Stroke Odysseys: post stroke performance arts, a service innovation for neurological rehabilitaiton

Lucinda Jarrett

Stroke Odysseys is a four-year practice research project to study, test and implement a performance arts model for neurological rehabilitation. It is led by Rosetta Life, a small arts in health innovation charity, and delivered in partnership with stroke survivors in south London and five London NHS trusts.

The project began at the National Hospital for Neurology and Neurosurgery in 2011 when a group of dancers, physiotherapists and a neurologist came together at The Place, a contemporary dance centre in London, to explore how dance and movement might contribute to neurological rehabilitation. This led to a clinical audit on the wards, the conclusion of which was that dancers worked with image and improvisation in ways that might support neurorehabilitation. A dance project was organised for patients, led by Professor Nick Ward and supported by the physiotherapy team. Sessions ran weekly for one hour in the hospital gym and the project was subject to clinical audit.

The results were clear: dance raised the energy levels of people who participated, contributed to optimism and hope after the trauma of a stroke, and it helped people remember who they were. Staff were interviewed about the impact of the project and the findings were produced in a film called Remembering Who I Am (http://tinyurl.com/ya8gke9u).

A woman who was afraid of going home danced to carnival tracks brought in by her daughter and found the courage to go home with hope after recovering her sense of who she was. Another woman who was struggling to cope with her identity as a person with disabilities said she had found 'a new vocabulary' through movement.

Many people who have had a stroke struggle to recover language as well as movement so, in 2014, we successfully applied for a grant from Guy's and St Thomas' Charity to extend the movement project and explore the potential of combining movement, song and performance.

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The first six months were spent designing the model with people living with the effects of a stroke, researchers and clinicians. Practitioners, artists and researchers come together with people living with the effects of a stroke in practice research workshops. These workshops addressed specific themes: arts in health and neurorehabilitation, dance and the ethics of intimacy, music and rhythm and performance.

Rosetta life took the questions that arose from these discussions into the production and design processes run by dancers and musicians in collaboration with the stroke survivors. Each of these processes led to a performance and reflective practice concersations with the audiences that were in turn fed back to the research practice groups..

Pauline Boye, who had been a nurse before she had a stroke that left her without the use of the left side of her body, highlighted how taking part was important to her:

> **'We don't feel forgotten. Just because we have had a stroke does not mean we have to stay at home. We want to take part in life.'**

The model was tested in the community where it was evaluated by health psychologists. There was a clear understanding that 'the focus on ability and not on inability builds confidence and the likelihood that people with persist with the intervention' (Simonds and Cropley, unpublished observations). One participant said:

> **'Well what can I say? This is always the way—if people concentrate on what you can do rather than trying to penalise you for what you can't do, then you know you will build up confidence within yourself, and you will come back.' (Simonds and Cropley, unpublished observations)**

Most significantly, the intervention changed participants' attitudes to their disability by enabling them 'to show what they can do and, and as a result, changing their relationship to disability' (Simonds and Cropley, unpublished observations).

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1. Jonah Brody, musician; Haide Rollo, stroke ambassador; 2. Rachele Rapisardi, dancer; Marek Dziurman and Haide Rollo, stroke ambassadors; 3. Lil Sullivan, stroke ambassador; Sara Augieras and Rachele Rapisardi, dancers

Advocates for life after stroke

The participants chose to stay connected with the project, so Rosetta Life offered them training to become advocates for life after stroke. They developed creative skills to work with musicians and dancers in workshops to advocate for life after stroke and to support people who had experienced a stroke in more areas.

These 'stroke ambassadors' supported dancers and musicians working at five London NHS trusts, where patients from the stroke wards and neurorehabilitation wards attended group sessions that took place in the gym, the day room or the occupational therapy activity room. Sessions took place at a regular time each week and participants were referred by a named contact who managed the project on the ward. This person varied between hospitals; in some places it was a nurse, in others is was a ward manager, physiotherapist or occupational therapist. Between two and 10 people took part in each group, depending on the size of the ward and whether it was an acute stroke ward, where numbers were often smaller, or a neurological rehabilitation ward, where numbers were larger.

Effects of sessions

It is important that the sessions are not compulsory—not everyone will want to take part in movement and song. However, those who do have reported many benefits. Those who attended have spoken about how important it was to try something different and to achieve something they may not have thought they could do.

As one participant from a complex neurological rehabilitation ward who took part in the project, said:

> **'Singing was enjoyable … it is not something that I thought I would do but I … feel as if I have discovered something new … it brought something out of me that I did not know that I had really … I felt that I could engage with it, really.' (Jarrett)**

Participants also commented on the importance of a social group as a means to reconnect with their past and present selves, the benefits of the exercises that reconnected people to their bodies and the

Box 1. Tour dates

25 October The North Wall Arts Centre, Oxford

3 November Greenwood Theatre, Kings College London

8 November Lakeside Arts, Nottingham

16 November Circomedia, Bristol

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Sara Augieras, dancer; Rachele Rapisardi, dancers; Pauline Boye, stroke ambassador

significance of being able to feel free when confined to hospital. They also experienced joy and playfulness in clinical contexts, which do not lend automatically lend themselves to play. One participant noted:

> **'Being in a hospital, you are not free—you are bound by rules and regulations and there is an element of restriction but to be able to do something creative and to do something on your own or independently is a key to opening a door that you can be yourself' (Jarrett)**

The combination of self-expression, mastery of a new skill that had hitherto been undiscovered, the group dynamics promoting social interaction, the connection to the body and the opportunity to experience the feeling of freedom are surprising and significant outcomes of this research into performance after a stroke.

When this clinical research is combined with the health psychological research into the community interventions that demonstrated positive change in perception of disability (Simonds and Cropley, unpublished observations), we realised that this intervention could be a positive complement to rehabilitation.

Evaluation

Rosetta Life commissioned an ethnographic evaluation of the stroke ambassadors (Harrington, unpublished observations). Dr Jean Harrington, an ethnographer from King's College London, concluded that the training and skills opportunities offered to the stroke ambassadors built kinship. This is a sharing of characteristics that engenders trust, understanding and empathy.

This kinship provided a foundation to build a bridge between recent stroke survivors and the community. Harrington observed that participants felt less isolated and lonely, regained 'voice' and 'power' and improved communication and relationships with people outside the 'stroke community'.

The stroke ambassadors are the legacy of the project. They can advocate for new opportunities for life after stroke and represent the possibility for change in how people who have had a stroke are perceived.

Going on tour

These findings encouraged Rosetta Life to secure funding to develop the project. In March this year, it secured funding to work with the stroke ambassadors to create a performance that would tour the country to share these findings and enable the performance itself to advocate effectively for life after stroke.

The performance premiered at The Place in May 2018 to a standing ovation and tours the country this autumn. The stroke ambassadors are travelling by plane to Belfast, by coach to Penrith and by train to Oxford, Nottingham, Bristol and Southampton. They will be opening doors for people who have had a stroke across the country and teling wider communities that they cannot be forgotten and will not be left behind the closed doors of their home. **BJNN**

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Simonds LM, Cropley M. Testing the efficacy of a singing and movement intervention on quality of life for stroke survivors. In progress



Rachele Rapisardi, dancer; Haide Rollo, stroke ambassador; Lea Cornthwaite, singer

Pictures: Stroke Odysseys Pari Naderi

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