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The Stroke Ambassador; an ethnographic evaluation

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The aim of this Report is to convey the findings of a pilot ethnographic study carried out between 2017-18 evaluating volunteer stroke survivors in their role as Stroke Ambassadors in the music and movement intervention Stroke Odysseys.

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Lucinda Jarrett, Creative Director of Rosetta Life, conceptualised the study. Jean Harrington and Nina Fudge formulated the design. Christopher McKevitt and Jean Harrington gained ethical approval. Jean Harrington structured the approach and carried out the observatiothe ns and interviews. Jean Harrington and Nina Fudge developed the analysis framework. All authors reviewed and approved the final report.

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Conflicts of interest

There were no conflicts of interest in the writing of this report.

Contents

1. Summary

Rosetta Life, who commissioned the study, has sitting within its organisation 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. In 2015, during the early stages of Stroke Odysseys, twelve stroke survivors, who had experienced the intervention, stepped forward to co-produce, with Rosetta Life, a model of peer support for new participants. The emerging 'Stroke Ambassadors' worked within the Stroke Odysseys intervention between 2017 and 2018 to test and embed the model in hospital trusts and non-NHS community settings. Likewise, between 2017 and 2018 a pilot evaluation of the role and value of the concept of the Stroke Ambassador was undertaken. Following ethnographic observation and interviews, the key findings of this study point to several benefits for the Stroke Ambassadors, the people they work with and the wider stroke community. Firstly our data point to significant physical, cognitive, psychological and social value of the role to the Stroke Ambassador themselves. The study also indicates the physical, cognitive and social value of the role to stroke survivors in the community and patients within NHS sites. Public Performances by the Stroke Ambassadors, (stroke survivors in the community and patients within NHS sites) provide powerful, personal perspectives on what it is to be a stroke survivor in our society. In conclusion, the role of the Stroke Ambassador produces noteworthy improvement in the quality of life for the Ambassador themselves and members of the local stroke community. It also provides a conduit to wider society through which the experience of stroke survivors may be better comprehended. As the role evolves we predict there will be challenges and opportunities concerning the utilisation of the specific capacities and skills of individual Stroke Ambassadors and scaling-up the concept across the varying urban/rural landscapes of the UK, including taking into account socio-economic differences and the complex administrative and institutional structures that will need to be in place to support the Stroke Ambassadors' work. However, these challenges, if surmounted, present an opportunity for the role of 'Stroke Ambassador' to sit alongside the standard care of the neurologically disabled

enabling an improvement in quality of life for those to whom there is little long term therapy available. Likewise new opportunities for the intervention and Ambassadors are emerging, for example in other areas of neurological damage where benefits associated with the plasticity of the brain can be nurtured.

Note: *Each of the Stroke Ambassadors has been assigned a pseudonym. This meets with the study's ethical approval, however it must be noted that several of the Stroke Ambassadors did not wish to be anonymous, in fact they specifically asked to be named and identified. This is an important issue, echoing findings within the study highlighting that it is important for stroke survivors to be acknowledged, and by so doing regain identity, worth and presence.*

2. Introduction

Rosetta Life, who commissioned the study and this Report, describe themselves as 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*'. They aim to '..... *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.

In 2015, during the early stages of Stroke Odysseys, twelve stroke survivors who had experienced the intervention stepped forward to co-produce, with Rosetta Life, a model of peer support for new participants of the programme. These stroke survivors were known as 'Peer Ambassadors', although this name was later changed to 'Stroke Ambassadors' at the request of the stroke survivors themselves. Following the formation of the group the Stroke Ambassadors worked within the Stroke Odysseys intervention between 2017 and 2018 to test and embed the model in hospital trusts and non-NHS community settings. This was an opportunity for the post-stroke community - who have been described by Rosetta Life as '*gaining voice and self-confidence through their participation in Stroke Odysseys*' (https://www.rosettalife.org) - to share their experience with other London stroke survivors and to encourage grassroots participation in the project.

In 2016 Nina Fudge was approached by Lucinda Jarrett to give her opinion on the viability of a pilot ethnographic study of the Stroke Ambassador. Following this Jean Harrington was drawn into the conversation and commissioned to carry out the study, accompanied by Nina Fudge during the analysis of the findings.

3. Aims and Objectives

The primary aim and objective of the study (*Stroke Ambassadors: An Ethnographic Evaluation*) was to carry out a pilot evaluation of the role and value of the concept of the Stroke Ambassador in the Stroke Odysseys intervention. The study does not form part of an evaluation of Stroke Odysseys the intervention programme, but focuses *purely* on the Stroke Ambassadors, their role and the value of the role to themselves, the stroke community, the wider society and inherently to Stroke Odysseys. As a transformational study, a secondary aim was to highlight challenges and opportunities and to make recommendations for the development of the Stroke Ambassador model.

4. Methods

A qualitative, ethnographic approach was chosen to provide in-depth data from which the value and impact of the role Stroke Ambassador could emerge. Ethical approval for the study was facilitated by Christopher McKevitt and awarded through King's College London in 2017 (Ref. No. LRS-17/18-5262).

Between June 2017 and November 2018 ethnographic on-site observation of ten Stroke Ambassadors carrying out their role took place at Community Workshop spaces (n=2), NHS sites (n=3), Rehearsal sites (n=2) and Performances locations (n=4). A total of 16 separate events, spread between these locations, were observed, totalling, approximately, 80 hours of observation. Semi-structured interviews of four Stroke Ambassadors and one carer were carried out during the same time frame. Each interview was between 45 mins to 2 hours, totalling approximately 7 hours. Four interviews were carried out face-to-face and one took place over the telephone. Alongside the observation of the ten Stroke Ambassadors carrying out their role were nine community setting stroke survivors and thirteen hospital patients receiving the Stroke Odysseys intervention accompanied by one physiotherapist and four carers, and ten artists and two administrators supporting the Stroke Ambassadors and Stroke Odysseys, . However, the focus of the evaluation was on the Stroke Ambassadors; pseudonyms being Matthew, Rose, Angelina, Imran, Julie, Gary, Tomasz, Jennifer, Victor and Patricia. Consent to observe was sought from each of the Stroke Ambassadors following the supply of an Information Leaflet. Those being interviewed completed a second, interview specific, Consent Form, again following the provision of an Information Leaflet. Reference to any other person in this Report is in order to bring clarity to the role and value of the Stroke Ambassador model. Where this occurs a pseudonym has been provided with the exception of Lucinda Jarrett, the Creative Director of Rosetta Life.

Following observations and interviews narrative transcripts were promptly produced for the purpose of on-going analysis.

Analysis

Jean Harrington carried out on-going analysis during observations and interviews, keeping observation diaries and memos of analytical ideas, threads, and theoretical lines to pursue alongside data collection. Jean Harrington and Nina Fudge first carried out analysis of the full data independently, with both applying thematic coding to the narrative transcripts. Following this a comparison of findings was made and the outcomes iteratively discussed. The emerging key findings, including challenges and subsequent opportunities and recommendations for improvement and growth of the role, are contained in this Report along with indications of theoretical relevance. It is anticipated that two academic papers based on the results from this study, will be published at a later date.

5. Results

Our findings fall into four categories. First, the emergence and developing nature of the role 'Stroke Ambassador'. Secondly, the value of the role to the individual Stroke Ambassador. Thirdly, the value of the role to the newly disabled, either in a hospital or community setting and, fourthly the value of Performance to the Ambassador, the newly disabled, to the wider stroke community and society.

Category One: The emerging and developing role of the Stroke Ambassador

The Stroke Ambassador arose from a desire on the part of early participants of the Stroke Odysseys intervention to support new programme participants whom they considered may be uncertain about what to expect from the intervention. As Rose, a fine artist, singer songwriter and Stroke Ambassador, tells us "*We just wanted to have a say, as stroke survivors …. I think that was a good choice – because without us nothing would have happened because we were definitely in the mix. Lucinda is always interested in our feelings and how we feel. She did it with us, not at us*."

The various elements of the role were co-produced between Lucinda Jarrett and these early participants. Co-production is defined by NHS England as '*a way of working that involves people who use health and care services, carers and communities in equal partnership; and which engages groups of people at the earliest stages of service design, development and evaluation. Co-production acknowledges that people with 'lived experience' of a particular condition are often best placed to advise on what support and services will make a positive difference to their lives. Done well, co-production helps to ground discussion in reality, and to maintain a person-centred perspective'* (http://coalitionforcollaborativecare.org.uk/a-co-production-model/). Observation of, and interviews with the Stroke Ambassadors highlight that co-production, as defined by NHS England, is inherent within the concept of the role.

At this moment in time the role consists of mentoring and supporting new programme participants and creating, designing, rehearsing and engaging in Performances. The second criteria has many functions, not least in order to elucidate the position of stroke survivors within society. Ambassadors attend Stroke Odysseys' intervention sessions held in both the community and NHS hospital settings, participating in the sessions alongside those receiving the intervention, acting as a role model and support to the artist(s). Observation of the role, and what it entails, reveals that the emphasis continues to be focused on the concept of co-production right through from NHS/community setting to full stage Performance. For example prior to and following the intervention being run in a hospital setting Stroke Ambassadors are involved in the design of the session including exercises, visual aids and music. Following the session they are involved in a full de-brief, being asked their opinion on the overall impact of the session on participants, both individually and collectively. The following are notes from Observation Diary (OD) 06.03.18; Carol, Brenda and Anne are pseudonyms for participants of the intevention. The notes refer to the debriefing, '**Gary refers to Carol and her not wanting to be here. Rose points out that it was because her son had arrived. It was his first visit and she wanted to be with him, not in a therapy session with him, but just with him, "*We can't blame her for that*". Brenda's aphasia was discussed and Gary and Rose point out that she had no tools available to control what was happening to her. Gary adds that it was clear that Anne had enjoyed the session!'**

Where Performance is concerned Rose tells us, "*If I want to do something nobody will say 'no'! I will try to do it. For instance I had an Irish song and I wanted everyone to try to learn this song and they did*". The song that Rose refers to was performed by the cast of actors during several Performances to the paying public, for example at the Greenwood Theatre, King's College London, on the 3rd November 2018.

Emergence of the role

Related to co-production, one of the key findings is the ongoing *emergence* of the role, sculpted by the expanding work of the Stroke Ambassadors and their relationships with intervention participants, artists and wider society. Below are three examples of the manner in which the role is continuing to come into existence.

Example one: Stroke Ambassadors display different capabilities and skill levels, this can be as a result of their stroke, life experience or 'personality'. For example, some have an extraordinary level of empathy and intuition, encouraging participants to join in the intervention, observing difficulties they may have with movements, cognitive tasks or voice exercises and adapting their responses accordingly so that the participant can be involved to the best of their ability. They see and respond if there is embarassament and discomfort, displaying empathy and acknowledgement, and providing unobtrusive care. Others are natural Performers, able to nurture a rapport with audiences and hence the skill to provoke a change in public opinion concerning stroke survivors and their place in contemporary society. For example at the Performance on the 3 Dec 2018 at the Greenwood Theatre, King's College London, both Tomasz and Jawad provoked extensive applause following their demonstrations of 'physical ability'; Performing capacity instead of incapacity, ability instead of disability, functionality instead of disfunction.

Rose tells us, "*Everyone has a different soul to add to the mix. Everyone has an opportunity that they can give what they do best. I think everyone has something they can contribute, no matter how small and it's good for them and good for the organisation as a whole. It's amazing. It takes a while to see what a person gives to an organisation – somebody could be a really good mover, somebody could be a poet, somebody could be a really good listener."* Finding the optimum role for an Ambassador within the programme presents challenges, but could be addressed through various means. For example during the period of observation a system of accreditation was discussed with the Ambassadors. Within the accreditation would be pathways

that would lead Ambassadors to become 'experts' in specific areas, say hospital involvement or publc Performance. This would maximise the benefit for both Ambassador, participant, the stroke community and society as a whole.

Example two: The NHS hospital setting within which Stroke Odysseys takes place and the Stroke Ambassador works is presently dictated by space, time and internal structures. It is evident that the evolving, increasingly skilled, Stroke Ambassador has the capacity to build positive relationships with the newly disabled resulting in improved mood, and as a consequence improved health, for the patient. These relationships are currently nurtured in the community setting during informal tea breaks, evidenced during observation. However space, time and institutional factors make this impossible in the hospital setting. In discussion with Stroke Ambassadors they report that they would warmly embrace the possibility of spending more time with the newly disabled in the hospital setting; Angelina *"They are shocked* [referring to the newly disabled]*... they don't know what is happening ... I would be happy to spend time, two hours or more ..... it is good, it helps them."* From Rose we hear "*... I went to the hospital and one woman recognised me and she said "Auntie", "Auntie", "Auntie!" and it was so nice that she remembered me. It doesn't matter that she called me Auntie, it was about remembering me, and that she would have a connection with me, and that is like a trucker's salute. Old truckers salute each other whether they know each other or not. It's the same with stroke survivors. It's like people who are having babies, they have a code of honour, and it's the same thing. She knew that I had a stroke and she had just had one and she was thrilled to see me."*

Example three: Over the course of 2018 Lucinda initiated conversations concerning the possible partnering of Stroke Ambassadors with General Practitioners (GPs) and stroke survivors. Imran told us of the benefit of one such partnering with which he was involved. Imran was introduced via his local GP practice to a man of similar age to himself who had recently had a stroke. Imran, who has aphasia and speaks in short sentences, explains he was, "*Able to visit stroke survivor. In his head he is human* [reference to the stroke survivor's mental state]. [I] *Think prevented*

suicide. Started visiting him, taking him to park, going shopping. Stroke survivor now much happier, able to visit his daughter in Manchester." The opportunity will be to facilitate the pairing of GPs with Stroke Ambassadors that meets current Health and Safety, Data Protection and NHS legislation in a manner that is acceptable to both the Stroke Ambassador and GP.

In essence the emerging role of the Stroke Ambassador affords improved quality of health opportunities for both the Stroke Ambassador and newly disabled. However, the manner it is pursued requires careful and delicate handling with all parties endorsing the necessary institutional changes and personal commitments.

Category two: The value of the role to the individual Stroke Ambassador

The aim for improvement in function is inherent within the Stroke Odysseys programme. For the Stroke Ambassador there is substantial opportunity for an improvement in their own quality of life. During the observation areas of improvement were seen in physical bodily function, such as (a) mobility, speech and voice, (b) cognitive improvement, and (c) an increase in self-esteem and confidence. Below we look at each area separately, although it must be stressed that we consider the three areas work collectively to improve quality of life.

Physical improvement

Matthew speaks of the benefit in simple terms, "*It's a form of exercise – and exercise is good*!" Rose tells us, "*every time we meet we always have a physical warm up with a mental warm up and then we do our sessions. …. No tablet will help as much as this helps*." Talking about other organisations for stroke survivors Angelina tells us, "*Since I met Lucinda and Stroke Odysseys, apart from Stroke Choir, I stopped all other groups. There's no time for me to go there, sit down there, talking, cup of tea, games, doing nothing. This, we are doing something, ….. exercises and singing."* During an observation Julie tells us that the exercises are "*helping getting me stronger."*

Cognitive improvement and enhancement of mood

Observing the Stroke Ambassadors over a period of 15 months has allowed us to record changes that have occured. It has become apparent that individual Stroke Ambassador's cognitive ability and/or mood improves.[1] Observation diaries show that tongue twisters that proved difficult for some members when we joined the group now literally 'trip off the tongue'. Activities that involve passing sounds from, say, a person on your left to a person on your right are carried out with more certainty and speed and less error. Engagement with an image results in more complex responses and more discussion. It must be added that the speed at which individuals have shown improvement has been varied, but overall it is apparent that cognitive improvement and significant mood enhancement is taking place within a high percentage of Ambassadors, observation would put this at approximately 80%. This we identify as a key finding as cognitive ability and mood are argued to be interlinked (Barker-Collo 2007). In her work '*Depression and anxiety 3 months post stroke: Prevalence and correlates*', Suzanne L. Barker-Collo argues that depression and anxiety are commonly experienced post stroke and that '*cognitive factors such as speed of processing and verbal memory were more related to mood disturbance than was level of physical independence'*. She concludes that '*cognition and mood post stroke are linked and both should be addressed as part of the rehabilitative process*.' With one Stroke Ambassador telling us that they had initiated the stopping of antidepressants since commencing the role the indications are that, as part of the rehabilitative process, the role may include factors that enhance mood with the knock-on effect being enhanced cognition - both of which lead to improved quality of life.

Self-esteem and confidence

As with cognitive improvement and mood, observing over an extended period has allowed us to record changes that have occurred in self-esteem and confidence. Following the Stroke

[1] As a caveat it must be stated that we do not assert that improvement was singularly down to the role of Stroke Ambassador and engagement in the various exercises.

Ambassadors attendance at community workshops, NHS sites, rehearsals and Performances indications of an increase in confidence and self-esteem are clearly visible. The following is a diary observation, OD 23.04.18 **'Angelina is asked to sing a new song. It is from her country of birth. She has a beautiful voice and she leads the group with confidence and certainty. Bentley, a stroke survivor, knows the song too and joins in. Angelina encourages him. Both are smiling broadly. It is clear that being able to Perform is important to them both and they are experiencing the confidence to do it.'**

An increase in confidence and self-esteem is also apparent when the Stroke Ambassadors are working with patients at NHS sites and stroke-survivors in community settings. Matthew puts this succinctly when he tells us "*the benefits are not only health, but positive attitude, confidence, belief in ourselves."*

For Imran it is "*purpose in life, very important – if not, just bed and eat. Richer, fuller life - more worthwhile, self-worth*". These points, although captured with just one word, indicate that self-esteem may be lacking in stroke survivors lives and the benefit that being a Stroke Ambassador brings. Imran continues, telling us he is "*very happy*" he has "*learnt new skills, dancing, learnt to do new things*". This he tells us is "*very important."* He carries on, "*life continues*", now he feels "*there is progression*", not just "*re-capturing*" but "*moving forward, little-by-little*".

The sense of 'progression' to which Imran refers is an essential key finding, intrinsically bound up with self-esteem and confidence. During observation and within interviews it is apparent that stroke survivors feel, and are often made to feel in their daily lives by key figures such as those in the medical profession, that they are continually looking backwards to the point prior to their stroke; aiming as Imran tells us to merely "*re-capture*". The role of a Stroke Ambassador allows for a better acceptance of '*who and how*' they are now by realising that they can learn new skills which they can display and impart to others. They refer to showing the newly disabled "*how*

much we have improved, that is a fantastic thing for them to see – they will see that there is life after stroke." (Rose).

Relationships, friendships, community and Kinship

During the period of observation the Stroke Ambassadors often had significant contact with each other. This took the form of a weekly morning or afternoon meeting in a Community setting and, in some cases, intense contact during rehearsals for Performances and the Performance itself (including travel to the location and overnight stays). During this contact there can be seen to be the building of relationships, friendships, community and importantly 'Kinship'. 'Kinship' here is understood in the metaphorical sense of developing a relationship on the basis of a shared history, e.g. the experience of a stroke. It is observed that the Stroke Ambassadors share characteristics that engendered trust, understanding and empathy. For example the working on another stroke survivors body, that is, allowing another person to touch, rub, press and massage (observation provides numerous examples); a lack of awkwardness or embarrassment when exercises are conducted together; leaning on each other, literally taking the weight of the other person; general 'banter' as beautifully captured by Gary to Rose at an NHS site, "*Are you dropping off* [to sleep] *there Rose!*" In these examples we see a manifestation of trust, significant when one considers the damaged bodies that are being tested. The repetitive telling of stroke stories, or parts of the story, too is emblematic of Kinship. The benefit this brings to the individual and group was nurtured by Stroke Odysseys' sympathetic space and specific artistic tasks, however, it was further nurtured by the continued and ongoing propinquity of the Stroke Ambassadors. The following is an example from an observation on the 27.06.18 of the sharing of a 'stroke story' in a Community Workshop:

'Angelina talks about not being able to reach the phone – "*something in my brain crawled, going to hospital, stubborn, trying to sit up, trying to get up, I don't know what is going on*." They didn't tell her straight away. OBSERVATION: the need to speak, to be heard – therapy. The group have immense patience, listening to each fully, nodding, empathising.

"I *am not the Angelina I was, I was a different person with a different life.*" She holds the floor for a long time, it is obviously a painful story, formed and shaped since the stroke took place.

The desired "*weight*" of work; a job

Many of the Stroke Ambassadors had to give up their careers following their stroke. Some are still grieving. Matthew however is of the opinion that "*Even if I can't do a job* [he was previously a bus driver], *I can still be a useful member of society.*" The concept of 'work' arose many times during observation. For Patricia, the role of the Stroke Ambassador had to be "*significant*". Patricia has aphasia, despite that the following captures her desire to be involved in a role with worth and gravitas, "*Want to be able to DO things. To give more. Importance of work. The weight that work carries.*"

For Rose the Stroke Ambasador "…..*is a willing job. I'm not interested in financially gaining from this. We can do it when we are fit. If we are not well or fit we don't have to go, so it is not a job in that way and for us that is a crucial distinction, we do it because we want to do it."* Here Rose raises the very important notion of society's accepted concept of 'work' and the various ways in which Stroke Ambassadors might challenge that concept and by doing so contribute in meaningful ways to society (Wolf et al 2009).

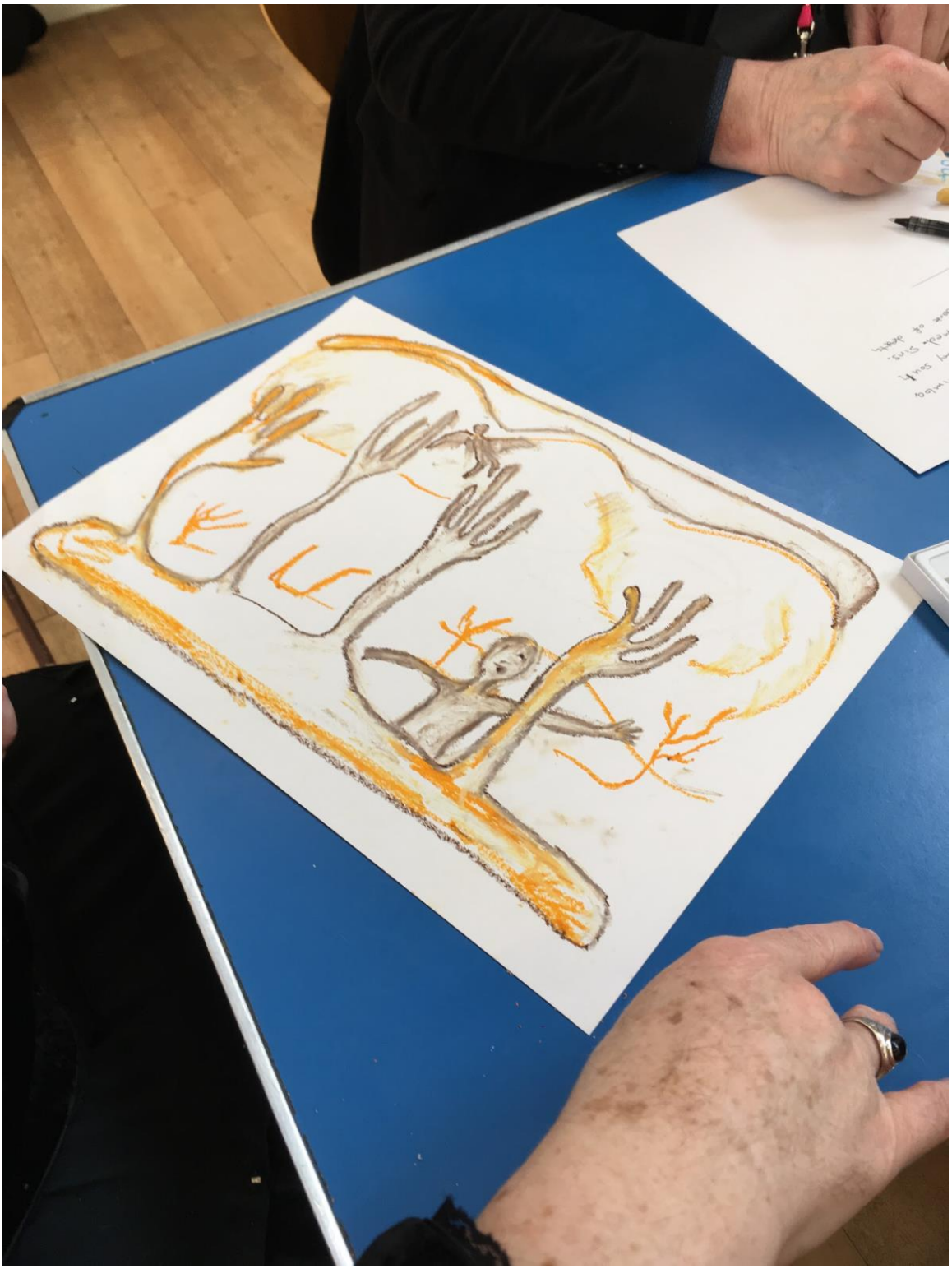
Throughout all the observed rehearsals and Performances it was clear that the Stroke Ambassadors 'work' hard. The Artists have high expectations and these expectations the Stroke Ambassadors seek to fulfil. The following is taken from the observation diary 06.03.18 '**When discussing the possibility of the group touring with their Performances the conversation is serious and focused. It feels like a group of people coming together to carry out a task, to produce, to be taken seriously. It feels like the discussion is about a job, about work. The emphasis has moved from a therapeutic environment to one of an activity involving mental or physical effort done in order to achieve a result**.'

The regaining of 'voice' and 'power'

Throughout the observation expressions have been used that identify the challenges that stroke survivors are faced with following a stroke. Certain expressions relate to regaining levels of 'voice' and 'power', for example, "*finding your feet*" and "*holding on to power*".

Lucinda uses methods that allow the Stroke Ambassadors to capture their voice through the medium of a few words, a drawing, a line of poetry or physical motion. This works well for the Stroke Ambassadors, particularly those with aphasia or speech difficulties, as part of the barrier to expressing themselves is removed.

Rose "*Again I have to say I am an assured person, but it has helped me to be the powerful person I am. When I rest in isolation – I don't like that place, it is always really nice to get back to the company and immerse ourselves and me into the organisation and just be one of the powers into a big power.*"



Category Three: The value of the role of Stroke Ambassador to stroke survivors

For those newly disabled who are accompanied and assisted by a Stroke Ambassador, be it in the hospital or community setting, there would appear to be a benefit both physically and cognitively. This we have recorded to be through the process of both observing and working directly with an Ambassador. At a community setting in June 2017 the Stroke Ambassadors spoke of how they would like to assist other stroke survivors: Tomasz said "to give them encouragement", Victor referred to "*self-improvement, myself as a role model*." Rose talked of "*guiding to the pitfalls; there are many, one needs to roll with the punches, and there is light at the end of the tunnel*". Jennifer wished to "*encourage them that they will be there one day*" and Imran "*helping with skills, significant, meaningful.*" Observation that followed these wishes indicated that the Stroke Ambassadors try to fulfil these individual objectives; Angelina, "*Sometimes they ask me 'are you a stroke patient?'. And I say 'yeah, look at my stick." They say 'Oh!" I say 'look, you too, one day you will be here, you will be like me.*"

There is also an opportunity for stroke survivors in hospital to experience the Kinship exhibited by the Ambassadors. Observations record the tenderness and thoughtfulness with which Stroke Ambassadors demonstrate tasks within the programme, ensuring that the newly disabled retain their dignity, nurturing a sense of self; Angelina tells us "*If you are in hospital you are sitting down, you are laying down, you don't know you have a body. You don't know nothing, your memory and everything may have gone. I ask, 'can I touch you?' And she say 'yes', then* [I ask] *can I tap you? And she say yes. Then she say, 'that's nice … it's good'. It helps how they feel because they don't know. To have a stroke you are not normal, you are not yourself anymore, you don't know what is going on with your body, you don't know what is going on in your mind, so if somebody help you know by tapping your body it reminds you of your body. It helps them to know that they have to do something ….. that's wonderful …. so you help people a lot in the hospital.*"

At a very human level the newly disabled benefit from the empathy that an Ambassador exhibits. With grace and humour the Stroke Ambassadors also demonstrate their quality of life, including their confidence and self-esteem. Advocating for recovery and sending the message that "*life will improve*", an expression used many times during observation.

The value of Performance

Performance is an inherent element of the Stroke Odysseys intervention programme. Although it is not the remit of this Report to comment on the role of performance in the intervention per se, we observe how the concept is essential to how the Stroke Ambassador undertakes their role and how the role is developing.

Within Stroke Odysseys there are different levels of performance. Firstly there is the 'performance' in the community workshops, with each stroke survivor performing the session exercises - the physical, visual, auditory and cognitive tasks. Next there is the 'performance' of Stroke Ambassadors in the hospital setting during their demonstration of the exercises. Here they display the transformed, rejuvenated, rehabilitated stroke survivor. This amounts to both illustration and encouragement for the newly disabled. Next there is the small Performance that is put on at the conclusion of the 12 week programme at a hospital site. Here you have the newly disabled benefiting from the sense of achievement that comes from performing *ability* instead of *disability,* for a short period of time challenging the categorisation of the '*sick role*' (Parsons 1951).

At the other end of the performance curve is the puplic Performance on the Theatre Stage where the Ambassadors enact their rehearsed selves through the use of their own created, designed and choreographed scripts, a literal 'on-stage' manifestation (Goffman 1956). Throughout they are encouraged to perform an intact performance as part of recovery, but with, as Jennifer tells us "*mistakes not corrected, flexibility, people not looked at as if we don't know what we're doing.*"

Translated through the Stroke Ambassadors, the varying levels of performance have value for (a) the newly disabled, in the actual demonstration of the exercises accompanied by a display of competence from a stroke survivor, (b) the Ambassador themselves in the confidence and self esteem it produces as captured by Matthew, "*Encouragement – at first people think "I can't do it" and after they find they can. Encouraging confidence – to perform in front of people – big milestone ..... after I feel very upbeat*." Finally, (c) via the public stage, it brings value in the form of a visual and auditory message about the condition of the stroke survivor in society.

6. Discussion

The above findings point to the significant physical, cognitive, psychological and social value of the role of 'Stroke Ambassador'.

Observation indicates that at this very early stage the value of the role is primarily embedded in the Stroke Ambassador; in the case of such a new concept we would argue this is understandable. As such we would recommend that future studies focus not only on the Stroke Ambassadors, but more broadly, including intervention stroke survivors, who may well provided data on what the Stroke Ambassadors mean to them. To be explicit, the regular physical exercises are valued by the Ambassadors as is the improvement in cognitive performance. Improvement in mood, confidence and self-esteem have been observed and spoken of as highly significant by the Ambassadors themselves. The kinship that has developed is also viewed as equally beneficial.

The study also indicates a physical, cognitive and social value of the role to stroke survivors in the community and patients within NHS sites. Public Performances by the Stroke Ambassadors, (stroke survivors in the community and patients within NHS sites) provide powerful, personal perspectives on what it is to be a stroke survivor in our society and provide value to all participants and, we would argue, importantly to the public.

In essence the role of the Stroke Ambassador produces noteworthy improvement in the quality of life for the Ambassador and members of the local stroke community. It also provides a conduit to wider society through which the experience of stroke survivors may be better comprehended.

However, the very concept of the Stroke Ambassador is quickly evolving, along with the incumbent Ambassadors, and will continue to do so challenging present infrastructures. Likewise new opportunities for the intervention itself are emerging, for example in other areas of neurological damage where benefits associated with the plasticity of the brain can be nurtured.

Taking the issue of the evolving role of the Stroke Ambassador we have highlighted the challenge of maximising individual Ambassadors' skills, conceivably to be met with a system of

accreditation that will work for both the Stroke Ambassador and those receiving the intervention. As numbers rise, balancing individual Ambassadors' desires and abilities with the needs of the programme will be important. As observation has made apparent that the role is of great value to the Stroke Ambassador it will be important for future planning to include in detail how the role will continue; leaving people without the role would obviously go against the inherent ethos of the programme. As the job is completely voluntary, and inclusiveness is an integrated factor, it will be important to continue to have co-produced systems in place.

Not only will the role of the Ambassador be evolving, the location too will change. It must be remembered that the role of Stroke Ambassador was enacted within Greater London, within certain parameters, i.e. urban location, good transport system, diverse population, and so forth. To underpin the findings within the study it would be essential to roll the intervention and evaluation out to other geographical and socio-economic sites within the UK. This would allow cross-comparison providing a more balanced evaluation of greater use to Rosetta Life and organisations such as the NHS.

It is highly likely that the concept of 'Stroke Odysseys' can likewise be expanded to bring benefits to neurologically challenged patients other than those who have experienced a stroke, for example those who have brain damage caused through a traffic accident. We would argue that this is a logical and positive step, however, the question of the importance of 'diagnosis' would need to be considered (Griffiths et al 2007). The Stroke Ambassadors changed their title from Peer Ambassadors to Stroke Ambassadors reflecting the power of Kinship. Indeed throughout the observation and interviews it was clear that Kinship based on empathy, identity and group mentality is important. This is not to say that the Ambassadors are not inherently open to working with those who have neurological damage caused by something other than a 'stroke'. As Matthew told us during his interview *"Diane Morris* [author] *doesn't call it stroke, but acquired brain injury – doesn't matter how – the outcome is the same 'if it quacks like a duck, it's a duck'."* As can be seen by Rose's reference to the "truckers salute" however, recognition

is also important. Expanding the concept longterm to, for example, Morris' terminology of 'acquired brain injury' would require transparent recognition of the tension between the importance of Kinship and the desire to work with those with various diagnosis. It must also not be forgotten that those with a different 'diagnosis' may also have opinions on the specific concept of a 'Stroke' Ambassador.

Careful consideration leads us to argue that the above challenges, if surmounted, present an opportunity for the role of 'Stroke Ambassador' to grow and sit alongside the standard care of the long term neurologically damaged within the UK offering improved quality of life to a group of patients to whom there is little long term support. Indeed in his article of 2016 titled, *Long-term support improves quality of life for people with stroke*, Professor Jonathan Mant discusses the changes to the updated NICE quality standard on stroke in adults, and the importance of rehabilitation following stroke. One of his key findings is "**Many stroke survivors report a feeling of 'abandonment' after discharge from hospital. Services are not currently configured to address this need**" https://www.guidelinesinpractice.co.uk/cardiovascular/long-term-support-improves-quality-of-life-for-people-with-stroke/352835.article.

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