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About Being: an interdisciplinary and collaborative arts and health project supporting the ongoing recovery of stroke survivors

Abstract

Arts and health initiatives can make a valuable contribution to the ongoing recovery of stroke survivors. This article focuses on a study of the About Being project, which provides dance and movement sessions for stroke survivors in the Cumbrian city of Carlisle, UK. The study evaluated the model of practice applied to the community project and how the sessions supported the ongoing recovery of stroke survivors. The methodology involved observations of the sessions and qualitative interviews. A unique feature of this project is that it brings together the fields of education, arts and health by engaging practitioners, academics and student volunteers, along with the stroke survivors who participate in the sessions. It is proposed that the success of the About Being project is attributed to its interdisciplinary and collaborative practice, person-centred approach and multidirectional learning environment, which is beneficial for all those involved.

Key words

arts and health, stroke survivor, interdisciplinary practice, collaborative practice, dance and movement, health and wellbeing

Introduction

The About Being project provides dance and movement sessions for stroke survivors in the Cumbrian city of Carlisle, UK. This community project, facilitated by the University of Cumbria, brings together the fields of education, the arts and health with practitioners, academics and university students working together to support the ongoing recovery of stroke survivors. This article will demonstrate how the About Being model of practice is underpinned by interdisciplinary and collaborative practice, along with a person-centred approach, which focuses on individual attributes rather than the impairments experienced due to the condition of stroke; a key benefit of this approach is the creation of a multidirectional learning environment that is beneficial for all those involved. In addition, the impact of this project will be shown through the stroke survivors' perceptions of how participating in the dance and movement sessions contributes to their ongoing recovery by enhancing their health

and wellbeing through developing their bodies and minds, enhancing their social connections and enabling them to reconnect with themselves; themes which have long been recognised as key aspects of post-stroke rehabilitation (see, for example, Clarke and Black 2005; Pringle, Drummond and McLafferty 2013; Chow 2015) and which suggest a key role for arts-based interventions.

Context

A stroke is a sudden and life changing event caused by an interruption to the blood supply in the brain, which can cause a range of physical, cognitive or psychological changes. With more than 100,000 strokes occurring each year in the UK, stroke has been identified as the fourth biggest cause of death, resulting in 38,000 deaths across the UK in 2016 (Stroke Association 2018a). However, according to the Stroke Association, there are over 1.2 million stroke survivors in the UK, two thirds of whom will have left hospital with a disability (Stroke Association 2018a). The effects of stroke can be wide ranging, for example: the physical effects can include difficulties with mobility (due to weakness or paralysis of limbs and gait asymmetry), balance, coordination, swallowing, speech, vision and post-stroke fatigue; the cognitive impact of stroke can affect communication, memory, concentration, spatial awareness and executive function (e.g. the ability to plan and solve problems); and the psychological effects typically include depression and feelings of anxiety or frustration (NHS 2019; Stroke Association 2018b). It is common for stroke survivors to ‘grieve for the life and identity they have lost so suddenly and unexpectedly’ (Stroke Association 2013) and consequently, many individuals experience depression (Hackett et al. 2005; Kadojic et al. 2005; Stroke Association 2018b), loss of confidence (Horne et al. 2014) and changes to self-identity (Stroke Association 2013; Sarre et al. 2014).

Using arts in health initiatives can make a valuable contribution to the health and wellbeing of people across their life course (All-Parliamentary Group on Arts, Health and Wellbeing 2017). For example, research into stroke rehabilitation shows that art programmes can improve a stroke survivor’s motor function, visual perception and cognition (Kim et al. 2008), along with enhancing their wellbeing¹ through enjoyment, mental stimulation, learning and being creative (Baumann et al. 2012). Specifically, music programmes can improve a stroke survivor’s cognition (e.g. including verbal memory and focussed attention) (Särkämö et al. 2008) and motor control (Schneider et al. 2007), along with reducing feelings of depression and anxiety, and improving mood and social interactions (Nayak et al. 2000; Särkämö et al. 2008; Kim et al. 2011; Tarrant et al. 2016). An evaluation of STROKESTRA -

a collaborative music project involving professional musicians, clinicians and stroke survivors (Royal Philharmonic Orchestra 2019) - identified physical, social, emotional and cognitive benefits for the stroke survivors who participated in the music-making sessions (Nicholson et al. 2016: 3).

Dance programmes also have the potential to provide a range of physical and psychosocial benefits for disabled people (Hackney and Earhart 2009; Heiberger et al. 2011; Brierley 2014; Bradt et al. 2015; Hashimoto et al. 2015; Mandelbaum et al. 2016; Bognar et al. 2017; Rocha et al. 2017). Studies conducted with stroke survivors have reported that dance can improve physical functioning, emotional and social wellbeing (Thornberg et al. 2014; Demers and McKinley 2015; Anderson et al. 2016; Wolff et al. 2017). Indeed, Stroke Odysseys (2019) is a participatory arts project which enables stroke survivors to work alongside professional singers, dancers, songwriters and composers to share their experiences through live performances. The stroke ambassadors involved in Stroke Odysseys reported several benefits of their role, such as: enhanced physical and cognitive performance; improvements to mood, confidence and self-esteem; and kinship through the shared experience of having a stroke (Harrington et al. 2018).

The About Being project

About Being is an arts and health project that provides weekly dance and movement sessions to support the recovery and ongoing rehabilitation of stroke survivors in the Cumbrian city of Carlisle, UK. The project, established in March 2018, adopts an interdisciplinary² and collaborative approach with the stroke survivors working alongside dance and health practitioners and students based at the University of Cumbria. The About Being project has three main aims: to support the ongoing recovery, health and wellbeing of stroke survivors in the Carlisle community by providing regular dance and movement sessions; to develop interdisciplinary and collaborative practice between the fields of arts and health, and extend this practice into universities and community groups; and to provide the opportunity for university students studying performing arts, occupational therapy or physiotherapy to gain first-hand experience of the value of arts in health practice.

The University of Cumbria hosts the About Being sessions in an accessible studio room at the Brampton Road campus in Carlisle. The project involves three facilitators: the dance practitioner who is responsible for choreographing and delivering the sessions (Facilitator 1), along with two academics from the fields of occupational therapy (Facilitator 2) and performing arts (Facilitator 3) who provide support based on their areas of expertise

and recruit the student volunteers. In addition, a unique feature of the project is the collaboration with students who are studying arts and health courses at the University of Cumbria. At the time of the study, the About Being sessions were regularly attended by five men and two women; all of the participants were stroke survivors, apart from one female who was the wife and carer of a stroke survivor. The group participants were aged between 67 and 85 years old, and they were approximately six to eight years post-stroke.

Research method

In 2019, Health and Society Knowledge Exchange (HASKE), at the University of Cumbria, conducted a study of the About Being project. The study aimed to examine the model of practice applied to the About Being project and explore how the arts programme supported the ongoing recovery of stroke survivors. Data collection involved observations of the dance and movement sessions, along with semi-structured interviews with the group members.

The research team conducted five observations to gain an understanding of the content of the dance and movement sessions, along with the role of the facilitators and students supporting the group, in order to explore the model of practice applied to the project. In addition, the research team observed the stroke survivors' engagement with the sessions and interactions with all those involved. The approach to the observations was 'fluid, exploratory and relatively unstructured' (Robson 2000: 96), and the researcher positioned themselves as unobtrusive to ensure their presence did not impact on the sessions. Descriptive and reflective field notes were made to record details about the setting, activities that occurred, social interactions, non-verbal communication and the behaviours of the group members.

Ten semi-structured interviews were also conducted with the About Being group members; five of the interviews were face-to-face and five were conducted by telephone. The participants included the project facilitators (three), university students (two) and stroke survivors (five). The interviews with the project facilitators and students focussed on the model of practice applied to the sessions, and the interviews with the stroke survivors explored the impacts of participating in the sessions. All of the interviews were audio recorded and transcribed. The basic principles of thematic analysis (Braun and Clarke 2006) were used to code and categorise the qualitative data.

Research findings

The selection of findings presented here will provide an insight into the model of practice applied to the About Being sessions and the experiences of all those involved. The first

section will focus on the format of the sessions and provide examples of the techniques observed. Following this, sections two, three and four will illustrate how the sessions are underpinned by interdisciplinary and collaborative practice, and a person-centred approach, which creates a multidirectional learning environment that is beneficial for all those involved. The fifth section will present the stroke survivors' perceptions of how participating in the About Being sessions has impacted positively on their lives.

1. The content of the About Being sessions

The About Being sessions follow the standard structure for dance practice classes within community projects (Facilitator 1), with the weekly sessions providing 1 hour and 15 minutes of movement, followed by dedicated social time for discussion and reflection at the end of each session (approximately 20 – 45 minutes). This ensures that the group participants have sufficient time to warm up (15 minutes), develop their movements (45 minutes) and warm down (15 minutes). The sessions are designed to incorporate a wide range of movements which focus on the upper body, arms, fine and gross motor skills, the legs, standing, travelling, breathing and creative work. The specific activities vary each session and are guided by the needs of the stroke survivors (see Extract 2 below), the skills of the students supporting the group, and the creative intentions of the dance practitioner. The About Being sessions are accompanied by music and involve a range of movements and dance phrases³ which are demonstrated by the dance practitioner and then practised by the whole group. Examples of the techniques used during the sessions include: repetition of movements to develop muscle memory, stamina and strength; bilateral movements to enhance symmetry for the body; partner work to build connections; mirroring activities to encourage the development of neurological pathways; improvisation to exercise the body and mind by using memory and cognitive decision-making skills; and the creative use of imagery to describe the intention of the movement and help the group to visualise (e.g. lower body movements were described as 'marching legs' and 'windscreen wipers', and upper body movements were visualised as 'raindrops falling on the face'). Extract 1 provides an example of the content of the sessions through an activity involving partner work:

Standing activity with partner work

...The group transfer from sitting to standing. Two of the stroke survivors use their walking sticks; three stroke survivors stand unaided.

Facilitator 1 explains the movements – transfer of weight from one foot to the other by swaying, feet positioned firmly on the floor.

(slow piano music starts)

The group are swaying gently from side to side. They move slowly in time with the music. Facilitator 1 encourages them to move one foot slightly forward to transfer their weight...

(music ends)

Facilitator 1 asks them to get into pairs and stand opposite each other.

(music starts)

Each group member has a partner and they are standing opposite each other. They sway and bend their knees slightly, making slow movements. They step forward with one foot to transfer their weight. Two of the pairs are supporting each other by holding hands whilst doing the movement. The partners are quietly having their own conversations. Facilitator 1 moves around the pairs and gives support with their movements....

Extract 1: Excerpt from field notes - an example of partner work

2. Interdisciplinary and collaborative practice

The About Being project is grounded in interdisciplinary and collaborative practice between the dance practitioner facilitating the sessions and the academics and students from the fields of occupational therapy, physiotherapy and performing arts. This collaboration with other disciplines forms an important part of the stroke survivor's ongoing rehabilitation as 'recovery is about the whole self' (Facilitator 1).

The collaboration with students on arts and health programmes is a unique feature of the About Being model of practice. The students are recruited by the academics based in the disciplines of occupational therapy and performing arts, and take part in the project as

volunteers. Collaborating in the project enables the students to put their academic learning into practice whilst providing support to the stroke survivors. For example, through their physiotherapy training, one student learnt about the 'sit to stand transfer' and shared their knowledge with Facilitator 1 (the dance practitioner), who then incorporated the transfer movements into a dance phrase and set it to music. When this dance phrase was used in the session, the stroke survivors copied the movements and practised them, and for some of the participants this enabled them to learn how to safely and independently transfer from a sitting to standing position (as shown in Extract 1 above and Extract 2 below). Collaboration between individuals and disciplines was also observed when an occupational therapy student introduced personal goals for the participants (which are based on the occupational therapy concept of identifying meaningful occupations for the individual), and a musical theatre student introduced voice work and breathing exercises. The students' subject-specific knowledge and skills are seamlessly incorporated into the dance and music sessions as Facilitator 1 collaborates with the students prior to planning the sessions and choreographing the movements.

During the study, Student 1 was observed reviewing personal goals with the stroke survivors, which they had individually chosen at an earlier date; the goals were assessed in terms of the stroke survivors' satisfaction and performance, which Student 1 explained is 'standard practice' within occupational therapy (see Wressel et al. 2002). As shown in Extract 2, this activity enabled the stroke survivors to reflect on their personal progress and recognise how their functional abilities had gradually been developed through exercising with the group:

Coffee time

The group are having several conversations at the same time [...]

Student 1 reminds the group that they set goals earlier in the year. She hands out paper copies of their original goals and explains that she wrote them down after the last discussion. The stroke survivors review their personal goals and discuss them with Student 1 [...]

The discussion highlights that Stroke Survivor 5 aimed to get out of his chair without aids and he can do that now; he appears to be surprised when he realises that he has achieved his personal goal. Student 1 explains that the key movements have been incorporated into the dance and movement sessions. They were previously supported by a physiotherapy student who taught them how to transfer safely from a sitting to standing position and the key movements were then included into the dance phrases.

Extract 2: Excerpt from field notes - an example of collaborative and interdisciplinary practice with Student 1

This excerpt demonstrates how the dance practitioner collaborated with the physiotherapy and occupational therapy students to draw on their expertise and subtly incorporate transferring movements into the sessions through choreographing the sit-to-stand dance which 'was purely based on people wanting to get better at what we call transferring - getting on and off a chair' (Student 1).

Interdisciplinary and collaborative practice requires teamwork and 'open channels of communication' (Facilitator 2) because 'you're taking very specific knowledge from different discipline areas, people who have a particular reason and focus for why they're doing their thing [...] and then trying to get them to meet in the middle somewhere' (Facilitator 3). Collaborating in this way can be beneficial for both the facilitators and students as they can share experiences and seek support from one another; for example, discussions had taken place between the students and facilitators about managing group dynamics and behaviours to ensure a consistent approach to the sessions (Student 1 and Facilitator 2). Furthermore, collaborating with the students affords the dance practitioner more time to reflect on the group

participants during the session: ‘Being able to take time back and see who’s coping, who’s not, who’s engaging – so that’s how it works for me’ (Facilitator 1).

Collaboration is also evident with the stroke survivors as the content of the sessions is sometimes guided by their needs (as noted in Extract 2 above). In addition, it was observed that the stroke survivors can influence the names of movements or dance phrases. For example, a sequence entitled Pea Dance (which starts with moving an open hand away from the body) was originally given its name after Facilitator 1 asked the group to imagine holding something they would not want to drop, and one of the group members replied ‘a plate of peas’.

3. Multidirectional learning

One of the main benefits of the interdisciplinary and collaborative approach used for About Being is that multidirectional learning takes place within the sessions, as shown in Figure 1:

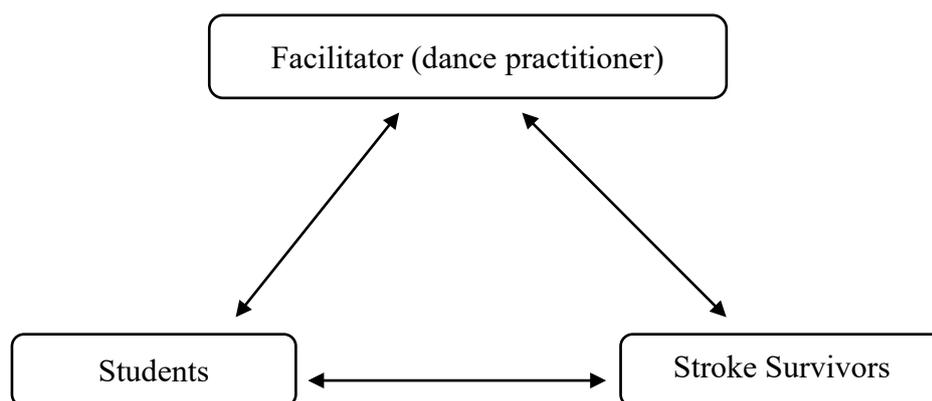


Figure 1: Multidirectional learning during the About Being sessions

Although the process of learning can often be viewed as one directional (e.g. from the facilitator to the group participants), the learning that takes place through the About Being project is multidirectional with everyone involved in the project benefitting in some way from the experience. For example, the stroke survivors have learnt about the potential of their bodies through participating in the dance and movement phrases created by the dance practitioner, along with techniques to support their daily functioning which have been introduced by the students. The university students have learnt about the lived experience of stroke and how they can support stroke survivors within their own discipline, and they have also gained an awareness of the benefits of collaborating with other disciplines and the value

of arts in health practice. In addition, Facilitator 1 (the dance practitioner) has learnt about the stroke survivors' experiences of their bodies and ongoing recovery, along with the students' academic specialisms, and used this insight to inform the creativity of the About Being sessions.

The students involved with the project described their volunteering experience as 'eye-opening' (Student 2) because 'it has introduced me to the arts in health, which is something I'd never really considered [...] opened my eyes to how that can be used' (Student 1). Through this interdisciplinary and collaborative learning environment, the students are able to model themselves and learn from each other, learn about the lived experience of stroke, gain confidence in their skills and develop essential team working skills (Facilitator 2). In addition, the intergenerational approach to the About Being project (with students in their twenties to stroke survivors in their eighties) provides the university students with the opportunity to learn about applied practice (Facilitator 3).

4. A person-centred approach

The About Being model of practice as discussed here, follows a person-centred approach to care by focusing on individual attributes and needs, rather than the impairments experienced due to the condition of stroke. This approach is aligned with guidelines for participatory arts practice (Waterford Healing Arts Trust and the Health Service Executive South (Cork) Arts + Health Programme, 2009), and is described by Facilitator 2 as being standard practice within the discipline of occupational therapy. The stroke survivors involved in About Being are actively encouraged to explore their abilities and how the various movements can be comfortably translated by their bodies. There is a strong emphasis on individual adaptations of the movements:

It's looking at what you can do [...] not what you can't do [...] and translation or adaptation of material, which is about peeling away what is the intention of the movement and then how can you actually take that into the body. (Facilitator 1)

For example, when participating in voice work, the group needed to count from one to five in time with a tune and use their fingers to keep count. In addition to exercising their voice and control, this task was designed to develop muscle memory and fine motor skills, and was 'also about the joy of making sound' (Student 2). The group were encouraged to

engage both hands to find a method of counting that worked for each of them, as shown in Extract 3. Facilitator 1 reported in their interview that as the stroke survivors became more confident in their movements and abilities, they started to push themselves further, and this was observed when Stroke Survivor 1 led the movement with her weaker arm:

Voice work

[...] Demonstration provided by Student 2.

Everyone joins in with the singing and counting in their own way:

- Stroke Survivor 3 - right hand (stronger side) is used to point to knuckles on left hand (weaker side).
- Stroke Survivor 1 – right index finger (weaker side) is used to point to fingertips on left palm which is open and facing upwards (stronger side).
- Stroke Survivor 5 – left hand (stronger side) is used to point to fingers on right hand (weaker side).

Extract 3: Excerpt from field notes - an example of how the stroke survivors adapt their hand movements

5. About *being*: the possibilities of the post-stroke body

The impact of the About Being sessions on the stroke survivors' overall health and wellbeing is captured through three key themes: body and mind; social connections; and reconnecting with self.

Participating in the About Being sessions enables the stroke survivors to develop their bodies and minds through experiencing a range of physical, emotional and cognitive benefits. For example, the stroke survivors described physical benefits such as improving their stamina, balance and standing, strengthening core muscles, transferring from sitting to standing, and furthering their ability to walk. As one stroke survivor notes: 'Everything to do with it is about strengthening the core, basically, and [...] working on your balance and standing and trying to move forward on the physical side' (Stroke Survivor 3). The bilateral movements incorporated into the sessions particularly encourage the stroke survivors to strengthen their weaker side: 'You have to often lift your other arm with your good arm, but you're still moving it so you're pushing and exercising it' (Stroke Survivor 2).

There was also evidence of cognitive and emotional benefits as some of the participants valued the mental stimulation provided by the sessions (Stroke Survivors 3 and 5) and reported being able to ‘concentrate better’ (Stroke Survivor 1). Although it is common to experience emotional changes after a stroke, the findings indicate that participating in the About Being sessions can be beneficial for improving state of mind: ‘This group makes you use your muscles more and exercise more, and it’s good for the body. You don’t get as depressed [...] it’s helping the mind more than anything’ (Stroke Survivor 1). One of the group members felt strongly that having access to the About Being sessions has impacted positively on their emotional wellbeing:

It’s the best thing what’s happened to me since I had the stroke [...]
If I didn’t have this class to come to, I’d just be sitting at home in
the same position all day, counting dots on the wallpaper. You
know, that’s no good for anybody. (Stroke Survivor 5)

The physical, cognitive and emotional benefits detailed here are particularly significant given that all of the stroke survivors were at least six years post-stroke and therefore, no longer received the intensive rehabilitation which is routinely provided immediately after a stroke occurs. Some of the stroke survivors felt that their recovery had plateaued prior to joining About Being so they were delighted about the profound impact that participating in the sessions had on their bodies and overall wellbeing.

In addition to exercising and moving their bodies, it is evident that the dance and movement sessions provide the stroke survivors with the opportunity to develop social connections. They explained that the sessions provide companionship and the opportunity to share their experiences, support each other and enjoy laughing together. For example, ‘meeting people is the most important thing’ (Stroke Survivor 4) and ‘laughter brings enjoyment and makes you feel better as well’ (Stroke Survivor 2). All of the stroke survivors commented on the companionship they experience through being part of the group: ‘People do thoroughly enjoy the sort of meeting together, the community side of it. Chatting, basically, and sharing their thoughts’ (Stroke Survivor 3). This companionship was also appreciated by the carer: ‘It’s the interaction with somebody else, as I say, you feel very isolated [...] it gets me out as well’ (Carer of stroke survivor). The significance of this peer support was described by another member of the About Being project:

Everybody is individual and everybody has their own story to tell, but we all get on well. And everybody has empathy with everybody else and appreciates the difficulties that we all have to deal with on a daily basis. And we applaud each other's successes. And you know, if somebody has an accident or something, then everybody's upset about it basically. But it's all positive thought, basically, that's the thing. (Stroke Survivor 3)

The findings highlighted that the process of developing physically, cognitively, emotionally and socially had the further benefit of enabling some of the stroke survivors to reconnect with themselves and their post-stroke bodies. The experience of having a stroke had impacted significantly on the group members' everyday lives, with several comments about losing independence, former roles and pastimes, and needing to rely on others or being forced to retire early. Walder and Molineux (2017: 629) describe stroke recovery as a process of re-establishing an occupational identity 'through connections with self, others and reality' and it was evident that participating in the About Being project had enabled most of the stroke survivors to regain some degree of control and independence within their everyday lives and develop a new confidence in their abilities. For example, through developing physical strength, stamina and balance, Stroke Survivor 1 had recently become more confident about using the bus independently and working in the garden: 'I feel as though I've got more control, because I like doing things myself' (Stroke Survivor 1). Stroke Survivor 5 described how his improved physical strength had enabled him to walk further, cook meals independently and use the stairs more confidently at home. These examples are activities that are often taken for granted, but regaining the ability to undertake everyday tasks clearly had a significant impact on the stroke survivors' daily lives. Finally, the About Being sessions were described as a mechanism for 'realising you can do things' (Stroke Survivor 3) by enabling the group members to develop strength in their bodies and minds, to explore their abilities and find a new confidence in their post-stroke bodies.

Conclusion

The About Being project wholly embraces an interdisciplinary, collaborative and person-centred approach to supporting the ongoing recovery of stroke survivors in the Carlisle community, which creates a multidirectional learning environment that is beneficial for all those involved. In doing so, this project demonstrates and encapsulates how the - normally

separate - disciplines of dance and performing arts, occupational therapy and physiotherapy can effectively work together, learn from each other and make a valuable contribution to arts in health practice. The collaboration with student volunteers from arts and health courses at the University of Cumbria is a particularly unique feature of the About Being project, which provides the opportunity for students to develop their skills and experience applied practice. At the heart of this community project are the stroke survivors who felt strongly that participating in the dance and movement sessions had enhanced their health and wellbeing by strengthening their bodies and minds, providing opportunities for social connections and ultimately, enabling them to reconnect with their post-stroke bodies.

There remain areas for further positive development, however. Initially the interdisciplinary aspects of the project were rooted in the presence of arts and health practitioners and allied health profession students within the same space, in order to explore the potential of this as a working model. The findings from the research suggest that there is far more to be said on a theoretical level, in terms of the ways in which the post-stroke body might be articulated through the discourse of arts research, in such a way that speaks clearly to disciplines such as occupational therapy. In particular, using dance as a form of connectivity – both with others and to participants’ own bodies – which went beyond simple social gathering provides an opportunity to re-imagine how the wellbeing of stroke survivors is framed conceptually as well as practically.

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¹ The term 'wellbeing' is subjective, but within this article it refers broadly to experiencing positive emotions and feeling satisfaction with one's life. Wellbeing can incorporate several elements of an individual's life e.g. physical, social, emotional, psychological, economic and spiritual.

² The authors use the term 'interdisciplinary' to represent the combining of two or more academic disciplines.

³ A 'dance phrase' is a short sequence of linked movements.