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What do people living with aphasia want healthcare professionals to know when supporting emotional recovery? Co-designing a series of short films

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Introduction

Rates of depression for people with post-stroke aphasia are estimated to be between 43-70%; yet healthcare professionals have consistently described lacking confidence in addressing the psychological wellbeing of this client group. This study co-produced training and awareness-raising films.

Methods

We ran co-design workshops with six experts by experience: four people with aphasia and two family members. The content of the workshops was allowed to evolve in a collaborative manner, with an assumed equality between members. We then co-produced four films to raise awareness and train healthcare professionals.

Results

The core messages from the workshops fell into two categories: behaviours that harmed emotional wellbeing; and helpful behaviours. Harmful behaviours included: feeling told off; being talked about rather than included; negativity about future recovery; not feeling listened to; not supported to communicate; not feeling treated like a human being. Behaviours perceived to help emotional recovery included: listening to the ups and downs; kindness and patience; noticing family members too; chatting to patients as people; friendly and warm manner; supporting people with aphasia to communicate; keeping hope alive. The co-produced films include suggestions for how to support emotional recovery. They are housed on the City Access – Resources for Aphasia Hub (cityaccess.org/carahub#videos).

Conclusions

Workshop members felt strongly that these messages should be heard by all healthcare staff, not just those who elect to go on specialist training courses. Their key message was that psychological care after a stroke is everyone's responsibility: they urged healthcare professionals to notice the person not just the deficit.