Stroke Odysseys

Psychological Evaluation Report

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Updated xxx,

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EXECUTIVE SUMMARY

This report focuses on the psychological evaluation of 'Stroke Odysseys', a novel community based, song and movement intervention for stroke survivors, designed and delivered by Rosetta Life. Rosetta Life subcontracted the University of Surrey (reference 100915 Supplier Contract) to conduct quantitative and qualitative evaluation of Stroke Odysseys to identify its potential effectiveness in relation to key psychological outcomes and putative mechanisms of action. This report provides an initial assessment of effectiveness, and gives a critical assessment of the methodology. Alongside the University of Surrey's evaluation, researchers at the London School of Economics and Political Sciences (LSE) were subcontracted by Rosetta Life to conduct an economic evaluation of Stroke Odysseys. Whilst the input of LSE researchers is referenced in this report, their economic evaluation is separate to the work reported here.

MAIN FINDINGS

The findings of the report is limited to the focus group (qualitative) data as there was insufficient quantitative data available for statistical power. This was partly due to logistics, as the workshops can only accommodate a small number of individuals, and the limited availability of the professional performers, and is also due to the limited number of locations which are accessible and close to the participants where the workshops can be delivered. In addition, the control comparison data — had too few responses and too much missing data — and what data was available was collected at a different time point to the intervention group, and therefore a direct comparison with the intervention group was not possible. This was unfortunate, however the lack of quantitative data is off set by the richness of the findings from our qualitative analyses.

Our qualitative analysis found seven main themes from the first focus group: (1) Pervasive Changes After Stroke, (2) Stroke is not the end of the Story, (3) Motivation to Participate, (4) Intervention Mechanisms, (5) Reorienting to dis(ability), (6) Acceptance and Expression, (7), Not For Everyone; and six main themes from the second focus group: (1) Group Cohesion, (2) Confidence, (3) Communication, (4) Staff, (5) Practicalities of the Intervention, and (6) Intervention Delivery.

The focus groups were conducted by different research assistants, however we found a high degree of consistency between both sets of analyses. Below we present a summary of the main findings from both groups.

Having a stroke had a marked impact of the participants and many discussed pervasive changes in who they are and what they were able to do following stroke. There was a loss of past life and acceptance of a type of 'rebirth' and adjusting to a new self. It was not the end but the beginning of a new chapter. Taking part in Stroke Odysseys, provided participants the opportunity to 'get out of the house' and connect with people and follow a shared goal; it also brought some structure to peoples' lives. Participants welcomed the opportunity to work with professional performers and were open-minded to a new

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experience. Indeed it was the novelty of being taught and learning new things which attracted people to the programme.

Participants talked about the pleasure derived by the creative nature of the intervention and enjoyed speaking/singing and the movement element of the programme, as well as the social aspect of being part of a group. Discovering something new about themselves through the creative process, or rediscovering something that had been forgotten within them, was found to be rewarding.

The supporting environment was something that was appreciated by the participants. Participating in the creative workshops was seen as a joint endeavour and the participants spoke about being very much part of the creative process. All appreciated the guidance by the professionals and the focus of what can be achieved was valued by the participants. Participants very much liked and valued the person-centred approach.

Engaging with the intervention gave participants a new perspective on their abilities and gave them a sense of what they can do. Participants spoke about changing their relationship to their disability as the intervention had given them the confidence to push further than they normally would. Participating in the workshops also created a sense of identity and the workshops were perceived as a joint experience. The nature of developing a performance gave people a shared goal and facilitated open discussion which is not always found in other support groups. The ethos of openness amongst members developed a sense of group cohesion and mutual empathy. Although the programme may not be enjoyed by all, and is clearly not for everyone — the participants were self-selected —the majority of participants enjoyed being part of the programme and there were clear benefits reported by those taking part.

MAIN RECOMMENDATIONS

Future work is needed with a larger sample in order to quantifiably test the intervention. Outcomes measures such as anxiety, depression, and quality of life, and other personality measures such a social cohesion and mastery, would add to our understanding of the benefits participation.

CONCLUSIONS

Our analysis suggests the Stroke Odysseys', song and movement intervention for stroke survivors, has the potential to improve the quality of life and wellbeing of stroke survivors. This is supported by the findings of two qualitative focus groups. Unfortunately, there was insufficient data to make a reliable interpretation of the quantitative data. Whilst the intervention may not be liked by all, it is evident from our analysis that the work of Stroke Odysseys' is contributing to the quality of life of the attendees. This qualitative research has examined two focus groups within a specific locality/context, and time, and therefore it is not possible to generalize from these research findings. Further work is needed to empirically evaluate whether there are actual clinically/quantifiable improvements and whether such improvements are sustained overtime.

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SCHEDULE OF SERVICES DELIVERED

Table 1 sets out the schedule of services in the contract and delivery against each service. In the contract, the service schedule was divided into three phases (with phase 1 further subdivided into phases 1a & 1b). However, as Rosetta Life progressed their delivery of Stroke Odysseys, they deviated from the phases outlined in the contract. As a consequence, the University of Surrey delivery against the initial services and milestone dates needed to be varied accordingly to respond to the change in progress of Rosetta Life's overall project. Resource issues also emerged that impacted on the provision of outcome data by Rosetta Life to the University of Surrey. This meant that some of the psychological outcomes of Stroke Odysseys could not be assessed fully. Table 1 also records further services that were supplied to Rosetta Life over and above those agreed in the schedule, most notably provision of specialist input and advice to Rosetta Life when they were preparing their NHS ethics application.

Table 1: Services contracted and delivery

Service and Milestone Date Phase 1a	Delivery
Supplier attendance at research practice workshop (1 October 2015)	*Attended by Dr. Simonds. Dr. Simonds sent notes to Rosetta Life following the workshop providing comments on data collection and intervention theory/delivery (**see Appendix A**)*
Supplier attendance at 2nd research practice workshop (16 December 2015)	*Attended by Prof. Mark Cropley*
Supplier attendance at 3rd research practice workshop (8 February 2016)	*Attended by Dr. Laura Simonds. Dr. Simonds subsequently sent comments to Rosetta Life and health economist at LSE involved in the project regarding Phase 1 delivery and evaluation of psychological outcomes (**see Appendix B**)*
Questionnaires agreed between all parties as appropriate for Supplier's use (January 2016)	*Consultation with Rosetta Life and LSE researchers on appropriate measures took place between January and June 2016. During this time, the suggested measures were piloted twice by Rosetta Life. A meeting with Rosetta Life and LSE researchers was attended by Prof. Mark Cropley and Dr. Laura Simonds on 21 July 2016. At this meeting, the final measures were agreed. Measurement issues are detailed in section XX of this report.*

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Supplier submission of application for REC approval for evaluating the intervention in September 2016 (March 2016)	Given that final agreement of measures was delayed, the application for University of Surrey Research Ethics Committee (REC) approval was not submitted until 11 August 2016. The REC raised initial queries on 24 August 2016. We were unable to resubmit until 16 December 2016 because Rosetta Life decided to bring forward running the intervention in hospital settings (and therefore apply for NHS ethical approval). This decision impacted on our own ethics application. Confirmation of REC approval was received on 17 January 2017.
Service and Milestone Date Phase 1b	Delivery
Project model implementation (September to December 2016)	*Rosetta Life commenced the intervention week beginning 9 January 2017.*
Supplier attendance at 4th research practice workshop (January 2017)	*There was no research practice workshop in January 2017.*
Supplier conducts one (1) x focus group to understand the evaluation as experienced by service users and carers (January 2017)	*Given the intervention did not commence until January 2017 and the focus group needed to take place after the intervention had finished, this could not be scheduled in January. The focus group was arranged for 25 April 2017 but Rosetta Life needed to cancel this and reschedule on 5 May 2017. The focus group was conducted on this date. No carers attended.*
Three (3) month follow-up data collected, and analysed by supplier (March 2017)	*Rosetta Life did not supply any follow-up data for analysis*
Report on health psychology evaluation produced by supplier (April/May 2017)	*A report on the first focus group data was sent to Rosetta Life on 6 November 2017 (**see Appendix C**). This was later than schedule because of the delayed start to the intervention, the delayed start to the control group data collection, and delays in receiving the questionnaire data some of which could not be matched or was incomplete. It was agreed that the report could not contain any quantitative outcome data because this was too minimal. Instead,*

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	it would be amalgamated with other intervention data and covered in the final report. See section X for implementation and measurement issues
Service and Milestone Date Phase 2	Delivery
Written papers submitted by supplier to charity for publication (Summer 2017)	*As outlined above, it was agreed that data at this point was too minimal to allow meaningful dissemination*
Supplier disseminates abbreviated report to delegates at conference (Summer 2017)	*The conference referred to in this phase did not occur*
Service and Milestone Date Phase 3	Delivery
Supplier conducts testing of project model using twelve week interventions in two settings: in a hospital and in a community setting with one control group and one wait list control group (September to December 2017)	*As noted above, Rosetta Life applied for NHS ethical approval prior to commencement of Phase 1b. This phase was redefined to be part of the work of a PhD by Lucinda Jarrett of Rosetta Life under sponsorship of Bristol University. Although not part of the contract, Dr. Simonds provided advice in drafting the ethics application throughout July 2016 to June 2017 when Rosetta Life received REC approval. However, it subsequently became apparent to Rosetta Life that they would not be able to collect pre and post intervention data from hospital inpatients. As a result, the supplier was only able to conduct analysis on data collected from the community intervention. However, no questionnaire data were supplied by Rosetta Life for the second community intervention.*
Supplier attendance at 5th and final research practice workshop (January 2018)	*Prof. Mark Cropley and Dr. Laura Simonds attended a workshop on 29 January 2018 and fed back the project findings to date.*
Supplier conducts one focus group to understand the intervention as experienced by service users and carers (January 2018)	*Due to slippage in the project timeline outlined above, the second community intervention did not complete until February 2018. The supplier conducted a focus group on 22 February 2018. SEE APPENDIX ??*
Three (3) month follow-up data collected, and analysed by supplier (March 2018)	*Rosetta Life did not supply any follow-up data for analysis*

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Final evaluation report prepared, disseminated and presented by supplier (Late Spring 2018)	*Due to slippage in the project timeline outlined above, the final report was not prepared until Summer 2018*

Subsequent sections of the report detail the following:

1. Overview of data supplied for analysis
2. Description of evaluation
3. Evaluation findings
4. Discussion of measurement and data collection issues impacting on the evaluation
5. Discussion of general process issues impacting on the evaluation
6. Conclusions and recommendations

Table 2: Summary of outcome measures used

Measure	**Interpretation**

The effectiveness of a non-randomized intervention is typically assessed using group-level analysis in which an active treatment group is compared to one or more comparison groups. The evaluation design indicated the inclusion of two comparison groups: (comparison group I) stroke survivors who met as a group in the community but who do not receive the intervention (to assess the effect of group); and, (comparison group II) individual stroke survivors on the waiting list for the intervention who do not meet other stroke survivors regularly (to assess spontaneous change). During implementation, it became apparent that Rosetta Life were only able to recruit participants to comparison group I. Whilst group level analysis may be applied to compare the intervention group with comparison group I, there needs to be sufficient numbers in each group to permit a valid statistical analysis (referred to as the study having sufficient statistical power). Rosetta Life supplied pre and post intervention data that could be matched successfully for X individuals from the first community intervention and X individuals in comparison group I for the first community intervention. However, the control group data were collected at a different time of the year (X months afterwards) so seasonal effects may also contaminate the comparison. Only X complete and useable sets of control group data were supplied. No control group data were supplied for the second community intervention. The plan had been to pool the two groups of data to attain greater power. Moreover, data could not be collected from carers. We did source three volunteer data collectors to assist Rosetta Life with data collection but, to our knowledge, they were not approached to collect data by the charity. In summary, group level analysis is challenged by a small amount of incomplete data that may not be directly comparable due to differences in when the data were collected. Statistical analysis and, specifically, non-significant findings must be interpreted in this context.

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Table 3: Comparison of Progress Tracker indicators at Induction, Review and

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APPENDIX A.

NOTES FROM DR LAURA SIMONDS, FOLLOWING THE FIRST RESEARCH PRACTICE WORKSHOP ON 1 OCTOBER 2015

The developed intervention needs to be:

- Standardized as far as possible (creativity obviously allowed within this)
- Manualized (i.e. the process can be recorded in steps and followed by people not involved in the development of the intervention)
- Replicable (the intervention tested in Phase 1 should be largely the same as that tested in Phase 3 – unless we have evidence from Phase 1 to the contrary)

Those running the sessions need to collect:

- Questionnaires from participants and their carers (anxiety, depression, self-esteem, quality of life, mastery/self-efficacy)
- Data on idiographic targets
- Time-points: before the intervention starts, mid-intervention, end of intervention. The most reliable method is to collect the before and mid intervention at the start of the session and the end of intervention measures at the end of the session. If carers are not present to complete their measures, they will need to be mailed out by those running the intervention
- 1-month and 3-month follow-up questionnaire data should be collected using an alternative method as the group will have discontinued meeting
- It became evident in the practice workshop that participants may have other physical and mental health conditions. A demographic questionnaire is needed that will allows us to describe the sample fully

Idiographic targets:

- These need to be taken at the start of every intervention session
- Target setting – this is done at the start of session 1.
- Each participant identifies 2 or 3 personally meaningful targets (i.e. things they hope the intervention will improve/change)
- These targets need to be scaled as best suits the particular target (e.g. N times, degree of intensity, etc.)
- Then, the targets need to be taken at the start of each session focusing on progress towards the target in the period since the previous session
- It might be necessary for careres to report on these if the participant is not able?

Focus group:

- This will be run by Surrey at the end of the final session. However, due to potential fatigue can the final session be tailored to reflect this? Or, would we be able to convene a subsequent session just for the focus group?

Theory and Intervention Delivery:

- What are the theoretical underpinnings of the design of the intervention? For example, is touch an integral component and what are the proposed mechanisms to achieve benefit in the outcomes we are looking at? And, other elements such as use of movement and use of voice. Is narrative and meaning-making central? In summary, how are we tying the outcomes to the intervention theoretically?
- What are the essential ingredients of this intervention that are theorized to deliver benefits? Is there an overarching framework (e.g. collective identity)? An idea was evident in the workshop that participants are partners and can shape the intervention/project.

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How does an individually-shaped/flexible intervention work from the perspective of testing a replicable/manualised intervention?

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APPENDIX B.

NOTES FROM DR LAURA SIMONDS, FOLLOWING THE THIRD RESEARCH PRACTICE WORKSHOP ON 8 FEBRUARY 2016

From: Simonds LM Dr (Psychology)
Sent: 09 February 2016 09:06
To: Lucinda Jarrett (l.v.c.jarrett@gmail.com); Mcdaid,D (D.Mcdaid@lse.ac.uk)
Cc: Cropley M Prof (Psychology)
Subject: Ethics application

Dear Lucinda and Dave,

Really good to see you both yesterday and the workshop was incredibly useful. Just to follow-up the conversations we were having after the meeting, I think we need to proceed on the basis we initially agreed that the first evaluation phase focuses on community settings only. We have thought about appropriate comparison groups for the community intervention group (i.e. stroke survivors who meet in the community but don't have the intervention, and stroke survivors in the community per se). If we were to attempt hospital evaluation at this stage, we would need appropriate comparison groups for inpatient stroke survivors. This makes this first phase much larger and would require NHS ethics. Also, there will be data collection issues with inpatients that are likely different to those in the community which we have not thought about or budgeted for in the first evaluation phase.

Dave raised the question re applicability to hospital from the first evaluation to the second which is a good point but I think is sidestepped by how we denote what the second evaluation is – retesting in the community setting but also seeing if the model can be applied to inpatient settings. Would that work Dave?

As raised yesterday, our evaluation isn't budgeted for us physically collecting the questionnaire data from stroke survivors (although we will be doing the focus groups in the evaluation). So, I think what also needs to be taken into the next 10 weeks of development is thinking how do we create a resource to allow stroke survivors to be assisted with questionnaire completion. As we all agreed yesterday, we need to try out a few formats with people in the practice research group to see which is likely to be most successful. We will also look at the literature and I can discuss with a couple of people here who work with stroke survivors. Also, the conversation I had with Manuela re how to collect data from carers was very illuminating and clearly we will seek consultation with Manuela again and other carers if possible to establish the most effective methods of data collection. I imagine this can be done through the 10 week phase Lucinda if I sent you the materials or came along to one session?

We will start working on the University ethics application this end and will be in touch soon with a series of enquiries that need to be taken into the next 10 weeks of development. As noted yesterday, I think it will be good for us to be in ethics in May in case any issues arise. For the application we will need a full description of the intervention and its theoretical/empirical foundation.

Does this seem a reasonable basis on which to proceed?
Best wishes
Laura

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APPENDIX C.

INITIAL REPORT OF FOCUS GROUP 1 THEMES – 5 MAY 2017

Theme 1.0: Pervasive Changes After Stroke

Three participants talked about the pervasive changes in who they are and what they were able to do following stroke.

1.1 Sub-theme: Lost Abilities

Participants (FG1), (FG2) and (FG3) described a widespread loss of abilities following stroke. (FG3) described the frustration of losing the ability to do seemingly small things that are normally taken for granted. His description of trying to hang a picture illustrates the pervasive loss of what might be considered simple functions:

"it's very frustrating at first, you know it's sort of things you've done all your life you take, take for granted, oh I want to put this picture on the wall and you try to like hold a nail and you can't do it, if you want and you can't do it, you can't feel it, you can't touch it, you can't, you don't know what to do".

1.2 Sub-theme: Loss of Self

Participant (FG1) and (FG3) described the changes in sense of self that occur following stroke *"You can't be what you were before"* (FG3). (FG1) described a change in independence as a result of increased personal vulnerability

"Well I, I used to go drinking down the [place name] *for a drink, different, and people would come to clubs and pubs and that, and I would take my time in them, and I can't now. 'Cause there's some who would take advantage of you, still do"*.

Theme 2.0: Stroke is not the end of the story

Two participants talked about stroke marking the start of new life. Whilst the two participants indicated a definitive end to their past life, they described a process of recovery – the essence of self is retained despite change.

2.1 Sub-theme: Moving on

Both participants indicated that stroke marked a definitive end of a past life and a need to move on to something new. However, moving on was expressed in different ways. (FG1)'s comment indicated a sense of moving on as just having to do it

"It really changes, because you realise you've had it, yes it is a lot, but you've just got to get on with it"

(FG2) expressed moving on as having a new life

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In other words the life you had is done, that's it. But that doesn't mean it's the end of the story you know, you can have a new life".

2.2 Sub-theme: Recovery/Adjustment

In their descriptions of moving on from an old life to a new one, both participants expressed the idea that the self is held onto during this transition. This is a core idea in 'recovery' - that function is reduced or changed rather than lost. This allows the person to retain an essence of self, as indicated in (FG2)'s comment

"That's what stroke recovery is, it's a different life, it's still you…moving to a new life, it's like when you move out of a house and you take a package with you"

(FG1) rejects his family members' negative views about what they witnessed in the intervention. To reject this idea, FG1focuses on the fact that abilities, although altered, remain following stroke

"My, my granddaughter don't like it, she said, oh my son, my son, my daughter, my wife and son came to the last one we had, and said that's depressing dad, I said what do you mean, I can't drive, I can't play the guitar, but I can a little bit".

Theme 3.0: Motivation to Participate

Three participants talked about what had motivated them to take part in Stroke Odysseys.

3.1 Sub-theme: Social Connection

(FG1) was motivated to join Stroke Odysseys as it provided an opportunity to get out of the house and to be with others

"Just for company, just so I can have some company".

Similarly, (FG9) saw that the programme offered an opportunity to be with and talk to others

"other than church when I could talk to people, I was very much on my own.

3.2 Sub-theme: Trying something different/unknown

(FG1) construed Stroke Odysseys as providing an experience outside of the norm, to *"see things that you don't see very often"*. (FG1) stated that he joined Stroke Odysseys not knowing what to expect and subsequently discovered aspects he had not anticipated

"before you go to this you don't really know what you're going to go for, I thought it was reading something to do with books or something…I wasn't expecting to dance, so much"

(FG4) had seen a performance of Stroke Odysseys live and (FG5) had been shown a film of Stroke Odysseys whilst in hospital. Both subsequently decided to try it out

"I mean I just thought, saw, saw, saw that I, I saw last year's um, and I thought we'll have a go you know, if we could do the same" (FG5).

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Theme 4.0: Intervention Mechanisms

This theme represents those characteristics of the intervention that made an impact on participants and could be proposed as the elements of the intervention that contribute to it being positively received and having its effects

4.1 Sub-theme: Novelty and Structure

The idea of novelty of the intervention was evidenced in different ways. Some identified the positive aspects of getting to meet professionals

"to meet people professional musicians and professional dancers was good" (FG1)

Some identified the novelty of being taught and learning new things

"Um, to work with um, uh, people, like, like a teacher for us um, I enjoy, I enjoy it, because for me it's um, it's different" (FG7)

"Also help you to learn something new" (FG6).

An ingredient in this was participants being encouraged to try something new

"But you know it's a case of give it a go, and that's it, that's what they encourage you to do" (FG5)

Attending the intervention was perceived to provide important structure to life

"I think that the important thing, which you get a lot with these sorts of things as well, at least you get appointments and things" (FG5)

4.2 Sub-theme: Creative transformation

Participants discussed how their experiences, abilities and feelings were influenced by the creative nature of the intervention. Pleasure was derived from using the whole self

"I get pleasure from coming now. From speaking and singing and moving your arms and everything" (FG4)

and from moving in particular ways *"A dance is funny. And moving"* (FG7).

The creative process itself provided enjoyment

"Um, and dancing, everything you make a story and you make a song, that's really enjoyable" (FG7).

Participants described discovering something new about themselves through the creative process, or rediscovering something that had been forgotten

"Do what you could, yeah, at the end of the uh, you know unusual, and be sort of reminded of things that you wanted to do or could do you know, but you know which you never did it" (FG5)

"*Um, we make um, a story it's like a poetry, and instead of making a point he make a song with it. And they composed like a song, and it's, the song is very nice when you sing it, it's very, very nice…Uh, um, I said I can do a poetry, I didn't know that I was making a poetry, but I am, just like that"* (FG6)

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Participants described how their experiences and memories were transformed into performance

"You know they, they, how do, everything you gave them you know, they sort of…worked on through with it, and then you know it's put into a performance, format as they say" (FG6)

The professionals also used creativity to support participants to engage in skills that had become more difficult

"*so he said to me why don't you change, try with the other foot* [participant stamps]*, so I took a guitar indoors, and I took some music indoors and tried"* (FG1)

4.3 Sub-theme: Feeling valued

The creation of material based on participants' experience and, more specifically, the focus on what participants were able to achieve, engendered a sense of feeling valued. Participants perceived that value was given to the very act of trying, and that this promoted a sense of any inability not being devalued

"But you know even if it did, you did do something it would be valued…your abilities are valued, but your disabilities are not devalued…I supposed that's the simplest way of putting it" (FG5)

(FG1) describes a feeling of being placed at the centre of creation by the professionals

"so these people, not only teaching you music and how to read properly uh, there was some of us who uh, individually asking what do you like, what's your last memory of the thing you like…Everyone here, and for them to take the time and to write that song uh, one, two, three different songs made a difference.

(FG5) indicated that the focus on ability and not on inability builds confidence and the likelihood that people with persist with the intervention

"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"

The engagement skills of the professionals engendered positive feelings about taking part

"All of the people was friendly with you, the games and they talked, and got you going so it's a nice feeling…and that's why we, we liked to do it" (FG8)

5.0 Main Theme: Reorienting to dis(ability)

Engaging with the intervention allowed participants to change their perspective on their abilities. This new perspective was related to perceptions about transitions to a new life.

5.1 Subtheme: Change of Perspective

The intervention allowed participants to relate to ideas about ability and disability in a different way. (FG5) used the idea of an advertisement about a chair lift to convey this

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"it's rather a sort of uh, uh, an emotional image…Mmm, and I suppose it's one you can sort of build on as well but…In another way it's looking at yourself in the opposite direction is what one way, looking at the other persons uh, perspective, looking up, it's you know, looking down as well"

The intervention allowed participants to show what they can do and, as a result, changed their relationship to disability

Moderator: *And what did you enjoy?*

(FG2) (people with strokes) *show what they can do and not affected by the disability*

The professionals engendered the idea that any movement was effective and that disability was not to be penalised, resulting in enjoyment and increased confidence

"It looks like really um, they make exercise but in a way we can move even if the bodies not really uh, good, as long as you can move, but even it's so funny, but it's, it's enjoyable…To watch it (FG7)

5.2 Subtheme: Transition

The intervention was considered to provide challenge, to encourage people to examine and push their boundaries

"you know you get one of the professionals said and you push…You know every time it's, it's a much as you can, in other words you, you, people are encouraged to go that bit further, if you can go that bit further do it (FG5)

(FG5) stated that the intervention builds confidence through the professionals focusing on ability rather than inability. This confidence-building was perceived by (FG5) to be the only way to move from the old life (before stroke) to a new life

"alright you won't have that life you had before, you can't do that, that's gone you know, you're into that twilight zone, you've got to come out of that twilight and get a new life…And the only way you're going to do that is through confidence.

(FG8) considered the intervention to provide a fundamental difference *"Just different for my life, before* [long pause then sighs], *dear god no*"

6.0 Main Theme: Acceptance and Expression

Thinking about how the intervention might have made a difference to them, themes of mutuality and openness were evident as exemplified by (FG9)'s comment

"I think what's been inferred here today is that we are all suffering from some effects of the stroke, so we could identify with each other and um, hopefully assist each other by um, talking things through, and people have talked very openly and I think that's been a very, very good thing, and I can remember many groups, I've had an awful job getting people to talk, but here they've done very, very well"

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The intervention was considered to provide a context in which people felt understood and accepted and in which they could express themselves.

6.1 Subtheme: Mutuality

When asked what was enjoyable about the programme, (FG2) stated *"And then, and the, the way um, people with strokes coming together"*. This sense of joint endeavour was noted by (FG9) when asked what it was about the programme that made a difference

"we can identify with each other and identify with the problems, and work things through together.

Identification was seen as a way to challenge feelings about ability

"I think it's good to be with other victims who have had a stroke, and to talk, and not be afraid of what they can do (FG7)

An ingredient in this was mutual empathy

"it does make a difference being able to empathise with other people" (FG9)

6.2 Subtheme: Opening up

Being in the group together facilitated greater openness and communication between members

"I'm very proud of this group and the way it's opened up to each other, and the way they've honestly talked about things, it's been good…people have become much more confident in speaking out (FG9)

Mod: *Did anyone else experience any changes from doing the programme?*

(FG8): *More uh, confident…Um* [pauses] *uh, making you socialise with people*

(FG9) considered that speech had improved during the programme

"it's been marvellous to see how people have improved speech-wise during the weeks we've been together

In response to (FG9), (FG1) wondered if understanding might have improved

"Have they improved or could you just because of the time you took you can understand me, but you couldn't when I first came here, what, what, what, it's talking, what, what, so like [other participant] *told me to slow down, so now I can entertain you.*

Increased confidence might also be indicative of the process of opening up during the programme

"Oh I think it gave confidence more than anything you know (FG5)

as too might be the sense of global positive effects from taking part

Mod: *So has it made any difference to your, your um, your mood?*

(FG8): *Yeah, yeah*

Mod: *Your health?*

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(FG8): *Everything it just, it just*

7.0 Theme: Not For Everyone

Three participants expressed views indicating that the programme might not suit everyone or might need to be modified to make it tolerable for some.

(FG3) expressed not understanding what was happening in the programme and that movement was not tolerable because it was unfamiliar

Mod: *Did anyone else have that experience of feeling that it's helped you in, in a certain way at all?*

(FG3): *Um, no, no, um, not, not for me*

Mod: *So what was your experience?*

(FG3): *Um, I, I couldn't understand what was happening, ok, and certainly movement is very much, I don't like it*

Mod: *Ok, what was the reason you didn't like it?*

(FG3): *Because I, I get, it's, it's all, it's because uh, I not, not, like used to it*

(FG6) expressed some caution about the tolerability of the programme in terms of pace and the experience of discomfort and pain

"I think sometimes maybe uh, make it a bit slower, sometimes a bit fast, I said oh, yeah, sometimes it's um, you get that and sometimes you had to do, doing this one, some people is not um, very uh, comfortable with, uh, moving this kind of hands, and it's just making this, and so when they have a pain, like [another participant] *one day she had big rub to hold and you had to move like this, and they struggled"*

(FG1) described a younger person initially joining the programme but then leaving perhaps because she was not able to tolerate seeing a future with physical difficulties

"But the young girl, she was about twenty years old, she couldn't understand, and she cried and left, you've got to understand it she's only twenty, you think you're going to live like that your whole life"

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APPENDIX D.

INITIAL REPORT OF FOCUS GROUP 1 THEMES – 22 FEBRUARY 2018

Theme 1.0: Group Cohesion

Participants talked about the cohesion of shared experiences within the group and accepting people as they are and what they are able to do. For example, (D) *"but I think, what you're doing, is just so wonderful because we are communicating, we're breathing, we're talking from the heart and we're saying to one another, guess what we're not alone anymor*e" (SO) we are a family".

1.1 Sub-theme: Non-judgmental

Participants described feelings of being judge but being non-judgement within the group.

(FG2.3) *"That's what she does when she's around people, you know Yeah so, that's really important, especially as someone like my mum, cos she, she can't, she, she",* (FG2.8) *"Yeah, but also we don't judge each other, by our outcomes from the stroke we see them as the person) yeah ".*

(FG2.8) *"we don't judge each other, by our outcomes from the stroke we see them as the person".*

1.2 Sub-theme: Socialization

Participant described how interactions with others within the group was beneficial.

(FG2.3)*"The more people interact with each other",* (FG2.4) "*yes")* (FG2.8) "*the better they become".*

1.3 Sub-theme: Support

Participant clearly felt being supported by other members and the professional performers.

(FG2.8) *"that's why I was very grateful for giving, that, the professionals that were running it were very supportive".*

(FG2.3) "*Ok, so you felt really well supported by",*

(FG2.8) *" Yep, yeah, people that ran it Yeah ok",* (FG2.2) *" yeah, I would say definitely".*

1.4 Sub-theme: Shared experiences

Participant described the sense of being together and sharing the experience, and feeling that they were all it in together, but people who have not experienced a stroke do not always understand.

(FG2.8) "It was confusing but, if you think about having a stroke it's a bit confusing",

(FG2.3) "Yep, so, it's obviously not scary confusing because obviously you've got other people here so you feel safe, erm, but you knew that, you needed to get to the end, to see, because there was a curious bit as well".

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Theme 2.0: Confidence

Many participants reported that their confidence has increased since joining the programme. E.g., (FG2.3) *"Well sometimes I, I (all laughing) couldn't do it before, you know, it was my first time dancing in front of people, but you enjoyed it, like that. Yeah I did enjoy it, You really liked it".*

32.1 Sub-theme: Acceptance

Participants described being accepted for who they area.

(FG2.3)*"it showed that when something really spontaneous happened people, weren't thrown, because I think they knew each other and it's an accepting thing".*

(FG2.7) *"so thinking of that as important aspect",*

(FG2.3) *"Ok, yeah".*

2.2 Sub-theme: Self-confidence

Many participants reported that their confidence has increased since joining the programme.

(FG2.8) *"I've gained more confidence, like I'm doing the ukulele now with, with Jenny".*

(FG2.2) "*All laughing which I would have never ever thought to do, erm, to try something new".*

Theme 3.0: Communication

Communication is a big issue with stoke patients but individuals reported being better able to communicate after joining the programme,

3.1 Sub-theme: speech

(FG2.4) *"The more people interact with each other".*

(FG2.8) "*yes, the better they become".*

3.2 Sub-theme: Listening

Participants described being accepted for who they area.

(FG2.9) *"I think it's very important".*

(FG2.9) *"Think that's very important".*

(FG2.3) "*Yeah very important, I think the best thing is to listen and to learn".*

(FG2.1)*"Keeps knocking my knee, it's the word please and thank you, so important in communication, stop hitting my knee, I don't think we know how to communicate without saying those words, and*

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when you do say something, you say please excuse me I am talking, and it's me and it's my turn, so I am being polite, please".

Theme 4.0: Staff

There was clear appreciation from all the participants of the support received from the professional staff.

(FG2.5) "The three of them were very good for people that had, that have had strokes."

4.1 Sub-theme: Accommodating to needs

(FG2.8) *"And obviously the lovely Vicky who looked after us".*

(FG2.2) *"I was really impressed how it was broken down and all put together, and made achievable and very touching, wasn't it. It was very touching the way people, what you're saying about being listened to. I didn't, sorry I don't want to take the floor too much".*

Although one person (FG2.6) *thought this was more "50/50".*

3.2 Sub-theme: supportive

(FG2.3) *"Yeah, so to try and hold on to it. I couldn't I was getting stuck, erm, so Vicki and Lin and that were very supportive".*

(FG2.10) "*Yeah they was) when that happens, other group members didn't understand it erm so it got a bit embarrassing, erm, but I think people learnt from that as well, other stroke survivors, because, as human being we do judge each other, so I get judged a lot, oh you look fine and you're not doing this and you're not doing that, but, I do have outcomes, so, that's why I was very grateful for giving, that, the professionals that were running it were very supportive".*

(FG2.3) "*Ok, so you felt really well supported by…*(FG2.8) *"Yep, yeah, people that ran it, Yeah, ok, Yeah",* (FG2.2) "*yeah, I would say definitely".*

Theme 5.0: Practicalities of the Intervention

There was a general acceptance of the programme, and participants seemed reticent about sharing ideas to improve the intervention, although when prompted, participants raised some issues.

5.1 Sub-theme: Prior Information

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There was appreciation of being sent prior information about the intervention but some (FG2.11) had difficulty opening the pack.

(FG2.8)*"This is it, they send you the pack"* (FG2.11)*"Can't use the handle"* (FG2.4) *"Yeah it's so frustrating"* (FG2.11) "*You can't even open the pack, you can't even read it. However the information sent was found to be useful".*

(FG2.5) "*behave very differently and that thing give you a pack was very very good, so even that came out of was very very good".*

5.2 Sub-theme: Accessibility

Six participants thought it would be good to open the programme to other groups (e.g., those with acquired brain injury).

(FG2.6) *"That would open it up, to so many more people".*

(FG2.8) *"Yeah, it is, yeah, open it up, more accessible".*

(FG2.7) *"when we are talking in general, about, about making sure that, it's not restricted to just strokes (All: Strokes) because the interest in the group".*

(FG2.8) "Y*eah, no, no. it's not specifically about stroke".*

5.3 Sub-theme: Logistics

Participants expressed differing opinions in respect to the number of sessions offered.
Some preferring more sessions:

(FG2.3) *"And did you think there were enough sessions. No, would you want more, more sessions",* (FG2.11) "*I say I would agree".*

While other thought the number of sessions was sufficient.

(FG2.8) *I think for me I would say it was enough".*

Theme 6.0: Intervention Delivery

On the whole, participants recognized the professionalism of the intervention and the way they, the participants were treated.

6.1 Sub-theme: Activity Feedback

The participants were keen to acknowledge the professionalism of the teachers. The professional staff were very good at adopting and accommodating the needs of the participants and this was something they all commented on.

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(FG2.5) "*The three of them were very good for people that had, that have had strokes.*"

6.2 Sub-theme: Novel

The novelty of the programme raised some anxiety but also curiosity.

(FG2.8) SA *"Personally, I know I'd had no idea, I'd never done performing arts or anything like that at school".*

(FG2.8) *"Well I did it because, Joseph, er phoned me and said it was happening".*

(FG2.4) "*I didn't know anything about it, and then I, then I, I brought David, sorry I'm scared, I don't mean to talk about you, erm, so yeah, just came with curiosity really".*

6.3 Sub-theme: Person Centred

The person-centred tailored ethos was something valued by all the participants.

(FG2.2) "*I was really impressed how it was broken down and all put together, and made achievable and very touching, wasn't it. It was very touching the way people, what you're saying about being listened to".*

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APPENDIX E.

FOCUS GROUP SCHEDULE

1.0 Welcome & Introductions

Thanks for agreeing to be part of this focus group. Introductions – moderator; assistant moderator; group participants.

2.0 Purpose of the focus group

We have been asked by Rosetta Life to conduct these focus groups. The reason we are running these focus to find out what you think about the Stroke Odysseys intervention. Staff from Rosetta Life will not be present in this discussion. We want you to share your honest views and thoughts with us.

3.0 Ground rules

- Only share thoughts and experiences you are comfortable with
- There are no right or wrong answers
- Every person's experiences and views are important. You can agree or disagree. We want to hear a wide range of views. Any opinion is valid and respected
- What is said in this room is confidential
- We will be tape recording the discussion so that we can capture everything that is said.
- We will not identify anyone by name in our report

4.0 Answer any questions. Take consent. Completion of demographic data

Questions About You

1. Did you attend all of the Stroke Odysseys intervention sessions?

Please circle: YES NO

2. If No, how many sessions did you attend?

*Please write number of sessions here:*_____

3. How old are you?

Please write age in years here: _____

4. I am

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Please circle: FEMALE MALE

5. Do you have someone at home who cares for you (e.g. spouse, partner, child, other unpaid carer)?

Please circle: YES NO

6. Approximately how long ago did you have a stroke

*Please write here in years and months:*_____

Focus Group Questions:

5.0 Engagement Questions

- What made you/the person you care for interested in taking part in Stroke Odysseys?
- What were your first impressions of the way Rosetta Life works with people who have had a stroke?

5.1 Exploration Questions

- Did you experience any problems in taking part in the intervention (for example, access, length and number of sessions, what you were asked to do)?
- Can you tell me about the people providing the intervention?
- Have you noticed any changes in yourself/the person you care for since being involved in Stroke Odysseys?
    - Do you think these changes were related to the intervention?
- What were your expectations of Stroke Odysseys?
    - How were these expectations met or not met?
- If you have benefited from Stroke Odysseys, can you explain how?
- Do you think there have been any negative effects of Stroke Odysseys?

5.2 Exit Questions

- What would you say to other people about Stroke Odysseys?
- If you could change something about the intervention, what would it be?
- Do you have any other comments to make?

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APPENDIX F.

COPY OF QUESTIONNAIRE MEASURES USED TO COLLECT QUANTITATIVE DATA

Stroke Odysseys

Questionnaire Measures

Date……

Participant ID Number……

On the next few pages we would like you to answer some questions.

If you need help answering any questions, please let us know.

This is not a test and there are no right or wrong answers.

If you do not understand any of the questions, please ask

You do not have to answer the questions

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Under each heading, please tick the ONE box that best describes your health **TODAY**

A. MOBILITY

I have no problems in walking about ☐

I have slight problems in walking about ☐

I have moderate problems in walking about ☐

I have severe problems in walking about ☐

I am unable to walk about ☐

B. SELF-CARE

I have no problems washing or dressing myself ☐

I have slight problems washing or dressing myself ☐

I have moderate problems washing or dressing myself ☐

I have severe problems washing or dressing myself ☐

I am unable to wash or dress myself ☐

C. USUAL ACTIVITIES (e.g. work, study, family or leisure activities)

I have no problems doing my usual activities ☐

I have slight problems doing my usual activities ☐

I have moderate problems doing my usual activities ☐

I have severe problems doing my usual activities ☐

I am unable to do my usual activities ☐

D. PAIN/DISCOMFORT

I have no pain or discomfort ☐

I have slight pain or discomfort ☐

I have moderate pain or discomfort ☐

I have severe pain or discomfort ☐

I have extreme pain or discomfort ☐

E. ANXIETY/DEPRESSION

I am not anxious or depressed ☐

I am slightly anxious or depressed ☐

I am moderately anxious or depressed ☐

I am severely anxious or depressed ☐

I am extremely anxious or depressed ☐

We would like to know how good or bad your health is today.

100 = The best health you can imagine



The ruler on the left is numbered from 0 at the bottom to 100 at the top

100 means the best health you can imagine

0 means the worst health you can imagine

In the box, please write a number from 0 to 100 to indicate how your health is TODAY. You can use any number between 0 and 100.

YOUR HEALTH TODAY = ☐

0 = The worst health you can imagine

For each item please tick the ONE response which comes closest to how you have been feeling in the PAST WEEK.

1. I feel tense or 'wound up'

Most of the time ☐

A lot of the time ☐

Occasionally ☐

Not at all ☐

2. I still enjoy things I used to enjoy

Definitely as much ☐

Not quite so much ☐

Only a little ☐

Not at all ☐

3. I get a frightened feeling like something awful is about to happen

Very definitely and quite badly ☐

Yes, but not too badly ☐

A little, but it doesn't worry me ☐

Not at all ☐

4. I can laugh and see the funny side of things

As much as I always could ☐

Not quite so much now ☐

Definitely not so much now ☐

Not at all ☐

5. Worrying thoughts go through my mind

A great deal of the time ☐

A lot of the time ☐

From time to time but not too often ☐

Only occasionally ☐

6. I feel cheerful

Not at all ☐

Not often ☐

Sometimes ☐

Most of the time ☐

7. I can sit and feel relaxed

Definitely ☐

Usually ☐

Not often ☐

Not at all ☐

For each item please tick the ONE response which comes closest to how you have been feeling in the PAST WEEK.

8. I feel as if I am slowed down

Nearly all of the time ☐

Very often ☐

Sometimes ☐

Not at all ☐

9. I get a frightened feeling like 'butterflies in the stomach

Not at all ☐

Occasionally ☐

Quite often ☐

Very often ☐

10. I have lost interest in my appearance

Definitely ☐

I don't take as much care as I should ☐

I may not take as much care ☐

I take just as much care as ever ☐

11. I feel restless as if I have to be on the move

Very much indeed ☐

Quite a lot ☐

Not very much ☐

Not at all ☐

12. I look forward with enjoyment to things

As much as I ever did ☐

Rather less than I used to ☐

Definitely less than I used to ☐

Hardly at all ☐

13. I get sudden feelings of panic

Very often ☐

Quite a lot ☐

Not very often ☐

Not at all ☐

14. I can enjoy a good book or radio or TV programme

Often ☐

Sometimes ☐

Not often ☐

Very seldom ☐

For each item please tick the ONE response which comes closest to how you have been feeling in the PAST WEEK.

1. I felt tired most of the time

Strongly agree ☐

Moderately agree ☐

Neither agree nor disagree ☐

Moderately disagree ☐

Strongly disagree ☐

2. My physical condition interfered with my personal life

Strongly agree ☐

Moderately agree ☐

Neither agree nor disagree ☐

Moderately disagree ☐

Strongly disagree ☐

3. Did other people have trouble in understanding what you said?

Couldn't understand at all ☐

A lot of trouble understanding ☐

Some trouble understanding ☐

A little trouble understanding ☐

Not trouble understanding ☐

4. I had little confidence in myself

Strongly disagree ☐

Moderately disagree ☐

Neither agree nor disagree ☐

Moderately agree ☐

Strongly agree ☐

5. My personality has changed

Strongly agree ☐

Moderately agree ☐

Neither agree nor disagree ☐

Moderately disagree ☐

Strongly disagree ☐

6. It was hard for me to concentrate

Couldn't concentrate at all ☐

A lot of trouble concentrating ☐

Some trouble concentrating ☐

A little trouble concentrating ☐

Not trouble concentrating ☐

For each item please tick the ONE response which comes closest to how you have been feeling in the PAST WEEK.

1. There is really no way I can solve some of the problems I have

Strongly agree ☐

Agree ☐

Disagree ☐

Strongly disagree ☐

2. Sometimes I feel that I'm being pushed around in life

Strongly disagree ☐

Disagree ☐

Agree ☐

Strongly Agree ☐

3. I have little control over the things that happen to me

Strongly agree ☐

Agree ☐

Disagree ☐

Strongly disagree ☐

4. I often feel helpless in dealing with the problems of life

Strongly disagree ☐

Disagree ☐

Agree ☐

Strongly agree ☐

5. What happens to me in the future mostly depends on me

Strongly agree ☐

Agree ☐

Disagree ☐

Strongly disagree ☐

6. There is little I can do to change many of the important things in my life

Strongly disagree ☐

Disagree ☐

Agree ☐

Strongly agree ☐

You have now reached the end of the questions

Thank You for your help

If you have any comments about the questions or what it was like to answer them, please tell us by putting your comments in the box below