RESEARCH PAPER

The meaning and value of taking part in a person-centred arts programme to hospital-based stroke patients: findings from a qualitative study

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Purpose: The importance of addressing mental well-being while stroke patients are in hospital has been recognized by policy makers but there is a gap between rhetoric and reality. This study explored the potential for using a person-centred, artist facilitated, one-to-one arts programme to improve the emotional and mental well-being of patients, which may be adversely affected as a result of the negative experiences arising from stroke and hospitalization. Method: The study focused on those patients remaining in hospital for above average durations and included patients with functional, cognitive and speech or language impairments. After participation in the arts programme and before discharge, semi-structured interviews were undertaken with sixteen patients, and in the case of two patients with severe cognitive loss, a relative, as a proxy, was interviewed. Interviews explored the experience of stroke and hospital stay and the meaning and value of taking part in Time Being Stroke and the data was analysed thematically. To underpin and contextualize the interview material, clinical status and treatment information routinely collected by the multi-disciplinary stroke team was obtained and analysed, in addition material on the content of each session was recorded by artists and analysed. Results: Patients’ accounts suggest that participation in a person-centred arts programme contributed to their mental well-being. As might be expected from a person-centred intervention, benefits varied across the sample, but the most commonly mentioned positive aspects of participation included the experiences of: pleasure and enjoyment, a sense of connection with the artists, mental stimulation, learning and creativity, engagement in purposeful occupation and relief from boredom, and reconnection with valued aspects of the self. These experiences of participation contrast strongly with the acute and chronic distress associated with stroke, impairment, and spending long periods of time in hospital. Conclusions: Arts interventions such as the one implemented and evaluated in this study provide a positive and valuable experience for longer staying stroke patients, contributing to their mental well-being during an otherwise distressing illness and hospital stay.

Keywords: arts, mental health, person centred, stroke

Implications for Rehabilitation

- Stroke and the resulting impairments and long stays in hospital cause considerable distress to patients, and a high proportion of patients experience depression and anxiety.
- Addressing emotional and mental distress in patients is a priority for patients and relatives, and for hospital trusts and policy makers, but clinicians rarely have the time to address the emotional aspects of stroke.
- Participation in a one-to-one person-centred arts intervention facilitated by artists with experience of vulnerable patients can offer enjoyment, learning and mental stimulation.
- Through these a contribution to patients’ mental well-being during hospital stay can be made, which may address emotional distress.

Introduction

According to the Department of Health around 110,000 strokes occur in England every year [1]. Stroke can have a major impact on patients’ cognitive and functional abilities – studies
considerably less time than they used to have to attend to self-efficacy and decision-making [13] – means nurses have of physical functioning, and addressing issues of autonomy, review therapy, motivational interviewing, and other support interventions [13]. But in practice, their role in this area is complex, but a number of studies indicate that rehabilitation is adversely affected by post-stroke depression [6,7] and/or emotional distress [8] at least in part due to depleted motivation and emotional resources to engage in rehabilitation [9].

The relationship between emotional and mental well-being and rehabilitation outcomes is complex; however, a number of studies indicate that rehabilitation is adversely affected by post-stroke depression [6,7] and/or emotional distress [8] at least in part due to depleted motivation and emotional resources to engage in rehabilitation [9].

The importance of addressing mental well-being whilst patients are in hospital was a key element of the White Paper “Our Health, Our Care, Our Say” [1]. With respect to stroke, addressing the risks of depression and distress is one of the ten components of multifaceted stroke specialist rehabilitation and support advocated in the National Stroke Strategy [12] and best practice in stroke rehabilitation is understood to encompass a range of elements [10] including provision of recreational and therapeutic activities to patients as an adjunct to essential functional rehabilitation, and the maintenance of a patient and family focus. Routine screening for depression is recommended, and where a diagnosis of depression is made, access to a “broad range of mental health and psychological services” should be provided [12].

However, there is a gap between best practice and routine care, and the emotional and mental health needs of many stroke patients may not be explicitly acknowledged or met in hospital. In reality, clinicians have limited time to undertake screening and it may only be undertaken, in some hospitals, for those who appear to be experiencing both chronic and acute distress. Access to liaison mental health and psychological services may also be limited to those with substantial needs.

Nurses, rehabilitation staff and mental health services could play a greater role in attending to the emotional well-being of patients. Nurses could undertake systematic screening and monitoring of depression, offer more information to patients to empower them, provide informal emotional support, and deliver specific nurse-led interventions such as life review therapy, motivational interviewing, and other support interventions [13]. But in practice, their role in this area is limited. The increasingly technical role of nurses in relation to patient care since the late 1990s – including promotion of nutrition, sleep, medical status monitoring, enhancement of physical functioning, and addressing issues of autonomy, self-efficacy and decision-making [13] – means nurses have considerably less time than they used to have to attend to emotional well-being of patients [14,15]; lack of training in supporting depressed patients is another reason [9].

Meanwhile rehabilitation staff (occupational therapists, speech and language therapists, physiotherapists) focus on functional recovery. Whilst engagement with rehabilitation and progress with recovery of lost functional abilities [16] may nurture hope and optimism for some patients, nonachievement of personal recovery goals can be a cause for further distress. Furthermore rehabilitation sessions can be a motivating and welcome stimulation for some, but others, especially those affected emotionally or experiencing depression may find it difficult to engage in rehabilitation activities [9].

Finally, it is important to acknowledge that hospitals are increasingly making available a range of facilitated activities, for stroke patients, but these do not provide for the one-to-one engagement that patients may need to address their emotional needs.

Mitigating distress is valuable in its own right but awareness of the relationship between distress and rehabilitative outcomes [6–8] should mean that activity and interventions which reduce distress are highly valued amongst health care providers and commissioners.

This situation provided the broad rationale for the development of Time Being Stroke, a one-to-one arts programme for hospital-based stroke patients which aimed to contribute to their mental well-being and recovery during hospital stay whilst complementing existing rehabilitation and nursing inputs and other initiatives focusing on improvement of stroke care. At the outset, both the arts team within the hospital (Healing Arts) and the multi-disciplinary stroke team considered that in addition to potentially affecting mental or emotional well-being, such a programme had the potential to make a positive impact on functional recovery by way of improving patients’ motivation to engage in rehabilitation and through this, reduce the length of hospital stay for some patients. Such outcomes would of course be of interest to both patients and clinicians, but also any cost impacts resulting from reduced length of stay would be of interest to hospital managers and health commissioners.

**Arts in health and arts for stroke**

The arts are used in healthcare in several distinct ways. The most common are display or exhibition of art in healthcare settings to promote a calming, therapeutic environment (e.g. visual arts and poetry on display in hospitals or general practitioners’ waiting rooms), the use of music during surgery to relax patients, art therapy (the use of arts by therapists with mental health qualifications working directly with patients in health care settings for diagnostic or therapeutic purposes); and participatory arts in healthcare settings (where professional artists provide access to arts participation amongst patient groups as a complement to other medical treatment).

There is a growing evidence base relating to the benefits and health outcomes for patients associated with the use of arts. There is not space to review this fully here, however, a few key studies are discussed. A wide ranging narrative systematic review of the evidence for the range of applications of arts and health undertaken in 2004 (for the period 1990–2004) found that the most commonly reported benefits relating to the use...
of arts in health contexts included reduced need for medicine (typically analgesics), decreased depression and anxiety and increased subjective well-being [17]. A more narrowly focused narrative systematic review of the use of creative arts for therapeutic purposes published in 2010 (focusing on studies published 2000–2008) found six areas of benefit including enhanced perceived control, building a sense of self, self-expression, transforming the illness experience, gaining a sense of purpose, and building social support [18]. Studies reported in this journal have also explored the ways in which participation in arts activity can contribute to mental well-being [19] and recovery from mental illness [20] for different patient groups.

In relation to stroke and other forms of neuro-trauma, a number of studies involving arts interventions have been undertaken, including clinical trials which tested the impact of highly specified arts based interventions on functional and cognitive recovery via neurological mechanisms [21–25], studies of art therapy [26,27] and a study of the use of actors [28] reading to stroke patients. In these latter studies [26–28], which are briefly reviewed below, benefits to patients were expected to arise through personal- and meaning-oriented dynamic means.

Art therapy approaches
Gonen and Soroker [26] investigated a group-based model of art therapy (visual arts) amongst stroke patients. Art therapists facilitated bi-weekly group sessions for stroke patients lasting 90 min for 10 weeks following the stroke event. The art therapy model was underpinned by the use of art language in therapy, a psychotherapeutic process, group interaction, and the application of art therapy principles and methods. Programme staff used questionnaires to explore patients’ perceptions of the consequences of stroke, their emotional state, interpersonal relations, and their attitude to art therapy processes. They used this information to understand patient needs, to tailor the sessions, and assess impacts. The authors reported that the work assisted patients with accepting and processing their new situation, and that the group acted “as a catalyst…it encouraged patients, who in this stage tend naturally toward an introvert attitude, to turn outward and relate to others while reinforcing their expression” (p49).

McKenna and Haste investigated the use of art therapy in helping patients adjust to life following neuro-trauma [27]. Following an introductory session, which allowed therapists to meet with each patient to prepare an individual programme of activities, participants engaged in five weekly one-to-one sessions each lasting one hour. The intervention incorporated a range of activities intended to stimulate and support creative expression using visual images, music, poems, making materials, relaxation techniques and visualization. The authors reported benefits in the areas of patient self-esteem and empowerment arising from patients’ experiences of personal space, escape, creativity and enjoyment.

Reading for stroke patients
Higgins et al. [28] explored the value of reading poetry to stroke survivors. Patients participated in at least one session either as a group member or individually. Patients reported a range of benefits including relief from anxiety, mental stimulation, improved motivation for participation in rehabilitative activities, and emotional catharsis. The authors note that the choice participants had over what was read to them was important.

Time Being Stroke
Funding for *Time Being Stroke* and its evaluation was provided through Her Majesty’s Treasury’s Invest to Save Budget, which funds innovative projects with the potential to transform public services. *Time Being Stroke* was developed by Healing Arts (the arts and health department of the Isle of Wight NHS Primary Care Trust) to explore the potential for using the arts to improve the emotional and mental well-being of stroke patients. The programme aimed to provide an opportunity for participants to explore their interests and undertake arts activities they had chosen (with the artist’s help), in a series of one-to-one sessions with a professional artist.

Relatives were invited to participate with patients only at the request of patients themselves, but they were strongly encouraged to participate if a patient had substantial cognitive impairment – in this latter case the involvement of relatives was key to establishing a menu of activities that might be enjoyable and meaningful to patients who could not be adequately supported to express themselves.

Five professional artists were involved in delivering the programme – each specialized in a different art form: including visual arts, creative writing, dance/movement, and music. The artists do not have formal qualifications in mental healthcare and are not therefore “art therapists”, but they are experienced in working with vulnerable groups in the context of healthcare delivery. Depending on patients’ choices artists would work both within and outside their art form – each artist had to be able to deliver the activities devised by the lead art form specialist for pragmatic reasons.

*Time Being Stroke* was designed and developed by the artists, led by one of the authors (GE), and in close collaboration with the multi-disciplinary stroke team. This ensured effective integration in terms of clinical, therapeutic and rehabilitative processes and relationships. It was piloted extensively and subsequently refined, prior to the main phase of the study, based on what was learned from interviews with patients, clinicians and artists.

Following the pilot, a detailed guide to the delivery of the programme was drafted (the *Time Being Stroke Delivery Guide*) and a session planning and monitoring tool was developed for artists’ use during the main phase of the study. A summary of the contents of the delivery guide is shown in Box 1 below.

The guide developed by one of the authors (SP) in collaboration with the artists, underpinned the design and delivery of individual sessions and aimed to ensure the consistent implementation of the final programme design and format between artists and to facilitate communication between artists working with the same patient. It also set out the theoretical basis for the development of the relationship between artists and patients in the programme and addressed...
a wide range of practice issues necessary to ensure the safe delivery of the programme on the Stroke Unit. Based on the learning from the pilot (which highlighted what patients valued and did not value about the initial programme design) the underpinning concept of person-centredness was reinforced in the development of the guide. It was agreed that the programme should adopt a Rogerian [29] “person-centred” approach to the development of a relationship between artists and patients and to the selection and delivery of arts activity. Artists, therefore, were encouraged to create a comfortable, non-judgmental environment, demonstrate genuineness, empathy and unconditional positive regard towards patients, whilst using a nondirective, collaborative approach (eliciting and responding to patients’ artistic and/or personal interests and history) to the development of arts activities and session planning.

Patients were able to participate in between four and six one-to-one arts sessions which might be facilitated by different artists (usually two artists were involved in working with any one patient, but on occasion three). The content of sessions emerged through collaborative dialogue between the artist and patient (and in two cases, with the help of a close relative). Sessions were devised around each patient’s interests and personal narratives, and activities were tailored by artists to suit each patient’s functional capabilities.

Examples of the activities that could be developed with each patient were explained at initial and subsequent meetings. The material in Box 2 below sets out the script that artists used to discuss what was “on offer” to patients.

Research aims and methodology

The study received NHS research ethics approval from the Isle of Wight, Portsmouth and South East Hampshire Research Ethics Committee in October 2008 and was registered on the United Kingdom Clinical Research Network Portfolio database (ID 7392).

Following the pilot, the main phase of the study, which took place between June and November 2009 explored the meaning and value of taking part in Time Being Stroke to stroke patients during their hospital stay. Other aims (not reported here) were: to explore clinicians’ perceptions of the role and contribution of the programme to patients’ physical and emotional recovery and rehabilitation; to explore the programme’s implementation – including practice and partnership issues; and to calculate its costs and potential cost-benefits.

The study was exploratory and couched in an interpretive paradigm of inquiry. The authors’ ontological and epistemological orientations were phenomenological and idealist, however, the study also had evaluative aims – such as providing structured feedback regarding what impacts (and in particular, systematic impacts) the programme might have had on psychological distress, rehabilitation, and recovery and how these impacts may have arisen. Epistemological
and methodological dilemmas were most apparent during the analysis phase as the authors grappled with the task of understanding and interpreting the meanings attached to experiences (interpretive paradigm) and meanwhile seeking to identify systematic pathways of impact (i.e. more deterministic, post-positivist paradigm). Throughout the study the authors were encouraged by the pragmatic approach that underpins the qualitative research approach of the National Centre for Social Research, as described in Ritchie and Lewis [30], which acknowledges the dilemma in applied qualitative research and adopts a ‘subtle realist’ epistemology combined with a scientific orientation to methodology.

The authors of this article were all substantially involved in supporting (or leading) the development and implementation of the programme as well as managing or delivering the (qualitative) evaluation reported in this article. There are inevitable tensions in any programme evaluation in which investigators play both supportive and evaluative roles. These tensions were acknowledged from the start, and considerable efforts were made during the delivery of the evaluation to reflect on potential sources of bias and, to ensure that data collection and interpretations of data were carefully checked to ensure maximum reliability and validity of interpretation.

Through its use of multiple art forms, varied activities, multiple artists with patients with varied abilities and disabilities, an emergent, negotiated, patient-centred approach to developing content and multiple potential routes to different types of benefit the programme might be defined as having both “complicated” and “complex” elements [31]. Given these features, the study used predominantly qualitative methods (interviews with patients) to explore and evaluate the programme, but in addition clinical data (on patients medical and treatment) and information recorded by artists on the content of actual arts sessions was collected and analysed.

Patient recruitment

Eighteen patients on the Stroke Unit were recruited to participate in the main phase of the study by the Lead Investigator (SP) – a registered nurse with specialist mental health training – following consultation with member(s) of the multi-disciplinary stroke team about patient eligibility. Patients were eligible to take part, following stroke, providing they were medically stable and likely to be in hospital for at least two weeks (to ensure they would be able to take part in at least four sessions). Patients were not eligible if they had had a transient ischaemic attack (rather than a stroke), were in acute medical need, or had pre-stroke cognitive impairment. All eligible patients entering or on the ward during the fieldwork period (June – November 2009) were approached to participate.

A high proportion of stroke patients have cognitive or speech and language impairments and collecting and reliably interpreting data from these patients can present significant challenges. For this reason many studies of interventions aiming to reduce psychological distress amongst stroke patients fail to involve such patients; thus the findings of such studies are not representative of the wider stroke population [32]. There was a commitment to include these patients in the present study, and therefore to test the programme with a representative group of patients.

Whilst this added somewhat to the complexity of the programme design and delivery, recruitment arrangements and research methodology, the associated challenges, once identified were overcome one by one. In terms of programme design a range of activities was developed that would be suitable for patients with widely varying abilities. To ensure artists were adequately prepared to work with patients with varying capabilities, including cognitive and speech and language impairment, training and detailed guidance was provided. To enable flows of information about patient capabilities, preferences, risks and issues associated with any planned activities, a range of project forms and materials were used to facilitate communication between artists and members of the multi-disciplinary stroke team, and a system for involving speech and language support in introductory sessions, and the involvement of relatives (to support person-centred activity planning, in the case of patients unable to express themselves) was also incorporated. In terms of recruitment arrangements a detailed flow chart and associated guidance was developed to underpin the different recruitment and consenting arrangements that would be appropriate for people with fluctuating levels of mental capacity. In addition four different consent forms were developed to accommodate the different consent processes for patients with different impairments. In terms of research methodology the researchers adopted different methods for patients with differing cognitive and speech and language impairments. We knew in advance that some patients would not be able to express themselves without detailed pictorial aides, and so the original topic guide used for patients able to be express themselves was fully illustrated with a range of symbols to facilitate possible positive/negative responses to enable patients with severe speech impairment or confusion to express their views by pointing at the symbols. We devised a classificatory system (outlined in the next section) which sensitized us to the likely communication support needs of different patients.

Informed consent to participate was obtained from each patient, unless a patient did not have mental capacity to give consent. In the latter case a patient was included in the study unless any member of the multi-disciplinary stroke team or the patients’ relative (who was involved in the consent process in all such cases) believed that the patient would not wish to participate or that they may experience distress or harm arising from their participation.

All participating patients took part in at least four arts sessions. Individual semi-structured interviews were undertaken with patients to explore their experiences of stroke, hospitalization and taking part in the programme. For two patients with severe cognitive and/or communication impairment, relatives of each patient were interviewed in order to gain a sense, at least from relatives’ perspectives, of how each patient had engaged with the programme, its suitability and potential value.

Qualitative data collection and analysis

Interviews were organized around patients’ communication abilities and support requirements:
- Group 1: Eight patients who were able to express themselves with relative ease;
- Group 2: Four patients with some mild/moderate cognitive impairment but no communication impairments;
- Group 3: One patient with mild/moderate cognitive and communication impairments who could be assisted to express his views;
- Group 4: Three patients with communication impairments but no cognitive impairments who could be assisted to make their views known; and
- Group 5: Two patients with severe communication and/or cognitive impairments where direct communication was not possible.

Sixteen patients were interviewed directly. A semi-structured topic guide was used in most interviews. The research team used communication aids specially developed for this study, for use with patients with mild/moderate cognitive impairments or speech or language impairments (groups 2, 3, and 4) and interviews were supported by a Speech and Language Therapist (CC) where necessary. The relatives of two further patients from group 5 were interviewed as a proxy for these patients due to their severe communication and/or cognitive impairments.

The interviews – which took place within a week of patients completing at least four arts sessions – explored their experiences of stroke, stroke rehabilitation, hospital stay and the meaning and value to them of participating in the programme (see Box 3 below for a summary of the topic guide). Although the researchers were sensitized to and interested in the emotional aspects of stroke and hospitalization and the potential impact of participation in the programme on patients’ emotional and mental well-being, the topic guide and interviews explored meaning and value in an open-ended manner. Two thirds of interviews were undertaken by SP, and one third by MB. All interviews were tape recorded and transcribed in full.

Sixteen of the eighteen patients interviewed were included in the main analysis. Due to time and resource pressures associated with delivery of the research, it was only possible to complete the resource intensive transcription, coding and summarizing of sixteen of the eighteen interviews. Data from the final two patients to be processed – (one from group 1 and one from group 2) were excluded from the analysis. Making a fundamentally pragmatic decision in the context of what was a painstaking research process is unfortunate, but we do not believe this is likely to affect the findings or conclusions of the research as the selection of each patient for processing was implicitly random and the two patients excluded were as likely as any other patient to be excluded.

The research team based its approach to data management and descriptive analysis of the staff and patient interview data, on the Framework approach, developed and used by the National Centre for Social Research [30] and also used its Framework software [33]. Extensive work was undertaken by MB and SP to develop a pragmatic high level index (and definitions) which could be used to reliably code the interview material. Interview transcripts were then summarized (or data was directly extracted from transcripts) within the agreed index, and in respect of material on the meaning or value of participating in the programme to patients all comments, both positive and negative were summarized in Framework, or included verbatim.

Detailed descriptive analysis of the material on meaning and value of participation was then undertaken. A long list of themes was derived from the researchers’ immersion and review of this material. The themes were debated and refined by the researchers. The themes that emerged at this point reflected many of the categories used in the Warwick-Edinburgh Mental Wellbeing Scale [34]; our reference to this scale helped to sharpen and crystallize the list of themes. All the summaries and verbatim material relating to the meaning and value of participation was then coded using the emergent list of well-being themes, allowing for the integrity (or goodness of fit) of the themes to the data to be further tested and the frequency of each themes across the sample to be ascertained. The summaries and coding performed by one of the authors (SP) were checked by the other (MB) (and vice versa) for consistency of classification and interpretation.

Our analysis focused on exploring whether there were consistent positive experiences arising from what we thought (implicitly) might be consistently active ingredients of the programme such as, for example a) the collaborative/patient centeredness of the intervention, b) the empathy, care and encouragement that was central to the relationship between artists and patients, c) the experience of being occupied in something creative which builds on the person’s own life and d) the experience of being removed from a busy ward to do something creative, absorbing and interesting. We did not aim or try to systematically analyse and interpret the experiences of patients using specific art forms or combinations of art forms

<table>
<thead>
<tr>
<th>Stroke/hospitalization</th>
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<tbody>
<tr>
<td>Experience of stroke event and first few days after it</td>
</tr>
<tr>
<td>Impacts of stroke on patient</td>
</tr>
<tr>
<td>Emotional state following stroke and during hospital stay</td>
</tr>
<tr>
<td>Availability and access to ‘expected’ sources of emotional and social support during hospital stay</td>
</tr>
<tr>
<td>Experiences of medical treatment and care in hospital and rehabilitation activity</td>
</tr>
<tr>
<td>Current emotional state</td>
</tr>
<tr>
<td>Hospital discharge plans</td>
</tr>
</tbody>
</table>

Taking part in the arts programme

- Deciding to take part in the arts programme
- Choosing art forms/activities with artists
- Content of the arts sessions
- Working one-to-one with an artist
- What was taking part all about for the patient?
- Views of how the arts programme helped, if at all
- Satisfaction with key aspects of the programme
- Discussion of the final session

Other

- Other activities undertaken outside of sessions
- Intentions regarding arts activity beyond discharge

Box 3: Summary of topic guide
because the content of the arts programme was so different for each patient. The quotations used in the text are illustrative of the high level “meaning and value” themes we identified through the analysis and we have deliberately resisted making what might be arbitrary interpretations about what may be specific patients’ idiosyncratic experiences of specific art forms.

**Additional descriptive data collection and analysis**

To underpin and contextualize the interview material two sets of data (including quantitative and qualitative material) were obtained and analysed. Firstly, information routinely collected by the multi-disciplinary stroke team on medical and psychological status, functional impairments, treatment and rehabilitation, and social issues, was obtained and recorded by SP on a specially designed Patient Data Template in respect of each patient included in the sample. Data was extracted from paper copies and entered into Excel by SP. The data from the Patient Data Template were entered as “attribute” data onto Framework as an aide to qualitative analysis. In addition the data set was analysed descriptively. Comparative analysis of study data with comparable data collected for all stroke patients passing through the unit was undertaken to understand the similarities and differences between the sample of participants and the wider stroke population.

Secondly, artists recorded information about each patient’s artistic and cultural preferences and interests, and the planned and actual content of sessions on Patient Activity Planning and Monitoring Forms. Data from these forms was extracted and entered into Excel by SP. The data set was analysed descriptively. The results of the descriptive and comparative analysis of data collected about the sample’s characteristics using data collected with the Patient Data Template and from clinical records are presented first. The results of the analysis of Patient Activity Planning and Monitoring Forms which were completed by artists are then presented, and finally the findings of semi-structured interviews with patients regarding their participation in the programme are presented.

**Profile of the sample of patients: descriptive and comparative analysis**

127 patients were either admitted to the stroke unit or already on it at the beginning of the fieldwork period. Of these 25 patients met the eligibility criteria, and 20 (80%) agreed to take part. Eighteen patients completed the programme (i.e. they took part in between 4 and 6 sessions).

The programme was accessed by equal numbers of men and women, a range of age groups (although naturally weighted towards older patients) and a mix of patients in terms of marital and working circumstances. It was accessed by patients with different types of stroke (although mostly ischaemic) and by patients with varying degrees of physical disability, speech and language difficulty, cognitive impairment and mental health issues.

Statistical comparisons showed that those taking part were broadly comparable with the wider population of stroke patients passing through the Stroke Unit during this period in terms of gender, age and stroke type (Table I). However, a key difference was length of hospital stay; those taking part remained in hospital on average 66 days longer than the average stroke patient (the average length of stay of patients taking part in the study was 110 days). This was a result of the design of the study which, as noted above, included only those patients likely to remain in hospital for at least two weeks following medical stabilization. Amongst stroke survivors, it is likely, given the focus on longer staying patients, that those taking part had higher levels of impairment than the wider stroke population.

**Content of sessions**

Reminiscence (during initial and later sessions) was a key way of eliciting from patients their cultural, artistic and personal preferences and narrative, and collaboratively devising a range of suitable arts activities to undertake and was also a substantive feature of sessions for many participants who valued this activity.

Most patients engaged in multiple art forms during the programme. Eleven of the 18 patients engaged with three or four different art forms and six engaged with two art forms. Nor were individual sessions restricted to one art form – most sessions (58%) involved two or three art forms; just 38% of sessions involved only one art form.

The individual and combined activities undertaken with each patient were different for each patient. Just over a half of all sessions involved music, just under a half involved two dimensional art, a quarter involved three dimensional art, and a fifth involved dance or music. A further fifth involved creative writing or literature.

Activities were tailored by artists to suit each patient’s functional capabilities; activities could be relatively passive or active depending on a patient’s wishes. Table II gives examples of relatively active or passive activities within each art form. For eight patients more than 50% of activities were classified as “relatively active”, whilst for 10 patients more than 50% of activities were classified as “relatively passive”.

In addition to the various arts activities and the initial (and on-going) reminiscence, conversation and giving patients the space to express themselves verbally was a key feature of sessions and formed part of the development of a friendly relationship between artists and patients. Artists recorded the

| Table I. Characteristics of those accessing the programme compared with all patients on the stroke unit. |
|---------------------------------------------------------------|---------------|---------------|
| **Time being Stroke** | **Those accessing** | **All patients on stroke unit** |
| Males | 50% | 43% |
| Females | 50% | 57% |
| Age | 70 | 78 |
| Stroke type | 79% ischaemic | 89% ischaemic |
| Length of hospital stay | 110 days | 44 days |
Music Singing Listening to CD
Dance and Creative writing/ 3D art Kneading clay one handed
2D art Making collage of images

Table II. Examples of active and passive activities.

<table>
<thead>
<tr>
<th>Art form</th>
<th>Relatively active</th>
<th>Relatively passive</th>
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</thead>
<tbody>
<tr>
<td>2D art</td>
<td>Making collage of images</td>
<td>Looking at photos</td>
</tr>
<tr>
<td></td>
<td>representing participant's life and interests</td>
<td></td>
</tr>
<tr>
<td>3D art</td>
<td>Kneading clay one handed (also to reduce tension)</td>
<td>Looking at stones and fossils from beach</td>
</tr>
<tr>
<td>Creative writing/ literature</td>
<td>Writing a poem</td>
<td>Discussing content and format of participant's book and how to present patient's experiences of stroke and hospital stay in a visual way.</td>
</tr>
<tr>
<td></td>
<td>Reading poems</td>
<td>Talking about literature and the 'idea' of writing down stories related to music</td>
</tr>
<tr>
<td>Dance and movement</td>
<td>Playing castanets and wheelchair dancing</td>
<td>Artist read from book on dance</td>
</tr>
<tr>
<td>Music</td>
<td>Singing</td>
<td>Listening to CD</td>
</tr>
</tbody>
</table>

dancing to music yes and then she had feathers and things...And she threw them all in the air and we caught them, it was lovely and I've still got one...I noticed [later on] I'd still got one of these feathers stuck somehow into my clothing. And that was lovely, I enjoyed that time yes..."

88 year old female patient, group 1 (66 days in hospital)

“...as I say... they were playing guitars and singing along. He was singing along. We don't know what he was singing but he was singing along to the record and everything like that and he was going along with her. Yes, he thoroughly enjoyed it.”

Partner of 73 year old male patient, group 5 (141 days in hospital)

The animated accounts of pleasure derived from participation contrast considerably with the literature on and patients' accounts of, their difficult experiences of stroke (shock, disbelief, anger, fear), impairment (distress and frustration associated with loss of abilities, immobility and dependence on others) and being in hospital (loneliness, boredom, being around people with high needs).

Feeling connected (13 of 16 patients)

Patients derived and valued a sense of connectedness with the artist(s) during their participation in the programme. This arose in different ways and through different mechanisms for each patient: for some it was associated with being listened to, having someone who had time for them, someone they could talk about their problems with; for others it was a consequence of sharing of common interests through activity or discussion, a meeting of minds or shared humour, or the value arising from being borne in mind by another person between sessions. Being treated as “an individual” by the artist and having the opportunity to reciprocate was also an important feature mentioned by some patients.

“...It's all to do with people and the people I'm surrounded by here are all people who have no time. That's the irony, they're people who have no time to sit with me; they're people who have no time to talk with me. And in my innocence when I came in first I asked a nurse 'would you read to me?' And you can imagine, she burst out laughing and said to me 'maybe you can try that with the night staff, we certainly don't have the time.' And I just didn't get it at the time, now I do... you have these outsiders [artists] who you can talk to, and it is care of the highest kind, engages your brain and your emotions and... [they say] 'what do you want to talk about?'; you know, and 'what do you like, your likes and dislikes and hopes?...somebody who is on that level as well, somebody who knows exactly what you're talking about, it's quite a beautiful thing. So, you know well it's really dragged me out of the doldrums...”

52 year old female patient, group 1 (115 days in hospital)
...it was lovely to experience other people’s experiences if you know what I mean and oh yes [being together with the artist] definitely gave me something, more than just me doing it, yes definitely.

88 year old female patient, group 1 (66 days in hospital)

The fact that the artists offered time and space for the person and that they treated them as an individual (rather than a patient) was important — and this contrasted with some patients’ experience of clinicians who understandably had less time available to engage with patients on patients’ own terms.

“I think it was very good actually; it was quite enjoyable to have someone to talk with about what you’re interested in and the interest also in what you’re saying...she’d come in with books of dresses and things; want to know what I wore and you know, what places I’d been to. And I’d try to remember most of them. What dresses I liked, and I made them all myself... She was very good actually; I think so anyway.”

87 year old female patient, group 2 (69 days in hospital)

Mental stimulation, learning and creativity (12 of 16 patients)

Patients described how they valued engaging in activities which required them to learn, discover or be creative. Most often this was specifically around undertaking new activities but patients also referred to the value of conversation with artists about the programme, or art and culture more generally.

“We put a few poems together and that was a great sort of learning process and great fun as well...I will leave hospital with skills I didn’t have when I came in.”

52 year old female patient, group 1 (115 days in hospital)

“Oh yes It was an interesting experience ...with eyes closed she would give me something in my hand to feel and then... You were supposed to draw what it felt to be...that was rather interesting...[and in relation to creative writing]... What she did on this occasion is cut up into squares different words out of a poem and she says this always works. You pick what you want out of it and at the end of it she said it will always come up similar to the poem. That’s a very intriguing idea isn’t it?...I thought that was very intriguing, I loved it that idea....”

88 year old female patient, group 1 (66 days in hospital)

One patient with substantial speech and language impairment was interviewed with support from the speech and language team using a specially designed topic guide. After being asked whether he had valued participation, he was asked what aspect of the programme he most valued:

Interviewer (SLT): “What did you think was the best? What did you most value about the sessions?”(Interviewer uses the accessible interview materials)

Patient: “Well I suppose it was that really (patient points to the image and words ‘being creative’ from amongst a range of possible options).”

83 year old female patient, group 3 (189 days in hospital)

Engagement in purposeful occupation and relief from boredom (12 of 16 patients)

As illustrated by the quotations below, patients commonly valued taking part in purposeful activity or conversation with artists, which provided relief (albeit temporary) from the boredom and under-activity which they associated with being on the Stroke Unit.

“I’m very depressed...very depressed and frustrated and bored... doing the arts programme did help...it gave me something else to focus on for a little bit of time.”

54 year old female patient, group 1 (158 days in hospital)

“I applauded it. I think it’s at a time when one is sitting in a chair or in bed and that sort of thing and wondering when the next meal is. There’s not much to do apart from reading a newspaper and watching television, something like that.”

85 year old male patient, group 1 (25 days in hospital)

Reconnection with self (9 of 16 patients)

The personalization of activities was a key feature of the programme and as intended, emerged through a reminiscence process facilitated by the artist. From patient accounts the subsequent tailoring of activities to emerging themes of relevance and meaning to the patient was effectively achieved in most cases.

Patients commented that engaging in reminiscence and then personally meaningful activities often gave rise to a sense of feeling reconnected with familiar or normal pre-stroke identity, activities, situations or realities. This was greatly appreciated by patients.

“I like talking, um about my past, and she’d ask me where I’ve been, what I’d been doing in my life...which I love to listen to (laughs)...I enjoyed talking about it, not necessarily the nasty parts where I was in the forces... but um, the nice parts and the things I enjoyed doing...it was just a pleasure...and it did bring back a lot of good memories [and in relation to one of the arts activities for which the patient was asked to close his eyes and imagine what had been placed in his hand]... well as I told you when I [repaired] machines I didn’t have to look at them, I could do it all by feel, so I said ‘my feel is quite good’”

73 year old male patient, group 1 (82 days in hospital)

It was also possible with the help of relatives to match activities in this way for patients with cognitive impairment. A patient’s sister and daughter who were interviewed together explained what they felt taking part meant for their relative:

Patient’s sister: “…it was almost like, ‘well I’m just looking at a magazine like I’ve done in the past.’”

Patient’s daughter: “I think this was all linking in with how she used to feel...what interested her...how they were...happier times...normal times... these are the things...I’ve always liked and I still do’ and can they come back in my life?...I would think, trying to sort of think how mum is, I would think it was quite reassuring to still link in, tune into the things that, whatever makes you happy…”

Sister and daughter of a 74 year old female patient, group 5 (40 days in hospital)

This benefit is important in providing a link between former and future self – a sense of continuity and an opportunity to try out, often for the first time since their stroke, meaningful and personally valued activities in a safe environment.

“It was very good of her wasn’t it?...She took photos all along the beach and collected fossils.... I was so pleased to think she’d gone to all that trouble. And she even recorded the sound of the sea...it was
Other authors [35] have highlighted the importance of addressing the link between former, current and future self within the context of hospital rehabilitation. In the case of the above patient, this activity was undertaken by the artist to try to help a very poorly and depressed patient to reconnect with valued aspects of her previous life and inspire her for the future, though in this case, sadly, the patient died in hospital. The effort of the artist to make this connection to valued aspects of her past life was greatly appreciated by the patient, as demonstrated by the quotation.

Other areas of benefit
Smaller numbers of patients (less than half the sample in each case) associated participation with other positive feelings and experiences.

Feeling cheerful (7 patients)
Some patients reported that participating had had an impact on their mood, enhancing their general outlook. This resulted from either the engagement in activities, the value of the relationship or both.

Feeling inspired/energised (6 patients)
Several patients also reported that they found the sessions a source of inspiration and/or something to look forward to, at a time when their motivation and engagement was relatively low.

Enhanced competence/confidence (5 patients)
For some patients the sessions resulted in or demonstrated an improvement in their confidence or competence with regard to specific capabilities. These might be in relation to artistic activity or basic functional abilities.

Calm (5 patients)
Some patients experienced quite severe distress and anxiety during their hospital stay and reported that the sessions offered a source of relaxation, tranquility or calmness and provided relief from tension, irritability, frustration or anger. These benefits were derived from either specific relaxation focused activities (such as breathing techniques which were part of dance/movement activities, or listening to music), getting away from the busy ward or from unwell patients for a while to do absorbing activities, and/or having time to talk to someone about issues affecting them.

Space to think and reflect (4 patients)
Psychological space to think about, reflect on, process, understand or re-frame experience was valued by four patients.

Feeling hopeful or optimistic (3 patients)
For a few patients taking part in the programme (sometimes the activities, sometimes the relationship) contributed to regaining hope, or optimism about their recovery and their future.

Achievement/pride (2 patients)
For two patients taking part in the programme resulted in a sense of personal achievement as a result of having made progress with a particular arts activity (produced an artefact).

Validation (2 patients)
For two patients the sessions resulted in them experiencing a sense of personal acknowledgement and worth largely through the conversation and engagement with the artists or through the things the artist did for the patient.

Empowerment (1 patient)
For one patient, with severe cognitive impairment the patient’s relatives perceived that she had benefited from having some influence or control in the activity which contrasted perhaps with her loss of control in most other aspects of self-care.

Negative experiences associated with Time Being Stroke
In the context of wider and generally positive accounts of taking part, several patients reported some negative aspects associated with the programme. These were idiosyncratic (i.e. not experienced by more than one or two patients) and unrelated to key features of the programme, but learning about these negative aspects was important for the arts staff leading and delivering the programme. For example one patient experienced difficulty and anxiety around making choices about which arts activities to engage in; another was saddened by the difficulty she had reconnecting with familiar pre-stroke activities; and another patient said her sessions were “often interrupted” by clinicians or other staff coming into the room where her sessions took place, and as noted earlier one patient with severe cognitive impairment experienced some distress during a session which took place without his partner. Knowledge of these difficulties and issues will be of use for any future implementation of this programme.

Continuation
All but one patient (for whom there was no information) indicated a wish to continue with arts activity. For eight patients the arts programme had enabled them to continue art activity or pursue existing interests whilst in hospital. For three further patients the arts activities they engaged in were new and their continuation or continued reference to the activities would represent a new interest in their lives. In four cases patients/relatives indicated that the sessions had been helpful in giving them examples of enjoyable activities patients and relatives could do together after discharge.

Discussion
Healing Arts successfully developed and implemented a person-centred multi-arts programme for stroke patients. The preparation work, development, programme contents and practice issues have been fully documented in the research...
Meaning and value of arts to stroke patients

reports and in the programme guide which are available on the Healing Arts website [36]. This documentation ensures that, in accordance with Her Majesty’s Treasury’s guidance for Invest to Save Budget programmes, the programme has the potential to be easily replicated both locally and elsewhere with similar groups of patients. It also provides firm foundations on which to undertake further development and research into the programme – which, given the promising findings which are discussed below, is recommended.

In contrast with the distress experienced by many patients, taking part in *Time Being Stroke* was, according to all patients included in the analysis (n = 14) and relatives’ proxy accounts (n = 2) a generally positive experience. Most patients’ accounts were indicative of multiple benefits associated with participation, and although patients’ experiences differed, and the specific reasons and meanings attached to patient narratives varied from one patient to the next we identified a number of commonly experienced benefits. These benefits were pleasure and enjoyment, a sense of connection with the artists, mental stimulation, learning and creativity, engagement in purposeful occupation and relief from boredom, and reconnection with valued aspects of the self. Other positive experiences mentioned by fewer than half the sample included a feeling of cheerfulness, enhanced confidence/confidence, calm/relief from anxiety, space to think and reflect, hope and optimism, a sense of achievement, validation and empowerment.

This range of emergent benefits maps well onto the constituent elements of the concept “mental well-being” (i.e. positive affect, satisfaction in interpersonal relationships and positive functioning) [34] suggesting that the programme contributes, in different ways for different patients to key aspects of “mental well-being”. This contribution to mental well-being in hospital may also make a contribution to rehabilitation – since, as was discussed earlier, depression amongst stroke patients can adversely affect rehabilitation outcomes [6–9] – however, further focused research would be needed to test whether *Time Being Stroke* could contribute to patient engagement in rehabilitation. These findings provide further confirmatory evidence of the value of the arts to stroke patients’ emotional and mental well-being, adding to the small but growing evidence base for the use of arts in stroke rehabilitation [26–28].

Whilst the most common benefits of participation are discernible and have been described, it was not possible, given the complexity [31,37] of the programme and patient population to develop a model or models of how the programme might consistently achieve these common benefits for different patients. Is the essential ingredient in the programme which gives rise to the pleasure so commonly reported associated with the creativity, calm and absorption experienced by patients of doing valued arts activities, or is it the value of being able to learn to do something new at a time of such considerable loss, or is it perhaps the appreciation of sensuality, flow, and aesthetics of an art form (e.g. listening to beautiful, evocative or familiar music or creating tactile forms using clay or fabrics)? Is the connection with artists a result of the opportunity to express oneself and share the pain and shock of an experience when there are so few others to talk to, or is it a result of the empowerment arising through patient-centred, and collaborative enterprise in an otherwise disempowering environment. Is it the value of tuning in to, and developing an understanding of, another person and finding areas of common interest – making friends at such a difficult time or the experience of reminiscence, looking back to remember and share life experiences with fondness in the presence of a friendly, and interested listener? Is the pleasure or connection with artists a consequence of the satisfaction that results from discovering the ability to take part in arts activities even with reduced functional capabilities or a result of the experience of humour and fun stimulated through light-hearted creative play? Detailed associative analysis or modelling of each of the four most common benefits could have been undertaken in further analysis to try to develop meaningful explanatory accounts for each benefit area, but this work would have been painstaking, and it was not the intended purpose of the study. In any case it is most likely that the causes of patients pleasure, connection with artists, value in being occupied, and reconnection with self are multiple and variable across the sample – reflecting the interpersonal, multifaceted and person-centred nature of the programme and the unique meanings each human being attaches to his or her experiences.

It is also likely that the relationships between different valued aspects of the programme as experienced by patients are symbiotic; for example the relationship patients have with artists appears to be developed and enhanced through collaborative arts activity and conversation, and the quality, and tailoring of arts activities is enhanced and improved through the growth in familiarity between patient and artist; the benefits and their drivers are then difficult to distinguish in what becomes a virtuous circle of engagement.

As in other studies [27,28] the one-to-one aspect of the programme appears to be important since a deeper relationship was able to develop between patient and artist allowing shared control of sessions, and informed tailoring of sessions. However, other studies have shown the value (in helping to avoid introversion) of group-based programmes for stroke patients [26] and an additional group-based element to the programme might also be valued by patients.

The findings of the study are based on the experiences of a sample of longer-staying patients with higher levels of need than the average patient of taking part in a carefully designed and highly specialized multifaceted arts programme. The findings are not necessarily transferable to other arts interventions or other patient groups. It is likely that those staying in hospital for longer periods have the greatest capacity to benefit from the programme, given the amount of time spent by these patients inactively, when not engaged in rehabilitative activity, living or other activities of daily living and due to their having higher levels of impairment (and potentially higher emotional needs) than other patients.

Patients staying for shorter periods (say 4 weeks or less) and making speedier recoveries might value the chance to take part in arts activities but these patients are perhaps less likely than longer staying patients to have high degrees of functional loss, enduring emotional needs or to experience long periods of inactivity, and so do not necessarily need to be facilitated in such an intensive, and sensitively planned one-to-one intervention.
Limitations and caveats
All but one patient (for whom there was no information) indicated a wish to continue arts activities in the future—either because the programme had allowed them to continue with previously valued activities and inspired them to continue after discharge, and for some because the programme had introduced them to new activities that they would like to undertake alone or with their relatives/carers.

It is regrettable, however, that it was not possible to undertake follow-up data collection to explore the longevity of impact and post-programme behaviours of participants—especially given the importance and value of hospital-based activities which prepare patients for life in the community post stroke [35,38] and the potential value of engaging in meaningful social activities to people who have had a stroke who can become dissatisfied with their time use following discharge from hospital [39,40].

Whilst the positive impacts on aspects of mental health contrast with the negative experiences of stroke and hospitalization, our analysis did not investigate whether, or how, the programme counteracts the specific sources of distress that each patient mentioned. Further analysis at the case-level, mapping sources of distress onto areas of benefit, could be undertaken using the data collected through this study to explore this. Other analyses of this detailed and rich dataset are also warranted. Production of case studies could provide further useful material for artists working with stroke patients, and more extensive associative analyses could be undertaken to try to generate theories around how the programme benefits patients with different socio-demographic characteristics and rehabilitative needs.

The numbers assigned to mental well-being themes—used in the results section—should be seen as indicative rather than definitive. Firstly, the categories used in “areas of benefit” were derived, in analysis, from material generated by broad open-ended questions about the meaning and value of the programme and the data analysis is necessarily interpretive. Secondly, readers should also recall that the interviews were undertaken, in some cases, with people with some degree of cognitive impairment or communication problems, and they generated accounts that were highly variable in terms of the level of detail offered and the degree to which the accounts could be fully understood. Making sense of accounts, which were sometimes difficult to understand, was challenging and as a result some experiences of participation may have been missed out for some people due to cognitive, communication or recall difficulties. However, counting the number of patients benefitting in different ways provides an indication of the most common areas of benefit and the spread of benefits within and across the sample as outlined in the results section—and goes some way towards meeting the evaluative aims of the study. Readers should also note that part of the analysis relied on proxy accounts of relatives of two patients.

Further experimental or quasi-experimental research would be needed to assess definitively the impact of *Time Being Stroke* on psychological distress and recovery, patient mental-well-being, and rehabilitation and to identify the cost-benefits of the programme. If including patients with cognitive or speech and language impairments, such research may require the development and validation of new research tools and/or techniques to deal with the challenges of reliably measuring mental health and rehabilitation outcomes, but length of stay would be a useful indicator of overall impact on rehabilitation providing treatment and control group had equivalent discharge policies, processes and resources.

Conclusion
Patients’ accounts of the meaning and value to them of participating in *Time Being Stroke* indicate that artists’ facilitation of one-to-one person-centred arts sessions contributed, during the period of their participation, to the mental well-being of long-staying hospital-based stroke survivors. These positive experiences contrast strongly with the acute and chronic distress experienced by patients associated with stroke, impairment, and spending long periods of time in hospital and may go some way to countering it. *Time Being Stroke* has been fully documented to enable local and wider adoption, and further development and research. As a valued programme, contributing to the well-being of patients remaining in hospital for extensive periods, its consideration by health commissioners and providers, and rehabilitation teams is advised along with further evaluative work.

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