Absent friends: including people with aphasia in friendship research

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Introduction

Disabled people are known to be at higher risk of isolation and loneliness. Loss of friends and diminished social networks following stroke and aphasia are commonplace (Hilliard and Northcutt, 2006; Davidson et al, 2008). Friendship studies however are surprisingly absent both from the literature on stroke rehabilitation and within disability studies. In this project an advisory group of people with aphasia identified friendship as a priority topic for collaborative inquiry.

This poster has been informed by meetings between the researcher and the project advisory group. It aims to:
• Provide a brief overview of the literature on friendship and some of the methodological challenges of doing friendship research
• Review the experience of working together as researcher and advisory group in developing the project
• Report on some of the challenges and benefits we have found so far from doing collaborative research

About the project

The working title of our project is Aphasia, Friends and Friendship. We have decided to focus on the experiences of people of working age. The project’s first phase has two main strands of inquiry:
1. Defining the meaning of friendship from the perspective of people with aphasia
2. Documenting the process of involving people living with communication disability in all aspects of project design and delivery.

Exclusion and involvement

Despite representing up to a third of people with stroke, people with communication difficulties are frequently excluded from research protocols. An agenda of increased public participation in research poses significant challenges to the ethos of research and traditional relationships of power and control.

A recent report by INVOLVE (Staley, 2009) highlighted the need to provide more detailed accounts of how excluded populations, such as those with communication and cognitive difficulties, can work collaboratively with researchers to co-construct knowledge.

About the project advisors

Ten people with aphasia are acting as expert advisors. Experience of aphasia varies from 1 – 20 years. All are under 65 and have both personal experience of aphasia as well as experience of supporting others with aphasia, e.g. as befriender, group facilitators, counsellor, advisors on stroke improvement boards.

Why is friendship research important?

Just gone. This is it. They gone...er...about six weeks gone. Gone...bye bye. This is it. I think its my...I can't...for a year about 6 months not communicating really. So they just gone (Parr et al, 1997)

Research shows that friends are good for your health. They play a critical role in providing emotional, informational and practical support. Personal convos of friends may help buffer the stress of illness, contribute to feelings of self esteem and competence and facilitate understanding of identities in transition. Friends can be an important resource in navigating the numerous barriers to full and equal participation in life. Research studies and clinical experience suggest that people with aphasia risk losing friends in the early period post stroke. Acquiring the skills, confidence and experience to manage social interaction differently takes time for all involved.

But friendship is a tricky business – it is notoriously difficult to define, it means different things to different people and there are qualitative and quantitative aspects of change over time. So how do people with aphasia define and experience friendship and what are their explanations of friendship change?

Friendship is a ship that contains you. Following aphasia some friends go overboard

Feeling the strain

Currently the advisory group and researcher meet monthly from 11.00-3.00. These are some of our reflections on the challenges of involvement from the first 6 months of our work.

Challenges for group members:
• Time
• Juggling different commitments
• Travel
• Energy
• Responsibility
• Concern about ‘opening up’ a can of worms’ by focussing attention on friendships and lack of friends
• Frustration with paternalism and lack of change from previous experiences of involvement

Challenges for the researcher
• Letting go of control whilst overseeing the research project
• Time and timescales – everything takes longer
• Additional focus on process means less focus on numbers
• Increased weight of responsibility to ensure project makes an impact
• Supporting group members to access academic material
• Bureaucracy of accessing funding for advisors expenses

Reaping the benefits

The involvement of expert advisors with aphasia has added depth, dynamism and authenticity to the project. Self reported impacts of involvement in the research process include the following:

Benefits for the advisors with aphasia
• Engaging with ‘the joy of the topic’
• Having control and being ‘given the reins’
• Having ownership of the content rather than being ‘guinea pigs’ – ‘Experts...experience...patients no!’
• Feeling that ‘our expertise and our intelligence are respected and valued’
• Responsibility and engagement in something dynamic and influencing
• Intellectual satisfaction’ in hearing others, engaging in discussion and ‘working out the different strands together’
• ‘It helps me think outside the box. Friendship is a subject so simplistic, and yet so profound it helps to come across avenues that I would not have ordinarily thought of’

Benefits for the research process and researcher
• Grounded thinking about the topic
• Challenging taken for granted concepts e.g. defining severity, the notion of ‘vulnerable adults’
• Constant reminders about individual diversity
• Support in developing and critiquing information sheets, consent forms, topic guides, presentations
• Practical help with recruitment and data collection
• Additional commitment to emotional wellbeing of interviewees and the practical long term impact of the research
• Feeling emotionally supported and energised by the group

Talking points

I need to define friendship or what is my friend. Maybe I have a restricted definition of friend

My career is my friend. We talk about everything together

I have my friends from school, my friends from college and my ‘fast friends’ – the people I have met who have aphasia

Without friends, without their close relationship... I don’t think I would have an identity

Explaining is hard with aphasia. I think for some people the stones are a more creative way of thinking about friends and feelings and changes over time

Next steps

We are in the process of recruiting 10 people with aphasia to interview, individually and in a group, for the first phase of the project. Based on our findings and discussions we will identify the focus for the next stage of the project.

References


Acknowledgements

Thanks to all members of the project advisory group: Harry Clarke, Catriona Grant, Basia Grzybowska, Carole Headley-Barton, Alan Hewitt, Jerry Johnson, Jasvinder Khosa, Cresilda Laywood, Neelal Mehta, Jane Stokes. And also to my project supervisors at Brunel University.

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