. Sadly, we haven't been using that at all.

I'm wanting to raise the profile of the role of depression in aphasia. It's a mental health disorder that we [speech pathologists] can have a major impact on. If you talk to any survivor who's bounced back, a lot of them have gone through a major depressive episode and these are the ones that end up being extremely vocal advocates for aphasia awareness. While they've bounced back, I'm not sure how many others with aphasia are still in that depressed state. In my current research, we're evaluating the ASK Program in a randomized controlled trial - which is essentially all the things we've learned about how to prevent depression in aphasia. These results should be available in 2019.

I can't emphasize enough that a lot of people with aphasia develop depression. Some studies show that up to 60% of people with aphasia develop depression in the first year. Also, it's important to know that their depression has a major impact on their rehabilitation. They may not want to engage in any rehabilitation or they don't want to participate in group therapy or withdraw from those services. There is also support in literature that depression impacts rehabilitation outcomes negatively. So, there's a very strong rationale for speech pathologists taking a more active role in preventing depression. We need to work with psychologists. It should be a shared role. Psychologists are not used to managing people with aphasia since cognitive behavior therapy CBT is talking therapy and there's a lot of problems with using talking therapy with people with aphasia.

But, there are things like behavioral activation that can help people manage mood themselves. One of my students is submitting her Ph.D. on Stepped Care for managing mood after aphasia. If you look at that model, which is an efficacious model, I think that provides a clue to how we can do this and incorporate some sort of intervention to help prevent depression - within our scope of practice. I hope we'll have more answers to that soon.

Do you have any final thoughts you'd like to share with our listeners?

I've become very passionate about our need to to prevent depression, but there is still a very big evidence practice gap in aphasia rehabilitation. There is a lot of what we know works, but it's not being implemented in the field. There is an emerging field of research which is about understanding what is the best way to bridge that gap. We need to bridge that gap that conscientiously and systematically. We can't expect clinicians to read every research paper that



comes across their desk or to analyse all the research. We need to make research much more clinician-friendly so that clinicians know what good practice is and that they can then implement it in clinical practice. That area of implementation science or knowledge translation is a key area that we need to focus on in aphasia rehabilitation and it is that nexus between clinical practice and research. I think that's rather exciting that we can get clinicians doing research and researchers doing clinical work and that it begins to overlap in a way that is much more meaningful than it is at the moment.

For more information on Aphasia Access and to access our growing library of materials, go to www.aphasiaaccess.org. If you have an idea for a future podcast series or topic, email us at info@aphasiaaccess.org.

Links for Episode

Preventing and treating depression in aphasia (including stepped care model)

Baker, C., Worrall, L., Rose, M., Hudson, K., Ryan, B., & O'Byrne, L. (2017). A systematic review of rehabilitation interventions to prevent and treat depression in post-stroke aphasia. *Disability and Rehabilitation*, DOI: 10.1080/09638288.2017.1315181

Living Successfully with Aphasia

Brown, K., Worrall, L., Davison, B., & Howe, T. (2010). Snapshots of success: An insider perspective on living successfully with aphasia. *Aphasiology*; 1-29.

Relationship-centered Care

Worrall, L., Davidson, B., Hersh, D., Howe, T., Sherratt, S., & Ferguson, A. The evidence for relationship-centred practice in aphasia rehabilitation. In Eds. Damico, J. S., & Ball, M. J. *Journal of Interactional Research in Communication Disorders*, 277-299.