EVALUATION OF THE POST STROKE PERFORMANCE ARTS INTERVENTION: STROKE ODYSSEYS

Delivered at St Thomas Hospital and replicated at Chelsea and Westminster Hospital, National Hospital for Neurology and Neurosurgery, Charing Cross and Hammersmith Hospitals.

Background:

Rosetta Life commissioned this study and report. Rosetta Life was founded in 1999. It is a group of artists who work with those living with life-limiting illness to shape and share stories that matter through movement, song, image, film and writing'. The charity aims to improve the mental and emotional health of participants and enable them to gain the confidence to take their stories to performance stages and transform the stigma of illness and change the perception of disability' (https://www.rosettalife.org). Sitting within Rosetta Life is Stroke Odysseys, a three-year practice research Programme (2015-18) designed to produce and embed an interdisciplinary arts intervention for London's stroke communities that combines movement, song making, storytelling and performance. The aim of Stroke Odysseys is to find out if an arts-based intervention, incorporating song, dance and performance, is effective in reducing anxiety and depression in people who have had a stroke and if it improves their quality of life and their sense of mastery of self and body. The model was tested within the stroke communities of South London and in clinical contexts across neuro rehabilitation wards in four NHS Trusts – Charing Cross and Hammersmith Hospital, Chelsea and Westminster Hospital, National Hospital for Neurology and Neurosurgery and St Thomas Hospital.

Rosetta Life commissioned health psychology research of the community interventions, practice performance research and evaluation of the clinical intervention and ethnographic research of the Stroke Ambassadors, participants of the community intervention who chose to remain connected with the project and received training to become advocates for life after stroke. This research informs the practice research and is the research of the clinical performance intervention. The aim of this research was to understand the patient's experience of a movement and voice intervention delivered across four neuro rehabilitation wards in order that it might inform the artists practice and understanding of the practice.

Stroke Odysseys

At Rosetta Life, we (a group of professional artists) devised a movement and performance intervention in 2010 for neuro rehabilitation that is based upon a somatic dance and voice practice, improvisation, anatomical awareness. In particular the dance practice relies upon the art of touch that facilitates movement in response. The shared experience of touch is hard to understand. When an artist is working with a patient on then wards, the artist can understand his/her own experience but not the patient's experience and it therefore felt important to understand the experience of the patient in these workshops.

We therefore used IPA, interpretative phenomenological analysis for the interview tools because it is concerned with an individual's personal perception or account of an event, as opposed to an attempt to produce an objective statement of the event itself.

The aim of interpretative phenomenological analysis (IPA) is to explore in detail how participants are making sense of their personal and social world, and the main currency for an IPA study is the meanings particular experiences hold for participants.

Structured questionnaire

In consultation with Dr Isaac Sorinola, a neuro physiotherapist working at Kings College London, we devised the following questionnaire:

1. What kind of health problems did you have before your stroke?

2. How did you experience your body before you had a stroke? that feel in your body?

3. How did you interpret your symptoms?

4.. What do you think might help you feel better at that time?

5. What is your experience of your body now?

6. What kinds of treatment do you think you need for your rehabilitation? Why? What do you think should be done to help you overcome your problem(s)?

7. Why did you decide to join the music and movement group?

8. What was you first / subsequent reaction(s)?

9. What did you think about the tasks you were asked to do?
How easy was it for you to join in the goup?

Was it helpful to you?

If your answer is yes, in what ways was it helpful?

What were the effects of the intervention on your mood and your fatigue?

10. Where would you go to seek help now? / What would stop you from seeking help?

Methodology:

We ran a series of twelve workshops in four NHS hospital wards, two hospital wards were acute stroke units, St Thomas Hospital and Chelsea and Westminster Hospital, one hospital wards was a stroke ward, and the fourth context was a complex neurological rehabilitation wards, the National Hospital for Neurology and Neurosurgery.

The sessions were designed for people living with the effects of a stroke, but on neurological rehabilitation wards some patients were admitted who do not have a stroke. We decided that we could not run a research project that excluded some patients and included others on the grounds of condition and therefore in order to ensure we were inclusive we offered workshops to all the patients on the wards. Our only inclusion criteria was that patients had to be able to tolerate groups activities – participants had to have sufficient cognition to be aware of others. Sessions lasted 1 – 1 ½ hours and took place weekly in the gym or activity room. Sessions combined relaxation, movement practices drawing upon improvisation, anatomical release and somatic dance, visualisation, imagination, voice, poetry and song and performance. People were referred by the multi-disciplinary team and a single person line managed the project and timetabled people to attend the sessions. Each session was supported by a health care assistant or therapy team member. Each session is supported by one or two stroke ambassadors

We ran a total of 36 workshops, 86 patients attended one session or more; 22 participants attended three sessions or more; 15 had the capacity to consent to research; 14 participants consented to research and 12 participants were interviewed.

We decided that participants had to attend a minimum of three sessions before they could consent to interview. In practice very few patients attended more than three sessions. People were then invited to participate in the interviews and if and when they consented, I contacted them to interview them. In many instances, this meant visiting people after they had been discharged from hospital and visiting them at home.

Conflict of Interest:

A team of six artists ran the workshops. In some instances the researcher ran the workshops and interviewed participants. We took care to make it very clear that the research was an opportunity to learn about the workshops and it was an opportunity for participants to have their voice in designing a new intervention, to share their experience and to teach artists what worked and what did not work. In many cases we were able to interview participants at home, which meant that their answers were not compromised by any anxiety about access to care. Moreover, we restricted our structured interviews to the experience of the interventions and tried to avoid questions about impact and outcomes which might have compromised participants

Analysis and Outcomes:

Of all those interviewed only one person had had any health problems before their stroke. For all participants, their neurological illness was a devastating traumatic event that changed their lives. Of all those interviewed, nine participants had had a stroke and three were living with the effects of complex neurological illnesses.

While all participants declared a common enjoyment of the sessions and declared that enjoyment and pleasure were important components of the sessions, each individual seemed to get something different out of the sessions. So for one person (TC) , who was "a builder, quite physical by trade", it gave him a chance to do something active, to be "quick on his feet" "I enjoyed it, I felt better, I like dancing", while for someone else (CC) it gave her a chance to find an opportunity for self-expression and for another it gave him (JC) a chance to find a project he could start and see through to finish, a song to learn and record, and for another (SB) it was a chance to connect to her faith and although she had been told her illness was incurable she believed that she could be cured through faith: "Jesus is my cure, my solution" she said…"I love singing because it gives peace… The Lord showed me you need to have peace" and so she found in the sessions a place where she could find what she needed, her healing, "in the Bible our father says, sing, dance and rejoice …. Our DNA has song…. There is something about the body that wants to live… the body wants to sing".

RS acknowledged that one of the challenges he faces was the emotional challenges and identifies the need for positivity as key and the performance arts group as a vehicle to helping him find this positivity:

"It is a bit difficult really because there are bound to be questions… I don't question myself too much… there is the thing that it is something that has happened out of the blue and you are not in any way you're not really ready to know how to handle it…."

"….I think it is because you have had an experience where yourself has been put in a position of you are not quite sure about who you are any more because you have taken a big change and you have not fully appreciated what it is… there is what has happened to you physically and what has happened emotionally and they are two quite different things and the physical things they can tell you about …. But I find that the emotional side of things or the feeling towards things are things that are more important than the physical things… … it is very much about staying positive and by taking that approach I feel that the results …. The music and movement group because if you enjoy something then that is a good input.."

The need for positivity was echoed by many participants and the ways that the performance arts project offered participants means to find positivity were clearly as diverse as the individuals participating.

Any reasoning why people were able to get so many different things out of the sessions is only speculation, but one common theme underlies all interviews. All participants talked about a feeling of freedom experienced in the workshops. "I felt free", It is a very free sort of feeling", "it was lovely to feel free" underlie all comments from all participants. Some were more articulate. One person who I will identify as CC declared,

" 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 "

SB echoed this thought, “When we do physio we have to concentrate but through music we get healing and singing”. For her freedom meant a space to release herself into emotional feeling:

“The body needs to cry because I was in a trauma …. It was the body needed to release what had happened”

Another gentleman, who I will identify as WP, articulated the same feeling through another lense and declared ,

“Fun and pleasure takes one away from the mundane and … one wants to work hard at getting better but the focus on getting better can be harsh and punishing sometimes .. it is not that this is the intention but it comes across as being pushed and if not then the patient feels that they are pushed… But with Odysseys there was no push .. it was a natural way of engagement with the body and so it felt easy…engaging fun”

WP links pleasure and fun to taking one away from the mundane, an escape or a freedom, ease and easy engagement which leads to mastery. “No push”, “opening a door” and “release” also suggest that one aspect of freedom might be the freedom to feel and acknowledge selfhood. One may speculate that the freedom to access one’s imagination opens a ‘door that you can be yourself’ but more specific analysis would be needed to understand if this insightful comment was echoed by others.

Freedom clearly means different things to different people. While everyone declared that they “felt free” in the sessions, for some that might have been an “escape” from a mundane routine (WP), for others it was a free feeling that was relaxing and for others it was a freedom that opened a door to becoming oneself. What is certainly true is that the freedom experienced in the sessions enabled all participants to take different outcomes from the sessions.

There are three themes aligned to freedom, the feeling that the sessions offered “something new”, the “ease and flow of the sessions” that meant “mastery” easy to achieve and the creative “playfulness” of all sessions. The importance of something new offered participants a chance to try something that they had never experienced before, so CC said “I had no prior expectation but I thought it might help. And it did… I know that I feel better when I have tried … Trying something new” another participant, MM, directly linked something new with creativity and playfulness explaining, “we laugh, something different.. someone making us happy we are happy to see you…. Your charity is good, what you are making is making different like theatre like theatre…. Because it is like life … you see art is something different I never see”. Playfulness is very important in the sessions and performance games and clowning have an important role to play in some of the tasks. For MM art was not part of his culture. He was Somalian, and spoke Arabic and Italian but had no direct experience of theatre or art. Innovation, creativity and art were directly linked.

Trying something new is of course also linked to mastery, finding tasks that one can achieve. In rehabilitation one is often faced with fixing things one cannot do, as artists we offer

people a range of stimuli that give people the opportunity to try new things, so RS said, "Singing was enjoyable … it is not something that I thought I would do but I was quite happy to do it and I feel as if I have discovered something new … I suppose what I did like was when we introduced new things… I found that with the singing particularly with the African songs those particularly were very good to join in with… it brought something out of me that I did not know that I had really…. I felt that I could engage with it, really.." while CC said, " When you are restricted you can't always do new things …. In this I recognise I can do that…Underneath it is all you " and BO said, "I could do it all.. that was important.. it was good I felt I can do it all… It becomes part of you the workshop becomes can become part of who you are… Now I can do my practice for myself because it is me". It is fascinating BO uses the expression that "the workshop can become part of who you are". She refers to it as "her practice", much like an artist will refer to a training as a practice, for her she becomes who she is with the practice of the workshops.

"Easy yes easy my body felt easy I felt easy" said BO, while SB said, 'Before I would be frustrated, 'oh I can't do this'… but now I let the body go, I pray and I let go…. Now I do our exercises and then let go, I let the body have a rest … It was really good……" The ease of the sessions was important because it enabled people to stretch themselves and achieve more than they felt possible. Music plays a key role in this. As DO noted "If there is a distraction when that happens then that is even better and that is one of the good things about the music and movement groups is that if you have to do something while you are doing something else to music or something else it helps to take away from the effort, it distracts you from the effort needed"

For DO the art was important, "I have had experiences in the past and I fell into a drama troupe by chance and it is a wonderful experience and the artistry of this is really important" while CC declared it was "self expression" that was significant and for JC rediscovering his voice and recording a song was most significant. For MM the experience of art was "different thing, making something like children playing [laughter], we are alive, we feel alive" This feeling of the discovery of being alive is interesting as a response to a question seeking understanding about on the "feeling of the workshops in their bodies". This in itself is a complex concept for people with damaged cognition – what is a "feeling in the body'? We were asking people to distinguish between emotional feelings and to try to understand and express the feeling / response to the workshop in the body. We were keen to find out what the physical experience of dance, performance and song might be for patients who had experienced trauma and the results were intriguing. One participant who was blind after a second stroke, BU, declared "After the workshops I felt happy, lighter … my body felt lighter…Brighter somehow …Easy yes easy my body felt easy I felt easy". The implication is that the body became more present, more accessible to the participant.

Sensory engagement through movement makes our body accessible to us and this makes it more accessible. This is particularly important to people who have had a stroke or lost relationship to the body. For example, CC said, "My left side is not as aware of the messages between the brain and I can't say where my arm is. If my arm falls behind me, I am looking for it… Last night for example I was looking for my arm. It was in the bed with me." While DO was living with Barr's Syndrome, an auto immune disorder that causes

paralysis which is caused by nerve damage, but is curable and the nerves can regrow said, “I have limitations, it is a slow process of coming to terms and I am trying to find my way. I can feel my legs and arms but the messages are taking a lot longer to get there until the nerves regrow. But I can feel my legs and arms”. Of the sessions he said, “It is a very free sort of feeling … I tried to stretch myself and that is always a good thing to see how much range I have in my arms… Relaxing , definitely relaxing ….”

Several participants specifically identified the use of touch in movement was helpful. “Yes touch helped” said JC, while SB said “touch helps, sharing and being ourselves” and RS made the point about making the body present and accessible most clearly, “When I had done the warming up quite often you could feel of awareness of your body…. “ and

“…. To actually think about the body and how they use it… being able to get the breathing working … it was really it really felt that it was given the feeling about myself that was better… I felt that I was connecting with how I was and who I was. This echoes CC’s comment already cited “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”

We do not have easy access to a language that explains our physical creative bodies and what it is to make this accessible, particularly when we have lost direct access to the body. It is astonishing how participants have struggled to articulate this and have managed to do so clearly. Several reached for spiritual language to explain it. For SB it was a “healing prayer”. DO declared “it is a really nice experience and it takes you out of your comfort zone and when you are recovering from trauma you need that …Especially for guys, it is gentle and good for the soul”. WP described it as a physical high “I don’t know what it is like to feel high but I felt high after session … I felt elated I felt lighter. It is like a lightness of mind that becomes a physical lightness … “ BO, despite being blind, uses the adjectives “lighter” and “brighter” to describe this access. For RS, he described it as “a greater feeling”. Connection to ourselves and our bodies is magnified when this connection is opened to the group itself.

The group itself is very significant in this “greater feeling”. In theatre and dance and performance, strong relationships are formed within the company. Within one single session we try to initiate feelings of a performance company. Trust exercises, working in pairs and trios, sharing work in informal performances, singing together and sharing songwriting and stories engender an intimacy and trust in the group which is immediate. TC declared, “I felt better. You met nice people and I like people anyway I’m a people person. And what we were doing was dancing and things like that. Connection, being in a group was really important. I have one to one sessions but it is not the same as a group… and you try and help people and we could in the group” RS declared, “I was not sure what I was coming to but I found it something that I was very happy to be amongst the people who had the same feelings as me “ and DO said, “Good interacting with the members of the group, interacting with other patients and a really nice way to interact with patients and to create a bond with other patients who are here. You get to make bonds because you do the exercises together, the call and response etc” . MM said that the bonds forged in the group continued through the week and mentioned how the nights on the ward were difficult because people were loud and disruptive and another group member would initiate

some of the performance games and they would play them on the ward when they could not sleep

> "[AK] in the night he was singing 'Ameyo' [calling to me]
> He blows to the bed across the ward ….He repeat what we were doing at night"

RS directly linked "a greater feeling" to the group and said, "I want to be part of that gives you a greater feeling…. That you also have other people in similar positions to yourself and the group … if you see someone else making progress that helps a lot as well… if you see someone making progress and enjoying something it helps you and it gives you a feeling that that is an example of how you will improve if you follow things".

Shared outcomes across the health psychology analysis of the community interventions and ethnographic observation of Stroke Ambassadors. All three interventions concur that the the intervention has the potential to reduce the anxiety and depression experienced after stroke. One of the key mechanisms of the intervention is the group and the possibilities that this offers for connection: this was reaffirmed in the ethnographic observation of the Stroke Ambassadors who declared that one of the most significant outcomes was kinship, relationship and friendship. It was also shared as a key theme from the health psychology evaluation and in two focus groups the significance of the "group cohesion" was identified.

Other shared outcomes was the importance of" innovation" The opportunity to try something new and make new discoveries was shared across the health psychology and ethnographic observations.

In the community and clinical interventions the theme of a reorientation to disability, a 'freedom" to become something new was shared across all interventions and was perhaps most significant.

Importantly, the element of public or informal performance was critical in the community interventions and to the Stroke ambassadors but was not mentioned by the participants in the clinical interventions. The "joy" or "elation" were not significant in the community interventions nor was the significance of the connection to the body, the awareness of physicality, the sensory connection to the body, and the perceived greater movement potential and fiend that this offered. This may have been because the structured interviews of the clinical intervention were asking participants about their experience of the intervention while the health psychology and ethnographic evaluations were asking directly about outcomes and impact which the clinical research tried to avoid.

CONCLUSIONS

1. All participants shared the view that the group was important, that a place where shared stroke stories were possible, and where participants were offered the importance of altruistic opportunities to help others. Connections were also valued - to the body and to each other in the group.

2. A key theme was awareness of the body and the forged connection between anatomical awareness and movement. This theme suggests that is an important mechanism of the intervention. Equally significant was offering tasks that forged a connection to the body that could be mastered and repeated and become part of "who you are". Offering exercises that could become daily practice, "part of you".

3. All participants shared an experience of joy and happiness in the workshops. It appears fundamentally useful to offer people traumatised by stroke and newly acquired disability an opportunity within their rehabilitation for joy and happiness that might increase motivation to participate in therapy and life after stroke and might support psychological healing.

4. All participants experienced a feeling of being "free". It is possible to surmise that this is a mechanism of the intervention. It would take more research to analyse what freedom meant for participants but in this analysis we identify, the freedom to escape, freedom to become oneself or find oneself, the freedom to play, the freedom of self expression, the freedom of finding a new way of being in the world, the freedom of imaginative engagement, the freedom of ease or relaxation or peace.

   We could hypothesise that this freedom is partly what creative practitioners refer to as creative process: "creative flow" or "being in the moment" or simply imagination. Eight participants expressed the significance of the shared experience of what RS called " the greater feeling", DO called "the soul" and what he surmised might be "artistry" and what SB called "healing", WP called "feeling high", BO called "feeling lighter, brightness in the body", or "ease" and AS simply "a good feeling". It would take more analysis or research to understand what this signified to each individual and how it aligned with an arts practice. Only one participant, JC, specifically spoke of making an art work, "and important for me to have a project to work on to learn the song… looking forward to improving my voice … looking forward to singing…I am going to have record that song again… I forgot a little bit but I will keep doing it until I get it and I am satisfied." This may be because he was the only participant who identified himself as a creative individual and therefore had a language to express this process.

5. What is certain is that the relaxation and freedom in the group not only led to joy and happiness but also led to increased awareness of what participants "can" do and an awareness that people could move and express themselves more within this framework than they had otherwise thought. It is clear that participants felt that this approach was different to traditional rehabilitation and offered something new. This suggests that there is a role for this practice within rehabilitation, particularly to nurture hope and optimism and to help support motivation to participate in wider therapy.