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ORIGINAL PRACTICE DEVELOPMENT AND RESEARCH

How are you feeling? A community poetry project for stroke survivors in Sussex

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Abstract

This community poetry project was theoretically underpinned by narrative inquiry, specifically the transformational power of narrative as poetry. It aimed to focus on the thoughts and behaviours evoked by having and recovering from a stroke, in order to shape positive healing, adjustment and supportive community among stroke survivors, their relatives and carers. After initial planning in 2010, a project team consisting of a St. Leonards-based performance poet and three academic staff from the University of Brighton were allowed access to several stroke clubs in Sussex in 2011. Stories of stroke experiences, previous lives and subsequent adaptation to changed circumstances were gathered from stroke survivors and their relatives, and from volunteer staff. These stories formed the basis for a collection of poems that was subsequently taken back to the stroke clubs and their contributing stroke survivors through performances. Participants and stakeholders in the project expressed that as a result of the overall experience, they developed a greater insight into the emotional language of the stroke experience and new ways of understanding it. This, together with consistently positive, wider, national and international dissemination and dialogues with individuals and groups in different locations in the United Kingdom, demonstrated the success of the project. In terms of relevance to practice, the poetry collection is also being used in curriculum development and staff induction for nursing and other healthcare staff involved in stroke care, and in training and local strategy development at the University of Brighton. It is hoped that the project will also inform future, more formalised hospital-based narrative inquiry research.

Implications for practice

- Poetry based on patients' stories of their illness experiences can help healthcare staff and other stakeholders learn new ways of understanding such experiences
- This can contribute to the development of humanities-based curricula to balance biomedical and related curricula
- Being involved in the overall process of turning experiences expressed in prose into poetic form can be transformational for patients, carers, care, volunteer and professional staff

Keywords: Arts in healthcare, stroke, poetry, experts by experience, health humanities, curriculum development, community engagement

Introduction: theoretical underpinning

At a general level, artistic endeavour is consistent with the broad concern of healthcare to engage with humanity, human suffering, adjustment and loss. Art represents and provides testimony to these experiences in its many forms, including narratives – stories told as prose or poetry (Sandelowski, 1994; Frank, 1995; Grant et al., 2011). As with any other art form, engagement with such stories as writer, teller, reader or listener can be therapeutic, healing, and facilitative of self-development for users of healthcare across the lifespan (e.g. Frank, 1995; Eakin, 2003; Staricoff, 2004; Stickley et al., 2007; McLean, 2010; Grant et al., 2011).

The specific mechanism informing this process comes from theoretical work on narrative identity. Broadly, this proposes that the identity of an individual is constructed out of the discourses, or stories, available to them at the point in space and time that they find themselves in (Burr, 2003; Richardson, 1990). Because people make sense of their lives in terms of the stories culturally available to them, in the absence of alternatives, biomedical stories of damaged selves may be all that individuals have to comprehend their past, present and future. Engaging with narrative, in either prose or poetry form, can help such an individual ‘re-story’ their experiences and futures in alternative, more comforting and socially supported ways, as will hopefully be illustrated in the **Outcome** and **Dissemination** and **Feedback** sections below.

This position is supported by neuroscience. Damasio (1999) asserted that consciousness is essentially narrative in character in storying life as it unfolds. From more broadly social and human science perspectives, it is argued that stories capture and shape the significance of human experiences within a time frame that deals with events in sequence into the future, aiding in the construction and re-construction of individual and socially shared memory (Ricoeur, 1984; Bochner, 2001). Poetry that tells the stories of people’s lives thus serves the dual function of memory-in-action and repository sites for the location of memories (Frank, 2010a). Poetry can therefore help make sense of individual and collective lives and experiences over the course of time, and provide meanings for coping with changing personal, domestic and social circumstances.

In the context of therapeutic narrative inquiry, poetry is thus also moral in representing the ongoing struggle of people to live well and to make the best sense of their lives. This is reflected in our perpetual search for validation and recognition from others who share our values. When it directly connects with their concerns and experiences, hope-imbued poetry can provide readers/listeners with a more coherent sense of lives that have resonance, have come from somewhere and have a future direction (Frank, 2002).

Such poetry always locates people in relation to others, and social location is the core of narrative identity (Bakhtin, 1981; Holquist, 2002; Frank, 2005). In this sense, poetry plays a vital symbiotic role in creating the social (Frank, 2010a,b) and in linking personal troubles to public issues (Frank, 2002).

Given the above, as qualitative performance work the *How are you feeling?* project is theoretically located within a form of narrative inquiry purposefully directed towards empathy, caring and identification with the suffering of others, and helping them move their lives forward through poetry. This coheres with an explicit social justice agenda that offers community solidarity to storied groups of people, promoting healing and adjustment, and helping those with marginalised identities to achieve agency (Frank, 2002).

In this broad social justice context, Frank (2000, p 136) states a manifesto position: ‘...to make ill people’s stories more highly credited primarily among the ill themselves and then among those who care for them’. This agenda is clearly politically activist, and aims to challenge the dominant cultural conceptions of illness as involving ill people who are the passive victims of disease and recipients of care.

Building on all these assumptions, it is further held that ‘experts by experience’ – those who can tell the story of their own difficulties – have something very important to teach others (Grant, 2011). One of the main lessons involves the struggle between personal and cultural meanings. Inevitably, stroke survivors and their carers and relatives must negotiate the spaces between their own experiences and lay and professional discourses of dysfunction. It is within these spaces that dominant understandings of suffering are constructed, defined and hold sway, vying with the situated significance of the experiences of individuals within wider, shared, communities of suffering. Such a struggle is therefore personal, relational, cultural and political (Bochner, 2001).

In this context, it can be argued that individual illness narratives are in perpetual danger of being silenced or erased by cultural master narratives (Gordon, 1997; Davoine and Gaudillière, 2004). Specifically, the significance, contribution and function of narrative art in healthcare are always at risk of being eclipsed by the dominant, positivist-informed biomedical model of healthcare research in the developed world. While the value of this research agenda is clear, its exclusivity serves to marginalise much of the knowledge of human suffering, adaptation and recovery held by ‘experts by experience’ (Grant, 2011). Clearly, such silenced voices, as artistic and narrative product, have much to offer healthcare practitioners, fellow sufferers and others in terms of the experience of illness, adaptation and recovery.

At an epistemological level, exposure to poems from projects such as *How are you feeling?* results in project stakeholders – patients, relatives, volunteers, healthcare staff and students, academic staff, and the wider civic community – engaging with a different kind of knowledge. All groups will arguably have been more or less conditioned into propositional ways of knowing, determined by and deriving from the assumptions and principles of positivist science. The poems from this project help readers and listeners begin to ‘see’, ‘know’ and ‘feel’ the stroke phenomenon differently, in a process involving holistic learning, through and with voice, bodies, images and metaphors. In this context, knowledge mediates social *connection* rather than, as is normally the case, *instruction*. Such embodied, experiential and relational forms of knowing facilitate increased sensitivity and attunement between individuals in new forms of intersubjective knowing; knowing with and responding to each other in different, more empathic, ways (Richardson, 1997; Liamputtong and Rumbold, 2008; Rapport and Sparkes, 2009).

Background

Performance poet Kate Tym was the creative practitioner who had the initial idea for the project, and subsequently led and co-ordinated it at a practical level. Before instigating the project, Kate had, for about two years, worked as a volunteer on the Egerton Stroke Unit at the Conquest Hospital in Hastings, south-east England. This work took the form of a monthly visit to the unit, when Kate would sit with patients and read them poetry. Kate would turn up with a collection of poetry books and ask individual patients if they would like her to read to them. Often the offer was turned down but those who chose to engage seemed to find the experience extremely positive. Kate found that, often, what started out as a reader/listener relationship would evolve into a more equal ‘conversation’. She felt that she would walk in to the unit viewing people as patients and leave viewing them as people with interesting lives and amazing stories to tell.

Kate felt she was privileged to spend time with people at this pivotal time in their lives. Something major and life changing had happened to them and they seemed to exhibit a range of emotions as well as physical characteristics related to having had a stroke or simply being elderly. A lot of time spent on the unit seemed to be 'dead' time, since it appeared that the patients had nothing to say, but Kate began to feel this was because nobody asked them anything except questions of a medical nature. The nature of the unit is such that staff are busy with the role of providing clinical care and time for simply chatting is obviously limited. And yet Kate got the feeling that the time she spent chatting was somehow therapeutic for the patients and that being listened to and sharing in a discourse was uplifting for them. She also recognised the 'humanising' effect these interactions were having on her. She stopped just seeing stroke survivors and began to see more of the people beneath the condition. She began to feel increasingly compelled to find a mechanism to bring these stories to light and share them.

Kate had a personal insight into survivorship of strokes; her stepfather had had a severe stroke and lived with the consequences for seven years before his death in 2009. Through the stroke he lost his speech and the use of his right arm (he had been right handed). To give the power of words to people such as her stepdad who, literally, could not speak for themselves would be a powerful motivating factor for Kate.

The project

Kate Tym set up the poetry project, under the broad rubric of narrative inquiry, to work in partnership with the Hove, Woodingdean and Hastings Stroke Clubs. She was supported by Debbie Hatfield and Drs Kay Aranda and Alec Grant (the project's administrative and theoretical lead), lecturers at the School of Nursing and Midwifery in the Faculty of Health and Social Science at the University of Brighton.

Around 100 stroke club organisers, volunteers and members gave consent to involvement. Organisers consented to having the project conducted on stroke club premises. Volunteers and members consented to sharing their stories, and a total of 21 of those that were collected were subsequently worked up into poems (Tym, 2011). All stakeholders consented to having the poems disseminated through readings in the clubs, and published in booklet and journal form for national dissemination, including readings at conferences.

In addition, nursing student volunteers Guy Chetwynd-Appleton, Deb Simmonds, Grahame Gillespie, Michelle Bunce and Ermelinda Da Costa offered practical support by taking part in the collection of stories that formed the basis for the poems. Sarah Rodgers, a sports science student, also took an interest in the project and attended one of the performance sessions.

Kate did the initial groundwork, contacting the clubs and encouraging their involvement. All three clubs contacted were enthusiastic and accommodating. After project preparation and initiation, Kate and her university colleagues and student volunteers had four points of contact with each club. The first was an introductory meeting, which involved her explaining the nature and aims of the project, and negotiating access and consent. Kate went to each of the clubs on her own to introduce herself and set the scene for how the project would work. The second and third visits enabled Kate, her university colleagues and students to gather and record the stories from stroke club members, and their relatives, friends and volunteer staff. This formed the basis of the poetry collection.

The project involved story gathering by the team with student volunteers, through conversations with stroke club organisers and attendees. There was much discussion at the outset as to how these conversations should be formatted. The academics were used to a formal 'interview' approach,

whereas Kate favoured 'just chatting'. The chatting approach was adopted, although a basic crib sheet was provided to prompt the conversational areas that would be useful to cover (see Box 1).

Box 1: Example of crib sheet

Information gathering for creating poetry

Remember, no one has to take part who doesn't want to, and no one has to tell you anything they don't want to. People may give their name or remain anonymous, it's their choice. The overall feeling should be one of empowerment – that they are being given the opportunity for their thoughts and feelings to be heard. This is NOT research. It is simply the noting down of conversation with a view to capturing how people feel about having had a stroke, their subsequent care and treatment, and the impact it has had on their lives in general. The focus isn't on absolute verbatim accuracy but on honestly capturing the emotional story of people's lives and the part having a stroke has played.

Suggestions for conversation

Physical description: how would you describe yourself / what do you look like?

Back story: name, age, family. Growing up, adult life, work, activities, interests pre-stroke.

Stroke: how did it happen? What was the initial impact? What care/treatment did you receive immediately following it and since? How much of a recovery was made? How has it impacted on you individually/family? What could you do before that you can't do now? What have you learned about yourself, or in general, through having had this experience?

Life now: care – who, how, how much? Interests/activities? What do you enjoy doing? What makes you happy/sad/angry?

I don't think there's a need to refer back or check for accuracy, as long as you feel you have an honest reflection of the person's thoughts and opinions.

Write-up

As verbatim as possible would be good, but if the conversation goes off at a tangent that isn't relevant, feel free to cut. If you would like separately to write a short biography, that's fine. Or if there's a particular sentence or phrase that moved you, feel free to highlight it. And if you want to have a stab at a poem, go for it!

The student volunteers, who were vital to the success of the project in sharing the note-taking load, learned the importance of paying careful attention to the stories of stroke club members, relatives, friends and volunteer staff. Note taking from people telling their stories could take anything from 15 to 30 minutes approximately. The process was conducted in the main public rooms of stroke clubs, rather than in rooms that would provide greater levels of privacy. This was because storytellers expressly did not feel the need for more privacy when imparting their stories.

Students, who also had the opportunity to attend the later 'performance' element of the project, found the crib sheets helpful to follow. When they subsequently wrote up the notes, they highlighted particular phrases and metaphors that they found pertinent or poignant.

The notes they took, as well as those taken by the academic staff and Kate herself, were all fed back to Kate to be used as the basis for the poetry. She read through them and used what jumped out at her as a spark for a poem. Kate found the highlighted phrases and metaphors helpful, and sometimes used them in constructing poems, but not necessarily exclusively so as she primarily

relied on her own creative process. Kate's 'sparks' were sometimes single words or phrases, sometimes expressed feelings, or, often a shared set of experiences or emotions that appeared in more than one narrative.

For example *Life's Little Triumphs* was based on a specific incident. The stroke survivor, P, aged 70, related that she had had to re-learn to do things using her left hand. She took a certain amount of pride in this and said, with a smile, 'I can even wash my back!' Dr Kay Aranda, the academic who had written up this exchange told Kate that, 'It's about life's little triumphs'. This phrase, combined with the pride of re-learning to do things with ones 'wrong' hand, provided the stimulus for the poem.

Life's Little Triumphs

Learning to do everything with my left hand
I didn't understand
That along with the sadness of what is lost
There is a strange
Happiness in what is gained
A pride in re-learning old skills
Re-training my brain
To re-frame my actions
So that something taken for granted
For a whole lifetime
Becomes a lifeline in my struggle
To remain independent
So that being able to feed myself
And paint with my left hand
Is something I am proud of
Doing stuff left handed
Requires quite a knack
And I have acquired it
I can even wash my back!
I am triumphant
Dextrous, clever
I never knew
The things I could do
When I put my mind to it
I am not left handed
But when stranded
Without the use of my right
I put up a fight
And taught my wrong arm
To take over
And now when I succeed in
Achieving a left handed manoeuvre
I accept life's little triumphs
And smile

Similarly *Unconscious and Crying* was based on one person's highly personal experience of coming to after a stroke and finding her face wet with tears, where she had been unconscious and crying. She also told Kate that she lived alone and had had her stroke at the weekend but decided not to phone the doctor until Monday morning. She had not spoken to anyone over the weekend, so it wasn't

until she came to make the call to the doctor that she realised she actually couldn't speak. Kate found this story very moving and used it as the basis for the poem below.

Unconscious and Crying

I came too with tears on my face
I had fallen
It had been like sleeping
But when I awoke
I was weeping
Really crying
My face wet with tears
A release of anguish
A harnessing of my fears
Unconscious and crying
Lying on the floor
And then I came too
And carried on
As I had before
But different
A silent enemy creeping in my brain
Stealthy and cunning
Running little fingers through grey matter
Snapping synapses
Causing lapses
Where before there were none
Stealing from me
Whatever he could reach
Picking at my brain
And taking away my speech
I hadn't realised
I had been alone and silent
So when I came to try
And no words came
I understood why
I would lie
Unconscious
And cry

The poem *I Have Lived A Lifetime* was generated from the combination of two comments: one from a woman who said that her carer 'chops up my food and I don't like it – I'm not a baby' and one from a man who said of his wife's carers, 'They come to put her to bed at 6pm – she doesn't want to go to bed at 6pm, it's too early'. Although the comments came from different people, there was a shared experience that resonated between them.

I Have Lived a Lifetime

Don't cut up my food
I'm not a baby
Don't put me to bed at six
I'm not a child
I have been infantilised
By my need to rely on others
I am like a child in the way I need help
To wash, to dress, to eat
But I carry in my mind
A lifetime
Lived
Meals eaten
Buttons done up
And evenings ended
By my own choice
When I had a voice
So don't look at me
And see a baby
Who needs their food
Cut up
Look at me
And see
A lifetime
lived

Then *Tinker, Tailor...* was a less person-specific poem. It didn't emerge from one person's story, but more from a feeling that came from talking to lots of people who, while they had been chosen for the project because they were stroke survivors, had, of course, many other things that defined them. Many had lived rich, interesting lives and held a variety of occupations.

Tinker, Tailor...

Tinker, tailor, soldier, sailor
Shop girl, receptionist, plumber's mate
Miner, designer, mountain climber
deep-sea diver
Head of state
Investment banker, captain of a tanker
Dress maker, cake baker
Company clerk
Psychologist, escapologist
Head ranger in the park
Electrician, magician, beautician
Nail technician, dental nurse
Doctors, vets, fishermen with nets
Toilet cleaners or something worse
Teachers, preachers, trainers of creatures
Dancing girls and action men
Remember the office
The coal face

The shop floor
That's how it was
Way back when

Has it been left behind?
To leave you defined
By one event
Sent like a bolt from the blue
In like Flynn
Then gone again
Leaving your description altered
A new title firmly in place
From deep-sea diver
To stroke survivor
Dancing girl
To wheelchair waltz

But there's more to you
Than meets the eye:
Tinker, tailor, soldier, spy
Rich man, poor man, beggar man, thief
Tinker, tailor, soldier, sailor
That's what's underneath

At the final, fourth contact, the poems were performed and feedback from clubs and story contributors was sought. Throughout the overall process, Kate, Alec, Debbie and Kay also had six progress meetings to keep the project moving, focused and on track.

The poems that emerged from the collected narratives were then used as the basis for a poetry collection, subsequently published with an accompanying CD (Tym, 2011), which includes two additional poems, one each contributed by Dr Alec Grant and Graham Gillespie. As an ongoing part of the project, the collection was performed to nursing and other healthcare students at the University of Brighton. The feedback from this event, which cohered with that detailed in the next two sections below, demonstrated the experience of stroke and its effects, and the power of arts-based healthcare education and learning.

Outcome

Apart from the poetry collection text and accompanying CD, which, because of staggered funding, was published and produced some months after the last point of contact with the stroke clubs, the project generally unfolded in a reasonable way. It corresponded to what we had hoped for in our original outline plan. Feedback gathering was both deliberate and opportunistic. Feedback was purposefully sought locally, and national feedback largely occurred as a result of the project's publicity, including an example of the poetry in the winter 2011 edition of *Stroke News*, the magazine of the Stroke Association (see next section).

According to feedback from all local participants and stakeholders, who number around 200 people at the time of writing, the project was generally successful in the following ways. Local, and subsequently national, feedback (detailed below) suggested that commentators felt that they had benefitted from an insight into the emotional landscape of the stroke experience and new ways of understanding it. Their comments were made on the basis of either hearing the poems performed in the local stroke clubs or in reading them as a result of their subsequent publication. In keeping with

the theoretical basis of our project, we believe that this constitutes support for the proposition that such poetry can make a positive difference to healing and adjustment in relation to 're-storying', and to the development of a supportive community.

In keeping with the epistemological assumptions discussed above, nursing student project volunteers commented that they had found out things that would have escaped them in their usual practice roles because the questions, concerns and ways of knowing inscribed within project were very different:

'Thanks so much for allowing us to take part in the poetry project. I feel that I grew from the experiences that were shared with us by these wonderful and amazing gentlemen.'

Debbie

'I would not have seen this in the hospital.'

Guy

The volunteer staff of stroke clubs and members whose stories were re-told as poems also felt they gained helpful insights into the experience and phenomenon of stroke as these were reflected back to them in a different and more evocative way:

'Kate must have really listened to what everyone had to say, as her poems were so accurate and really resonated with the experiences members of our group have had. She must have worked very hard to get her poems so "right". They are very moving.'

Anne, stroke club organiser

'Your poems are so astute and speak so well of the feelings of people who have had a stroke.'

Janet, stroke club organiser

'We'd love these poems to go everywhere. Having a stroke is different to everything else and sometimes we feel really misunderstood. Maybe these will help people understand better.'

A, stroke survivor

'There is prejudice, but this helps break it down.'

J, stroke survivor

Involving the stroke clubs from the outset introduced the important element of reaching and working with and within the community. Stroke clubs welcomed the project and seemed delighted in the university's interest in their activities.

For project members on the university staff, this was also an opportunity to experience first hand the combination of community engagement, service user involvement and the role of arts in healthcare. The benefits they experienced while working alongside a performance poet were described at a presentation, involving Kate and a student nurse volunteer, at one of the twice yearly School of Nursing and Midwifery general staff meetings. Feedback from other staff present at this meeting was very positive, with some expressing an interest in running similar performance poetry projects, for example in relation to experiences of pregnancy and childbirth.

Dissemination and feedback

The project will be included on the International Health Humanities Network website in the autumn of 2012. It was presented at annual Centre for Learning and Teaching Conference at the University of Brighton this summer, and at the 23rd International Networking for Education in Healthcare Conference (NET, 2012), at Robinson College, University of Cambridge in September, as a core paper within the 'Humanising healthcare education' theme. Kate also spoke at the Stroke Association's 2012 UK Stroke Assembly, in Birmingham in July.

The magazine of the Stroke Association, *Stroke News* (Winter, 2011), featured the project in an article and included the sample poem, *I Am On A Different Planet* (Tym, 2011, p 3). It was written on the basis of a poignant comment from a story contributor who remarked that 'If your speech is affected you feel as if you're in a different country...'

I Am On A Different Planet

I am on a different planet
In a land of my own
Where the main thing I feel
Is alone
I am in a different country
Population one
Even the person I was before
Has up sticks and gone
I have landed somewhere new
Familiar but not the same
Where no one speaks my language
Or even knows my name
I was part of the population
Before I set out to sea
And landed on an island
Population – me
How I struggled
To communicate
To break through
Re-find my place
To walk to the same beat as everyone else
And re-join the human race
I was on a different planet
Even with everyone near
And the main thing I felt
Was fear

Publication of this poem evoked the following reactions from stroke sufferers and their relatives in different parts of the United Kingdom:

'...I felt I had to write to say how moved I was by your poem. My husband suffered a severe stroke and sadly died in 2007. Although he could speak, but could not move without help, I remember him saying soon after he had his stroke that his brain felt "scrambled". I am sure he felt just like the description in your poem. I do hope it will help others like it has me.'
Jackie

'My husband suffered a stroke 18 months ago. We read the poem I Am On A Different Planet published in the Winter issue of Stroke News. This poem really summed up how my husband

felt in the early days after stroke and sometimes even now. We wondered if there was a collection of poems suitable for stroke survivors available for us to buy?’

Lynne

‘I suffered a stroke this year and subscribe to Stroke News... I wonder if you have a copy (of I Am On A Different Planet) for me to frame to put up in my house as a reminder that I am not on my own in this?’

Liz

‘...I had my stroke 20 years ago which left me paralysed down my left side and unable to walk, work, drive and enjoy the sports that I enjoyed doing as well as a large slice of my social life... The sense of isolation felt by disabled people is enormous... I read your poem I Am On A Different Planet with a great deal of enjoyment and fellow feeling...’

Jim

‘I read this poem and it made me cry – because it was how I felt when I had my stroke three years ago. Thank you.’

Jenny

‘I am a stroke survivor and suffer from chronic vascular disease... I was so overwhelmed and emotional when I read your poem... I just could not believe that a person could write words that are in my head, waiting to escape and people would understand what it’s like to be on this strange planet. I can’t thank you enough... not just for me but for other survivors who can’t do so and yet desperately want someone like you to understand so well the despair we feel (how did you do that?)...’

Annie

As a result of the national reaction to the project, the magazine decided to launch a poetry competition. Kate was invited to be shortlisting judge and drew up a shortlist of 25 poems in May 2012, which was then passed to Andrew Motion, Poet Laureate from 1999 to 2009. He chose the winning poem, *Sonnet (Unknown Black Out to Light)* by Robert Peel. This was published in the Summer 2012 issue of *Stroke News*.

More locally, the Bexhill Community Stroke Team intend to use the published poetry collection and accompanying CD as part of the induction of new staff. It will also form the basis for Kate’s teaching contribution on a new undergraduate module for student nurses, entitled *Arts in Health*, written and coordinated by Alec Grant. Kate uses the material to teach post-registration nurses on a new stroke module in the School of Nursing and Midwifery, and is also a regular speaker for Women’s Institute groups and the NHS retirement fellowship. Finally, the project has helped contribute to and shape the direction of the School of Nursing and Midwifery’s Service User and Carer Strategy and Policy document, coordinated by Debbie Hatfield. This helps set the ‘cultural tone’ of the school in relation to health humanities, increased service user and carer involvement in higher education, and to shape the healthcare curricula more widely in the school and in the wider Faculty of Health and Social Science at Brighton University.

Future research and development

The fact that we believe that the project met its broad aim – of contributing to positive healing, adjustment and supportive community among stroke survivors and their relatives and carers – gives us hope for our future plan for hospital-based work. Alec and Kate intend to work together in a more formal narrative research and theoretical context to support her future writer-in-residence work within the East Sussex NHS Trust. To recapitulate, as a form of narrative inquiry, writing for recovery

is predicated on the theoretical and empirically supported assumption that engaging in narrative writing in either prose or poetry form, following or in the context of experiencing mental or physical ill health, is transformational (Grant et al., 2012a, b). As reflected in the feedback comments above, from sufferers, carers and volunteer staff, re-storying mediates the reclamation of positive identity.

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A commentary on this paper by Dawn Freshwater follows on the next page.

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COMMENTARY

On telling tales out of poetry

Dawn Freshwater

I was particularly pleased to be asked to comment on this interesting and evocative paper about a community poetry project, underpinned by a narrative approach to research. It focuses on the development of a supportive community among stroke survivors and the wider impact on carers and families. Narrative research is an area of increasing interest for clinical researchers, specifically those interested in harnessing the deep wells of knowledge, experience, expertise and healing that each individual storyteller brings to the text.

Narration is part of human nature, and as such all people have a natural desire to share stories of experience and communicate what they feel and think (Holloway and Freshwater, 2007). Story, narrative and plot are closely related and often, in the literature at least, confused and conflated. Copley (2004); Freshwater and Rolfe, (2004); and Holloway and Freshwater (2007) offer further detailed explanations. Suffice it to say, for the purpose and context of this commentary, it is important to note that human beings narrate past events and experience all through their lives, from childhood onwards to 'inform, instruct, entertain, empower, exonerate or cathart, among other things', (Smith, 2000, p 327).

When people tell their own story, (in this case stroke survivors, but also please note importantly, that the act of writing this paper means the researchers are also telling their own story), they reflect on the meaning and significance of their experience, and through this construct and reconstruct their identities. This is true whether the individual is recounting an illness experience, a life-changing event such as a marriage, a birth or death – a 'biographical disruption' so to speak; or recounting the story of co-creating, witnessing and making visible the stories of others, as the researchers in this community project do in this paper.

Historically, and traditionally, narrative accounts of research have been seen as subordinate to scientific reports, and formal language valued more highly than more personal and narrative language, such as those captured in the poetic prose here. This has changed in the past few decades, and rightly so. Nevertheless, publishing research that embraces poetry, prose, photographs and artwork still challenges our dominant ways of viewing evidence.

The knowledge acquired through narratives encapsulates human motivation – that is, why people behave as they do. While researchers who use paradigmatic cognition search for generalisations and often test or verify hypotheses, researchers who work in the narrative inquiry mode gain knowledge from individual and unique cases, from which they cannot generalise, though they might recognise similarities and patterns. These stories are people's versions of reality and not scientific constructions, but they also give 'evidence' of what individuals feel and think and how identities are transformed and re-constructed through life experience, including that of illness. Moreover, the

transformational experiences portrayed here, in this case represented through the medium of poetry, speak loudly and provocatively to members of the broader community and to society at large. I mean to say that individual identities are both constructed by experience and also construct the experience of others.

Narrative is, then, a social process and as such connects to issues of culture and power. Cultural concepts and beliefs provide a framework for individuals, in which they can become narrators of their story; social positioning also influences their storytelling. Narratives generate 'local knowledge' because of their link to social context and unique experience in time rather than universal statements that can be applied everywhere and forever. The generation of local knowledge is of particular utility to clinical practitioners and to the development of locally driven policies and care pathways.

In our society, health professionals and particularly professional researchers are seen as members of an elite culture. In storying, however, participants in narrative inquiry have the power to define their own bodies, identities and experience, rather than having their reality shaped by others. People are active agents in their own experience, not passive recipients; they are able to assert themselves, 'recover agency' and achieve self-esteem.

Narrative, while focusing on the subjective experience of narrators, also takes into account the bigger picture by exploring wider societal and cultural experiences – in this case, the experiences of a wider community of expert patients. As I have already stated, narrative is a social activity, a product of interaction between cultural discourses, material circumstances and experience. Narrative, then, is bound up not only with individual identity formation but is also connected to large-scale identities such as nations, cultures and subcultures. This is critical for clinical practice and for researcher practitioners. For both have cultures and subcultures, conscious and unconscious, which drive and motivate practices, and specifically the traditional practices that have dominated our understanding of what constitutes a helping and healing relationship. In this 'experiment', poetry, chronic illness, and fellow travellers and sufferers have all complemented and contributed to the healing and reconstruction of individuals' identities.

There are often periods in the research in which the emotional heat is most strongly felt, both in the relationships with the participants and within oneself. In this sense it is a time during which awareness, authenticity and congruence of identity can be confronted. Thus, narrative research not only provides an opportunity to explore and examine the concept of identity formation and construction through personal narratives, it also provides an opportunity for researchers, and practitioners, to reflect on their own experience of identity formation and reformation through the process of the inquiry itself. Of course, a degree of reflexivity and openness is required for this to take place. It would be interesting to know how the facilitators of this project were transformed and reconstructed during the process of project, and to what extent they themselves experienced the process as healing and one of learning, in the deepest sense.

I guess I am revealing my colours, when I suggest that, in my view, as with all life experiences, conducting narrative research is a chance to learn something new about oneself and to engage in a transformatory process (Freshwater, 2000). The same opportunity is afforded the participants, as narrative research not only permits but encourages participants to narrate themselves as carers and healers.

Writing up narrative research is not easy and is a lonely task for a single researcher. In this project, the loneliness of an illness experience (surviving a stroke) and of being a researcher was challenged through the process of narrative engagement. That we are alone in the world, the world of our own

experience, can never be changed. That we can share that experience of being alone, through narrative expressions, is truly a blessing. Sharing that experience has to be open to as many styles of presentation and representation as we can humanly manage. Hence, rather like the findings in this paper, presented as poetry and a story about poetry as a vehicle for healing, narrative research is written differently. Of course, research accounts need the requisite and appropriate number of steps but the narrative in this type of research often takes a different form. There are several differences: while in quantitative research researchers generally – though not always – adopt a neutral stance demonstrated by the passive voice, qualitative researchers, by the use of terms such as ‘the author’ or ‘the researcher’, acknowledge and demonstrate their active involvement and responsibility for what is written in the completed text. Language and style express the emotional connectivity of the researchers and highlight their priorities.

I am left with some questions regarding the degree of reflexivity engaged in by the researchers in this lovely community project; perhaps we could learn more about the intentions, voices and experiences of active involvement through further publications, particularly, if the intention is to inform health-related curricula, and thereby health educators.

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A response to this commentary follows on the next page.

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RESPONSE TO COMMENTARY

On telling tales out of poetry

Alec Grant

It gives me great pleasure to respond to Dawn's thoughtful and thorough commentary on our paper. She invites a response to the following issues: the extent to which we were transformed and re-constructed during the process of the project; the extent to which we experienced the process as a deep healing and learning one; and the nature of the reflexivity we engaged in during the duration of the project.

The project was part of a broader narrative inquiry remit which, in addition to practice development, includes autoethnographic research and dialogical narrative inquiry (Grant, 2006; Short et al., 2007; Grant, 2010a,b; Grant et al., 2011; Grant and Zeeman, 2012; Grant et al., (2012a,b); and Short et al., in press).

Dawn describes the binaried nature of research in healthcare, between narrative and logico-empirical cognition modes. The relationship between these two modes is by no means an easy one, and the politics of research is played out in bureaucratic and neoliberal higher education and healthcare organisations. This makes embarking on and sustaining an interest in narrative research of the range described above a sometimes-hazardous enterprise. In terms of engagement in such work as an extended reflexivity project, a thick skin and a clear focus on working to a social justice agenda are often required.

However, benefits outweigh costs, and Dawn is perfectly correct in saying that narrative inquiry is transformational. We write to become, in the never-ending task of aspiring to preferred identity (Grant and Zeeman, 2012). Involvement in the stroke poetry project was no exception. We were all aware at a theoretical level of the relationship between arts and health. But such is the insidious nature of the discourse of biomedicine that this remained more of an 'in principle' idea than a felt reality until we became increasingly involved in the project. I think I can safely speak for all of us in asserting that now we can use the material in teaching, and future writing, from more of a platform of felt, holistic conviction rather than idealism.

We certainly learned things, but did we heal? And heal from what? I guess the nature of our shared disorder before embarking on the project was a lack, or a deficit, around the need to account for the human and human-to-human experience of stroke. As a biomedical phenomenon, 'stroke' is something written on passive bodies, as the late, great Isabel Menzies Lyth (1988) might have implied. From her theoretical perspective our biomedical social systems of care ignore the human and human-to-human experience of stroke, perhaps because it is easier to work with bodies that have things that need doing to as opposed to with people we can get to know.

And we did. We got to know people.

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