What are the Experiences of Stroke Survivors with Managing Eating? (ESSME Study)

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“That cutlery is a life saver, my husband can’t eat independently without it, but why does it have to be so ugly and expensive”? 
“The everyday usefulness of the simple knife, fork and spoon, literally touches us all every single day, whether or not we consciously think about it”. (Benz, 2012)
The purpose of this research was to explore the complex area of eating difficulties after stroke and find out what assistive devices stroke survivors are using to support eating activities.

Mennell et al. (1992) distinguishes eating as an activity dominated by social, cultural, and religious factors that are essential to daily life.
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Methodology: Qualitative to understand and explore meaning and the way people make meaning (Braun & Clarke 2013).

A focus group: 7 stroke survivors and 1 carer brought together to talk about their lived experiences.

The purpose: To listen and gather information. It is a good way to find out how people feel or think about an issue, or to come up with possible solutions to problems.
Cultural probing involves using artefacts such as photos to facilitate discussion and engage participants in the research (Mattelmki & Battarbee 2002, Gaver 2004).

- To understand the real life experience of stroke survivors.
- Provides insights into eating experiences that the researcher wouldn’t have necessarily seen (Carter & Mankoff 2005)
Findings: Spectrum of Eating Activities

Sourcing & choosing food (shopping)

Accessing food (packaging)

Preparing food for cooking

Cooking food

Eating food
• The impact of stroke on eating experiences
  • Motor, sensory, cognitive function
  • Psychological and emotional function
  • The social aspect

1. Eating

2. Activities

• Change of lifestyle, roles and relationships
  • Coping with changes in lifestyle, role and relationships

3. After

• Adaptation & Coping Strategies
  • Striving for mastery
  • Adaptation and resilience
  • The value of support groups

4. Stroke

• Assistive Devices
  • Hacking everyday objects
  • Envisioning new technology
Theme 1: The impact of stroke on eating experiences

The literature review found a significant number of difficulties experienced by stroke survivors with eating.

This study found that eating activities were affected by motor, sensory, and cognitive function and eating was socially important.
Findings.... Visual, motor and sensory function

Ian- “I do bite when I am eating; I bite my lips, because I have no feeling in it”

Sarah –“because of the problems with my eye sight I would only eat on one side of the plate and it took me ages and ages so what I had to do was start turning my plate round like this...”

Clive “the pan is hot, it's just boiled up but you still go and grab it you just don't think, that process just isn't there”
Ian- “people weren't looking at me but I thought they were looking at me and then my wife kept coming up and wiping my face which used to annoy me...I would be self conscious about whether I had dribbled all over my top or if I was making noises, so you tend not to enjoy the food as much as you usually would because you think people are looking at you so you don't enjoy it and so you opt to stay in”

Goodley & Lawthom (2006) note the experience of being stared at can adversely affect someone’s emotional wellbeing and self worth.
• Marini & Stebnicki (2012) discuss how having a stroke can affect how people perceive themselves which can lead to feelings of anxiety and cause social withdrawal. This could explain why the participants discussed feeling embarrassed and self-conscious with eating.

• The stroke survivors discussed the experience of feeling flawed in their performance they described this as feeling ‘child-like’.

• Marini & Stebnicki (2012) suggest that the impact of this could be a heightened sense of awareness, which leads to people being self-critical or avoiding the situation altogether.
The participants discussed difficulties with using numbers and mental maths for activities such as cooking, managing timings and following recipes.

Ian, a former builder said “I could walk into a house and tell how many tonnes or how many cubic metres of plaster or concrete it would take because I just knew.....when you look you just know instinctively just by the look of it”
Findings.... Change of lifestyle, roles and relationships

- Participants talked about how their lifestyles and roles had changed.
- Two of the men talked about how they had been unable to return to work and how they had become the home cook.
Several participants talked about how they had made changes to their diet as a result of diabetes or weight gain from medication.

They also discussed buying types of food they could easily open and in some cases these were not always the healthier options.
Striving for Mastery

Despite a variety of stroke impairments the participants were striving for mastery of eating activities.

This mastery was achieved by learning from experience, learning from others and by being innovative with problem solving.

Kielhofner (1980) suggests that occupation in activity is central to existence and arises from an innate desire to explore and master.
Ian “progressively my cooking got better, I was doing things like Sunday dinner and that's how I knew cognitively I got sharper and because you have got all different things coming together all at the same time before you sit down and eat... Yerxa (2002) people literally create who they are through occupations which connect them to their worlds and culture.
The group discussed different strategies for managing eating activities and different assistive devices that they have used for cooking or eating activities.

“I take my dycem mats everywhere”

“I would not be without my electric can opener”

“I buy frozen mash potatoes as it saves time struggling to peel vegetables”
Tasks that were difficult included, peeling fruit & veg, cracking eggs, using cutlery and opening packaging. These were particularly difficult for people that were one handed and those that lived alone.
The group talked about everyday objects, which they had adapted to meet their needs. A pasta bowl that served as a plate and a grapefruit spoon that becomes an eating aid.

Sally “yes I've got a pasta bowl which I use for a plate, rather than chase food round the plate”
Norman (2004) discusses the need for human beings to modify and customise products, to meet individual needs.

He describes this as bonding with an object and suggests personalisation influences the pleasure associated with an object’s use.

Norman (2004) suggests that everyone is a potential designer.

Resonant design is the process of personalising objects to meet individual needs (Pullin 2011).
The group came up with some innovative ways to manage eating difficulties. They were enthusiastic about visioning gadgets to solve current problems such as, a tie that wipes your mouth automatically to prevent the dribble.

Clive “glasses that make your food look bigger so you don't put too much on your plate then and make your food look big, so your portion is big but actually small...”
Findings..... support groups

• The group laughed a lot together whilst sharing stories.
• They were familiar with each other and were supportive of each other.
• They shared ideas, strategies and assistive devices.
Conclusions

• Eating is a fundamentally important activity in culture and society and OTs have an important role to play in enabling stroke survivors to adapt to disability and regain eating activities.

• Qualitative research can help us to see beneath the layers of complexity to explore the lived experience informing OT intervention.

• Research methods such as cultural probing can provide an opportunity to obtain data about real life experience in real life contexts providing insights that would have been otherwise missed.
Implications for OT Practice

• Participants demonstrated resilience and resourcefulness whilst striving to overcome the difficulties associated with eating after stroke.

• OTs are best placed to facilitate stroke survivors in problem solving skills helping people to realise their potential.
Implications for OT Practice

• Assistive devices helped people to master tasks and achieve independence in cooking and eating activities.

• Negative aspects to using assistive devices included feeling stigmatized, cost of devices and limited opportunity to ‘try before you buy’.

• Participants were adapting everyday objects to meet individual needs for eating activities
What next? Dissemination

Patient & Public Involvement
What next?

Application to NIHR for £500 grant to develop a PPI panel to develop research ideas.

Create a team of experts including stroke survivors to support further research.

Write a patient information leaflet on eating difficulties and assistive devices.
Thank you!

Sheffield Women of Steel Commemoration
1914 - 1918
1939 - 1945

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References