



“I’m still the person!”: Returning to work with post-stroke communication disorders

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Why?

- ▶ Around 1.3 million stroke survivors in UK, around a quarter to a third of working age (e.g. Radford 2020)
- ▶ Loss of employment major factor in economic cost of stroke- e.g. estimated £1.6 billion in UK 2014-15 (Patel 2020)
- ▶ Cost to individual: financial and psychosocial
- ▶ Return to work affected by cognitive/communication impairments
- ▶ Prevalence of communication difficulties among stroke survivors e.g. 23.7 % of stroke survivors had aphasia and 27% had dysarthria at three months stroke (Ali et al 2015)
- ▶ Preliminary literature search- little/no research specific to returning to work with post-stroke communication difficulties.

How ?

- ▶ Three-year NRS CSO Research fellowship:
- ▶ Step 1: Scoping review on literature on returning to work (RTW) post-stroke with/without communication difficulties:
 - ▶ Interventions
 - ▶ Factors
 - ▶ Barriers and facilitators

(Coutts E, Cooper K; Return to work for adults following stroke: a scoping review of interventions, factors, barriers, and facilitators. JBI Evid Synth. 2023 Sep 1;21(9):1794-1837. doi: 10.11124/JBIES-22-00174. PMID: 37255032.)

Scoping review

- ▶ 106 records included in final review
- ▶ Just 4 records specific to communication:
 - ▶ **Literature review by Graham et al in 2011 finding that people with post-stroke aphasia were less likely to RTW than stroke survivors without aphasia (28% vs. 45%)**
 - ▶ Case study on individual's frustrated attempt to RTW (Morris et al 2011)
 - ▶ 1 qualitative study on aspects of living with aphasia, with RTW being one such aspect (Manning et al 2021)
 - ▶ 1 review of potential barriers and facilitators to RTW with post-stroke communication difficulties (Sandberg et al 2020)

Qualitative study: ConQueSt

- ▶ The return to work experiences of people with **communication** disorders post-stroke: a **qualitative** study
- ▶ Questions:
 - ▶ What are people with post-stroke communication disorders' experiences of attempting return to work?
 - ▶ What barriers and facilitators are experienced by people with post-stroke communication disorders when attempting to return to work?
 - ▶ What do people with post-stroke communication disorders perceive their informational and support needs to be in relation to return to work?
 - ▶ How and by whom do people with post-stroke communication disorders perceive that any informational and support needs could be met?

Qualitative study: ConQueSt

- ▶ 11 people recruited through SLT departments in Grampian, Greater Glasgow and Clyde, Highland
- ▶ Participants interviewed online (Glasgow and Highland) or face to face if in Grampian, in their own home or in healthcare settings
- ▶ Interview transcripts analysed by 3 researchers informed by Braun and Clarke's methodology for reflexive thematic analysis(2021)
- ▶ 5 themes developed from these codes

1: Reality of returning to work

- ▶ Initial thoughts:
 - ▶ Hopes, anxieties and expectations:

“My [initial] belief was that I would go back to work within .. one or two months. ... even though I couldn't speak, I'd be back doing my job, and that was just unbelievable when I think back now”

1: Reality of returning to work

- ▶ Planning stage:

- ▶ Discussions with employer and OHS: in-depth vs cursory:

"[OHS] rang me ... and said that's fine, you can go back to work. ... I did say to them "you know, I am using the wrong language sometimes. But I am aware". And she said, "do you correct yourself?" And I'm like "yes." "Well, that should be fine.""

- ▶ Negotiating phased RTW and other adaptations (e.g. extra time):

"Usually we have half an hour to write our observation of the day ... I really hope to ask for fifteen minutes more because ... I think it will be much more complicated to write down the daily record rather than before."

1: Reality of returning to work

- ▶ Initial visit to workplace or actual first day back could feel overwhelming:

"It took me all morning to be able to do something myself, I really struggled to do things. Obviously there was quite a lot of talking to people as well."

2: What hinders: intrapersonal factors

- ▶ The communication difficulties themselves:

"Is [speech] going to cause me a problem? Yes, I think it will, ... because once you bring in a degree of stress, which comes with the working environment, then I know myself that stress makes me speed up, which makes my language fall off the track."

"I was in the staff room the other day, and ... I couldn't hear what people were saying ... I just couldn't cope with like fifteen people all talking at once, it was just so loud and ... that's really annoying because I'm like quite a sociable person and I like chatting and stuff like that but I just couldn't make out what they were saying or anything"

3: What hinders: external factors

- ▶ Lack of joined up, timely, specialist healthcare support:

"They did say they were going to refer me to one of the guys here. I'm not sure if he's an SLT or an OT who deals with people going back to work, but hasn't done yet."

"These services are in a black hole. ... I'm totally unsure. I don't know what support there is out there."

- ▶ Lack of communication support to negotiate RTW process and benefits system:

"My aphasia was quite strong, but I don't remember having any help to understand .. how do I cope with my stroke in terms of benefits and ... whatever."

3: What hinders: external factors

▶ *Lack of support and understanding from employers:*

“When I first went back, ... I had a student ... I knew what I needed to do with them, but I couldn't deal with it at that moment. ... And the third day I had a newly qualified [colleague] who I was working with.... I was like ... “You're not making allowances for the fact I've had a stroke here.” They knew I'd had the stroke, ... but they just put me straight back into the role. ... it did annoy me.”

“I don't think that [employers and colleagues] realised what a struggle it is because you haven't got a broken leg, you're not on crutches. To the outside world you're normal.”

4: What helps: intrapersonal factors

- ▶ Motivation: financial, social aspects, sense of purpose, return to normal:

"My job was kind of a fulfilling of my life before. ... to go back to [work], it gives me more purpose in life to be able to do something for my community, for people that are not just ... people in my family."

"I could go back to work and be, well not be perfectly normal, but be back to what I was before I had the stroke, I wanted to carry on and do it. Sort of trying to take myself back to what they say is normal."

4: What helps: intrapersonal factors

- ▶ Improvement, use of strategies, determination, awareness of competence:

"I can do everything ... it's fine, my legs [legs], my arms, and everything ... even my brain is okay, but I understand everything. I understand machinery, is no problem. It doesn't make any difference for me. ... Talk to the boss and say "You know, I'm still the person!" Write down what you want to say: "Look, I'm the same person, I can still do the job!""

5: What helps: external factors

- ▶ Support from healthcare professionals for language and cognitive skills:

"[The SLTs] went through the computer with me, so I could get on the system and do the things that I needed to do on the computer ... They worked on my multiplication and my maths, because of work. Because I needed to know the maths for work."

"[The OT] gave me different advice to start to manage my daily routine, for example she said during those weeks before [planned RTW] I needed to get up early in the morning to organise my day and to understand if I manage the fatigue during the day. ...Next time for example, [the OT] wants to see me in a busy environment rather than at home ... to see ... how I will react in different environment."

5: What helps: external factors

- ▶ *Support and understanding from employers, colleagues and service users:*

"I said I'm not comfortable speaking on the phone and things like that but they're absolutely fine with it. Really good about it so that makes it a lot easier for me I think."

5: What helps: external factors

- ▶ Other sources of support: family, friends, stroke groups:

"The engagement of [the stroke group] was magnificent because it allowed me ... to understand that this will get me back to work quicker ... and bring my confidence up a bit ... These people ... were also able to give me guidance and tips and hints, because a lot of the people there have had their stroke ten years ago, eight years ago ... For me, that was tremendous."

Conclusion

- ▶ Returning to work with post-stroke communication difficulties can be a daunting process
- ▶ Facilitators include personal attributes and support networks, the support of individual healthcare professionals, sympathetic employers and colleagues
- ▶ There is a lack of specialist and/or joined-up support for people with post-stroke communication disorders

What next?

- ▶ Complete write up, disseminate
- ▶ Explore funding sources for next step:
 - ▶ Co-design an intervention to support people with post-stroke communication disorders aiming to return to work, based on findings from qualitative study

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Questions?