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Creative  
Practices  
for  
Improving  
Health  
and Social  
Inclusion



## **Creative Practices for Improving Health and Social Inclusion**

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# Introduction. Art cares for us: contributions from Health Humanities

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A few years ago during the restoration of the Chiaramonte Palace in Sicily (currently used by the University of Palermo), drawings and epigrams were discovered on the basement walls of some prison cells in. These drawings were studied systematically and it was discovered that these artistic expressions were made by the prisoners of the Spanish Inquisition during the 17th and 18th centuries. The prisoners, isolated and tortured, expressed their prayers, rage, fears and memories through poetry, paintings and pieces of text on surrounding walls. The evidence found also suggests that some artistic materials and tools for painting were supplied by the prison officers. There are numerous examples of the application of creative practices as a medium for self-expression in particularly vulnerable situations. One other example includes the numerous artwork produced by residents of psychiatric hospitals and asylums. In this same context, it is relevant to mention the contribution of Prinzhorn, a German psychiatrist and art historian, who collected pieces of art from patients receiving psychiatric care at Heidelberg Hospital.

We do not have to go to such extreme and dramatic circumstances in order to appreciate the healing qualities of such artistic practices as well as the positive effects on wellbeing, social inclusion, and building new meanings.

For most of us, the appreciation or active engagement with creative practices are an essential part of everyday life and without them it would be very difficult to even understand ourselves. It is in this standard and social context, beyond the romantic perspective of art as a subliminal or psychoanalytic expression as a means of in-depth self-understanding, that we would like to frame this work.

Any creative practice is social practice and as such, is guided (constrained) by norms, values, meanings and techniques from the different communities that practice them. That is, the iconic images of the 'crazy artist' or 'genius' and who many scholars have followed through history are totally wrong. Many people with severe mental illness living in psychiatric hospitals and asylums who became art creators and were praised as exemplars of original art, often received formal artistic training. In fact, we can observe one of the therapeutic characteristics of the creative practices, as it is not possible to make an artistic contribution without participating from a specific tradition or culture. Art cannot be executed in isolation. Art allows us to develop new meaning and innovate. Simultaneously, art emerges from a specific community of practice, at least symbolic. This basic characteristic inherited by all creative practices needs to be acknowledged if we want to grasp and comprehend the beneficial effects that art-based practices can have in vulnerable and stigmatised groups and victims of social and psychological isolation such as people with a severe mental health diagnosis.

We would like to rescue the etymological meaning of the word 'therapy' and bring back its original meaning to health professionals such as psychologists, psychiatrists and other clinicians. Homer (1991/2004) uses the concept 'therapon' when describing Patroklos, Achilles' own personal attendant and companion who supports the warrior all his life, especially

during battle, taking care of and assisting him when needed (Gonzalez, 2010). In this way, art-based practices can become a 'therapon', a companion that looks after us for the rest of our lives. If we rescue the original meaning of the concept of 'therapy', we are conscious that the meaning is reduced, which now relates more to the concept of 'cure' within biological and medical contexts. We support the view, however, that the etymological meaning of the word 'therapy' should be closer to holistic and more integral health models.

It is clear that the exhausted semantic of the word 'therapy' is a product of the divide between Humanities and Health Sciences. We want to tackle this division through the "Health Humanities International Network". According to Health Humanities' definition, health is understood with epistemological, constructive and pragmatic principles against the biomedical paradigm (Crawford, Brown, Baker, Tischler, y Abrams, 2015). Therefore, creative practice and humanities disciplines play a vital role in discussion, reflection and analysis as well as an important health tool.

Many contributions from varied disciplines have shown us that it is impossible to separate health and illness from socio-cultural, symbolic and contextual factors. As Sapolzky (2007) points out: "the belief that stress and health can be understood in purely biological terms is unsustainable". Other authors like Napier et al. (2014,p. 1630) have also concluded that "The systematic neglect of culture in health is the single biggest barrier to advancement of the highest attainable standard of health worldwide (availability, accessibility, acceptability, and quality)". In this context, it becomes clearer that multidisciplinary work that includes creative practices and humanities, can become a powerful instrument and framework to promote health and well-being. Creative practices support the emergence of

new meaning and therefore, have the potential to rebuild damaged identities, as well as becoming interventions for cognitive recovery due to the fact that they can reactivate several cognitive processes. Moreover, creative practices entail a training in social and communication skills. When the creative practices are organised a part of a group activity they promote social inclusion, improve networking and reduce stigma.

In the last few years, we can find numerous examples of empirical evidence demonstrating these positive effects. For example, the framework 'Creative Practices for Mutual Recovery' promotes the idea that shared creativity, collective experience and mutual benefit can promote resilience in mental health and wellbeing among service users, as well as their healthcare professionals, family and friends. Mutual recovery challenges the traditional recovery model as an individualised and unidirectional process, providing a more inclusive space for recovery through creative practices (Crawford, Brown, Baker, Tischler & Abrams, 2015). Recently, Professor Williamon's research team at the Royal College of Music (London) have shown significant benefits on anxiety, depression, social resilience and inflammatory immune response on a group of mental health service users and their carers when engaging in a 10-week rhythmic/percussion workshop. These benefits were still present after a 3-months follow-up when compared with matched controls (Fancourt, Perknis, Ascenso et al., 2016). PérezVallejos, Ball, Brown, et al. (2016) from The University of Nottingham also found that after a 20-week Kudalini yoga workshop, children in care and their carers reported individual (e.g., feeling more relaxed) and social benefits (e.g., feeling more open and positive), as well as highlighting the importance of enacting togetherness to promote wellbeing. Similarly, Saavedra, Pérez, Arias and Crawford (2017) from the Universidad de Sevilla,

reported the positive effects on social inclusion and wellbeing on people with severe mental health illness and their carers after participating on a 6-weeks art-based workshop that took place in a museum of contemporary art.

Though it is important to keep conducting research in this area, there is already a vast amount of evidence that indicates the beneficial effects of creative practices. Not only because its effectiveness in the context of health promotion and social inclusion, but because of its cost effectiveness as well as the lack of side effects and iatrogenic effects.

With this edition we intend to promote a selection of the contributions presented at the 5th “Health Humanities International Conference” held in Seville in September 2016. This edition is an opportunity to share ideas, projects and results across the world from a variety of disciplines. The contributions presented at this conference, which are mainly applied, describe in some cases the development of workshops and art-based techniques.

We have organised this volume in five parts. In the first part, ‘Representations of the body, health and illness: theoretical discussions’, we discuss the experiential representation of illness applying literary creations or a philosophical approach. Hannah Williams reflects on the utilisation of creative writing among women suffering dyspareunia and anorgasmia. Cristina Rodríguez Pastor analyses how the female body was represented in the texts from the Victorian health professionals. Anjhara Gómez Aragón y Jacinto García Fernández explore the cultural differences when representing illness due to two tragic events in Japanese history; the nuclear bombs of Hiroshima and Nagasaki and the most recent nuclear accident in Fukushima.

To do that, these researchers analyse text and documents both from Japanese and non-Japanese authors. Finally, taking into consideration the work of the French philosopher Maurice Merleau-Ponty, Aimie Pulser offers a new perspective of understanding dance as a therapeutic tool far from the influential bio-medical disciplines.

The second part, 'Creative practices, social inclusion and well-being', is dedicated to the use of creative practices, usually among residential communities, with the objective to promote well-being and social inclusion. Fiona Macbeth, Carina Ripley and Megan Alrutz take advantage of the shared joy that personal story telling produces as basis for a participatory art installation described as 'aural patchwork of personal stories and experiences'. The main objective of this intervention is to construct connections among community members. In the second contribution, Janis Timm-Bottos describes an experiential workshop based on the methodological tradition and principles, and community background 'La Ruche d'Art' (The Art Hive), an open space, specially designed for the most vulnerable, located in St. Henri, Montreal, and conceived for creative practices and a platform to enable communication. Liz Brewster and Andrew Cox, explore the therapeutic use of digital photography when it is shared online, an everyday action that nowadays is easy to take for granted. Their work involves interviewing 16 participants for 'photo-a-day' project. Paulina Avellaneda Ramírez y María Teresa Buitrago Echeverri bring from Colombia an intervention programme that includes dance and music improvisation. Irene Pujol Torres proposes in her contribution the application of vocal group improvisation as music therapy and examines its potential to explore emotions, relationships and creativity. In the last contribution of this second part, Susan Hogan presents 'The Birth Project', in

which women explore with creative practices their experiences when giving birth and their identity as mothers. This project also includes the translation of these experiences into a documentary production.

The third part of this book is titled: 'Professional competences: integrating creative practices and health' and is comprised of three contributions; two of them are the works of Ramón Blanco-Barrera, Yolanda Spínola-Elías and Rocío Garrido Muñoz de Arenillas on one side and the work of Audrey Shafer on the other hand. These works focus on the personal development of health professionals working on humanities disciplines and creative practices. The work of Raquel Lázaro Gutiérrez y Francisco Vigier Moreno analyses the consequences of not being able to find professional interpreters in the medical context to support the communication between health professionals and patients within a multicultural context.

The way the space in which we operate is organised conditions and influences our psychological processes and well-being. In the fourth part of our book, 'Creative spaces for well-being', we group four contributions that focus on the concept of 'space' as the object for studies from different disciplines. In the first contribution, Susannah Hall and colleagues present an arts-based research project lead by the artist Sofie Layton that culminated on a series of art installations exhibited at the Great Ormond Street Hospital for Children NHS Foundation Trust. This project explored how children and family members interpreted their condition and understood the medical information provided by the health professionals. In the next work, Saara Jänttiexplores with ethnography how a group of people, diagnosed with mental health conditions living in residential settings, understand the concept of home as well as their experiences through theatre/drama. Santiago Quesada-García and Pablo Valero-Flores share some of the results



from the research project 'Designing tailored spaces for the absence of memory' which has the objective to determine the best physical environment for Alzheimer patients -as much as possible- with the view to retain and promote their autonomy and agency. Finally, Nicole Porter, Johanna Bramham and Martin Thomas explore the relationship between mindfulness therapy and the physical stage through the description of a workshop that took place during the conference.

In the last part, 'Art and Ageing', different proposals designed for older adults are presented. Most of the contributions focus on the benefits that creative practices have for dementia patients. In the first three contributions, research groups lead by Noemí Ávila and Sara Torres Vega from the School of Fine Arts of the The Complutense University of Madrid describe their research projects designed for people with Alzheimer. An interesting aspect of these projects is the collaboration between academic and non-academic partners such as universities and healthcare centres or museums, for instance, the Prado Museum (Madrid) and the Queen Sofia National Art Centre (Madrid). In the fourth contribution, Michael Koon Boon Tan from Singapore shows preliminary results from a creative intervention developed to increase well-being among older adults living in nursing homes. Emma Hollamby and Michael Baum show us preliminary results of a creative intervention aiming to improve the wellbeing of older people in nursing homes. This research has been framed as a collaborative work between The Ben Uri Gallery and Museum and Hammerson House Care Home. María del Carmen Moreno Sáez and María Teresa Gutiérrez Párraga from the The Complutense University of Madrid describe a workshop about 'Cyanotype', a photography technique from the 19th century that has been applied by Mari Carmen Moreno and her team to work with early dementia patients. In

the last contribution of this part, Rosemary C. Reilly, Virginia Lee and their research team from Montreal analyse how art-based interventions can create new meaning in a very sensitive context such as cancer. Specially, this work focuses on the journey taken by ten women with breast cancer to rebuild their lives.

We would like to take this opportunity to thank all the delegates for their participation and valuable contributions and commitment to the conference. We are very grateful to all the colleagues who have supported the organisation of this event, especially to the local committee and the students who kindly volunteered their time to ensure the success of the conference. This book is the final product of many months of hard and dedicated work that started two years ago and we would like it to become more than the typical book forgotten on an office shelf. We hope this book is useful and inspiring. Most of all, we hope that while browsing the pages of this book, inspirational thoughts emerge. Thoughts that can make our work more meaningful.

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# **Section 1. Representations of the body, health, and illness: theoretical discussions**

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# Chapter 1. A theoretical discussion of psychosexual illness – creative reading and writing as care

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## **Abstract**

This theoretical study outlines the application of creative reading and writing to women affected by issues of sexual dysfunction. A frame of the UK healthcare system and current treatment practices will be maintained, with a view to exploring the possible applications of theoretical reading and writing in self-care for those who are affected by these illnesses. The paper will aim to briefly discuss two primary female illnesses of sexual dysfunction, namely dyspareunia and anorgasmia, and their relation to theoretical writing as a possible care practice. The huge diversity of experiences lived by women who are diagnosed with these conditions cannot be overlooked, and this paper will not attempt to provide answers to all of the multiple and complex issues that women seeking treatment for psychosexual illness may be faced with, but will rather be a focused exploration of one possible treatment avenue for psychosexual disorders. It will be argued that a practical use of creative reading and writing in the sphere of psychosexual illness is not only possible, but could be beneficial to women affected by these problems.

**Keywords:** female sexual dysfunction, psychosexual illness, dyspareunia, self-care.

## **Theoretical background**

In caring for women with psychosexual disorders, the extent to which health practitioners work with “‘non-specific’ issues is rarely recognised”, and further to this “clients rarely present with ‘a simple, focal problem; often this is embedded in complex historical and contemporary issues” (Firth & Mohamad, 2007, p. 222). Approaching care for psychosexual issues often therefore requires the service user to be the point of contact for many different agencies, including medical departments such as urologists,

gynaecologists, physiotherapists and psychosexual therapists, as well as being dynamic in seeking, regularly attending, and following up on care. In the National Health Service in the UK, waiting lists can be as long at 18 months in some trusts to be seen for an initial appointment by a psychosexual therapist, and the client is often left with a choice between receiving only medically based treatment until they are at the front of a long waiting list, or paying privately for therapy sessions. Dyspareunia, that is to say “recurrent or persistent genital pain associated with sexual intercourse” (Basson et. al, 2000, p. 890), and anorgasmia, defined as the “persistent or recurrent difficulty, delay in or absence of attaining orgasm following sufficient sexual stimulation and arousal, which causes personal distress”, (Basson et. al, 2000, p. 890), are two such psychosexual disorders which can be embedded in a multitude of psychological, physical, emotional, and societal issues. It is noted in psychosexual illness that there “appears to be significant co-morbidity among diagnostic categories (for example desire, arousal, orgasm, sexual pain disorders)” (Basson et. al, 2000, p. 890), as well as these being disorders which cause “marked distress” and “interpersonal difficulty” (Basson et. al, 2000, p. 890). In short, issues which may come to the fore as difficulty in sexual experiences for women may actually be involved in a much more complex dynamic, one which is seldom treated in a standard way for women presenting with identical problems.

Hélène Cixous, whose writing will be discussed in a moment, is an academic famous for her work on the concept of *écriture féminine* - loosely translated as ‘women’s writing’, with connotations of writing for women by also *by* women *for* women, and her ideas on emancipation of the self, especially the female self. Cixous herself (1994, p. xvi) states that ‘no one fragment carries the totality of the message’ in her work and that “[t]here is no true art which

does not take as its source or root the universal regions of subjectivity” (Cixous, 1994, p. xvii), stressing that her work may not be taken as conveying one simplified or singular message, but rather should be open to interpretation by the reader. In *Souffles*, this idea is explored in great detail. The narrator compares the creative process of writing, whether writing about one’s feelings, about life or about nothing much at all, as taking flight, and declares that “when flying, the primitive, greedy, avid, stubborn, wild woman releases herself” (Cixous, 1975, p. 180), and this flight of the unconscious is the only way to escape the “enslavement to Death” (Cixous, 1975, p. 181) imposed upon women by rigid political, stylistic and literary forms. The narrator then affirms that “we, those who are flying, we have a point to make – about bodily pleasure, about the right to ascend” (Cixous, 1975, p. 181), linking with certainty the idea of the contravention it means to let the unconscious take flight through writing and the “bodily pleasure” which can be obtained by writing about one’s sexuality. Cixous does not champion an essentialist view that women *must* write or that there is one single truth to be achieved through this writing; she is simply proposing a way for women to liberate themselves and their bodies through the writing of their own experiences, and if they so wish, their sexuality. She does not claim that there is a single homogenous sexuality that applies to all women, but that women might discover for themselves their own sexuality through self-expression and writing. This writing, as well as readings and personal interpretations of Cixous that guide such expression, can create a helpful interpretative distance between women and their illness, and offer a new and enriching perspective on bodily expression for those women affected by sexual dysfunction.



Just as in *Souffles*, we hear about the liberating and highly personal act of writing the self, in 'The Laugh of the Medusa', Cixous's seminal work, we hear about how writing is equated with the "extraordinary creative richness" of "masturbation" (Cixous, 1975/2010, p. 38), inextricably linking writing to sexuality. Avoiding the essentialist idea that female sexuality is "uniform" or that it is possible to talk about "a shared unconsciousness" for women (Cixous, 1975/2010, p. 38), Cixous identifies in *Souffles* that the expression and eventual recognition of female sexuality is only possible when factors such as maternity, a transparency in writing the body and its intimacies and a profound knowledge of oneself are fully achieved. Of course this liberating process will be different for all individual women taking part in it, and the subjectivity which is so important in treating individuals with psychosexual disorders is embraced and celebrated in the works of Cixous. She is, it might be said, at the forefront of proposing an inclusive reconsideration of female sexuality, presenting it here as intertwined with an exploration of the self and the unconscious, and of relations to others and possible sexual partners.

### **Method / Description of the experience**

Coward, in her discussion of alternative therapies, warns against the re-defining of health opinions where the "body and its well-being has become the major site where individual attitude, strength of will, and commitment of wholesomeness can be expressed" (Coward, 1990, p. 90), and the burden of treating, or of positively working towards more satisfying sexual experiences, is often left down to individual women. Psychosexual illness can be linked to any number of issues: physical or emotional trauma, hormonal imbalance, chronic illness, fatigue, stress, or relationship

problems, as well as in some cases arising and causing great distress for no apparent reason whatsoever. Individual attitude is in strong focus in treatments for psychosexual illness, and this proposition for creative reading and writing offers an entirely inclusive appreciation of sexuality and identity, where wholesomeness, or will to succeed in achievement of fixed goals is not a primary aim. Instead, it suggests an alternative means of expression to women, rather than imposing a plan that women need to adhere to. Significant co-morbidities, as outlined by Basson et al. (2000), and common lack of a “simple, focal problem”, as outlined by Firth and Mohamad (2007), render the provision of a structured and target-driven treatment plan unhelpful for some women, and this target-driven plan is often all that a National Health Service with limited resources can offer. Creative reading and writing, though perhaps more difficult to measure in terms of targets, are free to access for service users, as most of Cixous’s literature may be found for free online or can be reproduced for patients in any number of translations, and so this alternative is not only complementary to the treatments available without burdening women entirely with their own treatment outcomes, but is largely without cost to women and the health service where they seek treatment.

## **Results**

The difficulty of such an abstract approach is that it would take a certain level of motivation from service users, as well as perhaps further pushing the burden of their care back on to them if used systematically as part of a target-driven care plan. It could be proposed, then, that instead of using this ‘feminist’ literature as an element of the formal care plan, to be observed and regulated, it could be seen as something women could actively take part in

as and when it suits them, and when they feel it pertinent or necessary. This proposition has been discussed on a practical level with experienced and well-versed psychosexual counsellors, as well as specialist gynaecology nurses in several UK healthcare trusts. They have agreed that this is an entirely possible approach to treating psychosexual illness, but argue that without standardised management of psychosexual illness, treatments can lack structure and important physical or emotional issues may be missed. The conclusion reached was that with every case being different and often representing more than the simple problem of dyspareunia or anorgasmia alone, a sensitive, inclusive and well-constructed care plan is essential, and complementary or creative therapies for treatment would be welcome when received well by patients and service users.

Research needs to be carried out on a much larger scale about the efficacy of treatments for psychosexual health issues, and it would also be helpful to be able to gauge how many women and couples who are affected by psychosexual illness have used treatments other than those prescribed to them to attain a more fulfilling relationship with sex. Cixous's advice may seem abstract and perhaps idealistic, but at the heart of it is a call to action in much the same way that practitioners implement an action plan for women. Instead, it is a call for freedom of expression, without fear of judgement or boundaries. This is exactly what much of the movement for psychosexual therapy and current treatments encourage, and once physiological problems have been addressed, often the attention is turned to more psychological and expressive elements of disorders. This is especially true considering that even where problems were initially physical, the complex and private nature of psychosexual illnesses often means that talking about them can be seen as taboo, or highly emotionally charged. It is through exploration of

feelings, experiences and complex social and physical issues that the women affected by psychosexual illness often work towards an acceptable outcome in psychosexual therapy – often the relative lessening of pain on sexual contact for those with dyspareunia, or for those with anorgasmia, participating in satisfying sexual experiences with or without eventual orgasm. Alternatively, treatment can work towards a reframing and reconsideration of the sexual experience for women or for both partners in a given couple, where perhaps orgasm is not an end goal, and sexual pleasure is sought through alternative means, or sex is redefined for individuals to avoid physical sites that cause pain on contact. Services such as psychosexual therapy, which are often already approached as complementary to traditional medical treatments, are often the only services touching on these intimate subjects, and despite the fact that nearly 1 in every 10 British women finds sex painful (Roberts, 2017), there seems to be a lack of awareness or knowledge about the available treatments, and further potential difficulties such as long waiting lists and poor co-ordination between agencies once treatment is sought.

## **Discussion**

It is difficult to define the experience of women who suffer from disorders of sexual function as singular, and this is clearly reflected in broad history-taking in clinical settings. Once this subjectivity is acknowledged, a frame can be constructed to allow free, supported and supportive expression for those women who feel that writing and reading would aid their recovery or better their situation, as a complementary option to the treatment options available in the UK on the NHS. Where writing is not a priority for individual patients, reading might be suggested as another option, with the

writings of Cixous actively encouraging women to consider their relationship with their bodies and their sexuality. Whilst readings of real patient testimonies and provision of factual information put forward by some support networks can be helpful, reading theoretically about female sexuality and its expression offers a more abstract, impressionistic view on such problems as dyspareunia and anorgasmia. The focus on 'wholesomeness' or measurable targets is not present in such a reading and writing, and neither is the distanced, objective language of medical dialogue or information leaflets. The multiplicity of experiences brought by women with psychosexual illness to clinical settings may therefore be embraced, and an alternative avenue for exploration of sexual practices, experiences and self-regard may be forged, to find alternative and better ways of approaching sex and sexuality for women with psychosexual disorders.

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## Chapter 2. Brain fever in Gaskell's *Cousin Phillis*: reading and hiding love in the body of Victorian heroines

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### **Abstract**

When we consider Victorian literature, it is striking to note the high number of novels that participated in the growing debate of the time around health, in particular that of women. This debate was encouraged by the attention nineteenth century medicine paid to the female body. Thus, there are countless examples of novels in which the heroine falls mysteriously ill at a certain point in the plot, disconcerting family and friends and requiring the immediate assistance of the doctor and the nurse. Contemporary medical theories warned about the somatic consequences of both emotional excess and repression, particularly in the case of women, considered by nature more emotional than men. Therefore, medical anxieties focused on women, especially bourgeois women, scrutinizing their bodies for external signs of emotion. The female body, subject to the medical gaze, turns into a text that offers her readers privileged access to her emotional life. Its vigilance and the control of her emotions was necessary to grant her health and that of the Empire. Despite the effort of doctors to acquire it, this ability to read bodily signs of emotion was directly attributed to women. However, it is interesting to analyse how novels like *Cousin Phillis* (1865) provided instruction in the emotional language of the body. Gaskell's novel supports medical theories about the threat of emotions to the fragile balance of female health while, simultaneously, questioning the supposedly natural association of women with affective hermeneutics

**Keywords:** emotions, signs, interpretation, language.

### **Theoretical background**

During the second half of the nineteenth century, literature interacted with medicine in multiple ways in order to construct a model of femininity that



represented the middle class woman and differentiated her from her counterpart in the other social classes.

At the height of its professionalisation, medicine circulated theories about the supposedly pathological nature of women, insisting that their health was controlled by the tyrannical influence of their reproductive system. According to notorious physicians like Thomas Laycock (1840), the uterus was connected to every single part of the female body, so any alteration of its functioning, due to physical or emotional causes, could lead to a collapse in their health. Given the workings of this *uterine economy*, strict vigilance was deemed necessary. The health of reproduction, and consequently the future of the nation was at stake.

So, medicine insisted that women were naturally more prone to emotions, more delicate, that their place was at home looking after their families. Any attempt to pursue activities outside this role, would make them ill.

However, they also warned that it was precisely this tendency to feel rather than to think that made women innately weak. The threat posed to female health by emotions implied that any symptoms of disease revealed the emotional overflowing of the patient. The female body was then subjected to the *medical gaze*, as Foucault (1973) called it, searching the body for outward signs of emotion.

Curiously enough, despite physicians' efforts to learn how to interpret this emotional language, it was believed that women mastered the ability not only to read these signs in the body of others—hence the rise of the nurse as a Victorian icon—but also to hide them in their own body. Relevant sociologists like Herbert Spencer (1896) insisted that the hermeneutic ability

and the capacity to codify corporeal signs in order to avoid interpretation were skills women had naturally developed since primitive times.

Many historians such as Elaine Showalter (1987) and Mary Poovey (1989) have studied the repercussion of these ideas in the reality of women's lives and the construction of the feminine ideal.

## **Method**

The novel that occupies us constitutes one example of the education in this language of emotions and the complex interplay between issues about gender, interpretation and female health. Our analysis will try to show how its plot reinforces many of these theories while, at the same time, it reveals the contradictions implicit in their validation.

## **Results**

Elizabeth Gaskell's story, *Cousin Phillis* (1864) is told from the perspective of young Paul Manning, who arrives in a little town to work as an apprentice engineer in a new railway line. At his mother's insistence, he visits some relatives that live on a farm nearby: Ebenezer Holman, an Independent minister, his wife and their only daughter, Phillis, who is the same age as Paul.

Paul's description of Phillis when he meets her already reveals some of the cultural conventions associated with the feminine ideal. Physically described as an angel, Phillis is docile, respects her parents and helps with the housework. However, she seems different. In contrast to the classical shyness and silence of other heroines, she is self-confident. For instance, the

first time she is left alone with Paul, she does not hesitate to open the conversation. Her loquacity and the steadiness of her voice sharply contrast with Paul's stammering and awkwardness. A voracious reader and very cultivated, Phillis feels at ease with classical languages and literature. Her habit of reading in Latin and Greek with her father and her translating skills have made her regard the importance of words and the coherence between significant and signifier. Closer to her father's intellectual world than to her mother's domestic world, Phillis has received a better education than any of her peers, better than the narrator's himself, who often feels ashamed of his intellectual inferiority.

Unable to reconcile Phillis's intellectual qualities to the virtues required of her sex, Paul soon rules out any possibility of romance with his cousin: "she's so clever—she's more like a man than a woman—she knows Latin and Greek" (252). His father's reply— "She'd forget them, if she'd had a houseful of children" (252)—echoes popular beliefs in the separation of the intellectual and the domestic worlds reinforced by the medical debate.

During his visits to the farm, a gradual change in her way of dressing makes Paul witness Phillis's transformation from child to woman, a transition that apparently goes unnoticed by her parents.

When Phillis meets Mr. Holdsworth, Paul's worldly young master, her logical world clashes with the ambiguity of his language, full of irony and double meanings. Confusing her with his playful use of words, his alteration of Phillis's linguistic world is not just limited to the oral but also to the written language. One afternoon, when left alone in the dining room, Holdsworth looks through Phillis's books in front of Paul. An original version of one of Dante's works immediately draws his attention. The

narrator sees how Holdsworth, far from being intimidated by her intellectual reading, feels stimulated and even ventures to annotate clarifications of meaning of the words Phillis had underlined as difficult for her. This is perceived by Paul as a violation of Phillis's textual space.

One day Holdsworth asks Phillis to sit for him in order to draw her portrait. While he is fixing his gaze on his model, the narrator detects signs of agitation in Phillis: "her colour came and went, her breath quickened with the consciousness of his regard ..." (272). When required to look at him in order to sketch her eyes, Phillis cannot stand it and leaves the room. The protagonist's fear that her face and her eyes might reveal her emotions is a typical attitude in Victorian heroines. Despite women being considered experts in detecting these signs, it is Paul who notices them, for Mrs. Holman seems quite oblivious to them.

This episode contrasts with the evening Phillis gives Holdsworth a nosegay with the wild flowers he had previously admired. Holdsworth's signs when he receives them seem unequivocal for Phillis and the narrator himself: "I saw for the first time an unmistakable look of love in his black eyes ..." (273).

However, the news of Holdsworth's sudden departure to Canada for work purposes provokes a physical transformation in Phillis that does not escape the narrator's eye: "her face white and set ...never a question did she ask about the absent friend, yet she forced herself to talk" (278).

After this, one day Paul finds Phillis crying with a book in her hands. Holdsworth's notes in its margins help him identify it as "one of those unintelligible Italian books" (283). Holdsworth's efforts to clarify the meaning of Italian words for Phillis contrast with his own body language,

incomprehensible for Phillis, who fails to find any coherence between what she had read in his behavior and the meaning of these signs.

When Paul, anxious about her signs, decides to reveal to Phillis Holdsworth's intention to marry her on his return, she finally finds coherence between his words and his actions. This results directly in a transformation of Phillis's signs, which does not escape Paul's reading: "Her eyes ... expressed an almost heavenly happiness; her tender mouth was curved with rapture – her colour vivid and blushing; but as if she was afraid her face expressed too much ... she hid it again almost immediately" (285).

Soon, Phillis seems to have recovered health and speech. Just like sadness and despair had started to deteriorate her health, hope favours her recovery. Holdsworth's coherence has restored unity to her fragmented reality.

However, this coherence is soon to be broken. Paul receives a letter from Canada in which Holdsworth tells him about his plans to marry a rich heiress, Lucille, who, according to him, "is curiously like Phillis Holman" (291). This unfortunate remark reveals that, to his eyes, both women are interchangeable, lacking unique meaning. Phillis's intangibility for Holdsworth is here more evident than ever. When Paul shows her the letter, she strives to hide her signs from an improving reader. However, her tone of voice – "like a wail" (295) – betrays her once more so, she returns to silence.

From that moment, Paul studies Phillis's frightening decline. Her body signs and the changes in her voice grow more worrying, especially when the news confirming Holdsworth's wedding is received. Paul watches how painfully she tries to hide behind a forced loquacity: "I had less self-command; but I followed her lead" (302). As we can see, for him, it is a matter of self-control. Paradoxically, Phillis's effort to control her feelings culminates in the loss of

control over her own health: “her grey eyes had dark circles round them, and a strange kind of dark light in them; her cheeks were flushed, but her lips were white and wan. I wondered that others did not read these signs as clearly as I did” (304). When the minister finally awakens to the reality of these signs, Phillis confesses: “I loved him, father” (308). Unfortunately, it is too late for Phillis. Her own despair and her father’s accusations of selfishness make her suffer an attack and lose consciousness. When the doctor arrives, she is diagnosed with brain fever.

Over the course of Phillis’s critical illness, the patient’s silence extends around the house. The sickroom represents a sacred place reserved for the close family, so the narrator has to resume his reading from the corridor, looking through the half open door: Phillis lying on the bed, her hair has been cut, her beauty is a shadow of what it was and her behavior reminds us of that of a madwoman: “her head ... moving ... backwards and forwards on the pillow, with weary, never-ending motion, her poor eyes shut, trying in the old accustomed way to croon out a hymns tune, but perpetually breaking it up into moans of pain” (311).

Later, although slowly recovering her health, Phillis is not able to regain her strength, despite her family’s efforts. Curiously swapping roles, neither her father’s appeal to her shy coquetry nor her mother’s endeavour to reawaken her interest in books succeed in restoring her to her former self. After her illness, Phillis’s identity remains fragmented because she is no longer able to fit in the feminine domestic sphere or the masculine intellectual sphere.

## Discussion

Gaskell's novel shows the instability of the Victorian system of beliefs about gender roles that medicine had tried to reinforce through its theories. Feminist criticism has frequently underlined the passivity of Victorian heroines as something characteristic of their personality, derived from their extreme participation in the feminine ideal of the angel of the house which, in turn, precipitates their illness. Notwithstanding her linguistic education, Phillis must avoid conventional language to express her emotions and turn to silence. The only means to gain access to her feelings is through her body. Phillis submits to the linguistic manipulation of Holdsworth to such an extent that "he directed her studies into new paths, he patiently drew out the expression of many of her thoughts, and perplexities, and unformed theories ..." (271-272). Before his departure, he fantasizes with the idea of waking Phillis up from her lethargy, something that does not stop him from replacing her with a copy in Canada, while she must await his unlikely return.

Despite this, the question of Phillis's passivity remains problematic because it is not a permanent feature of her behavior. Therefore, those situations in which she displays personal initiative draw our attention, like during her conversations with Paul, when she defies the torment to safeguard Holdsworth's tools or when she gives him flowers. This oscillation between an active and passive role is particularly evident in the episode of the portrait, when Phillis lets Holdsworth manipulate her as if she were an inanimate object until she eventually resists her own passivation and leaves the room. Finally, her last words in the novel: "I can, and I will!" (317),

reveal a willingness to recover beyond the possibility of being awakened by Prince Charming.

Furthermore, Gaskell presents Paul's masculinity as ambiguous. His insecurities, his shyness, his fascination with Holdsworth's sophistication, and, most importantly, his progressive ability for affective hermeneutics are some examples. The reader interprets Phillis's feelings through Paul's reading. In this respect, Paul assumes the role of a nurse. For medicine, the capacity to read external signs of emotion was both feminine and potentially feminizing so, in this regard, Gaskell's novel supports nineteenth century medical assumptions. As a nurse, Paul reads his patient's emotions through her body but he also influences the development of her disease. His fear and naivety lead Phillis to create unrealistic expectations about Holdsworth's intentions that threaten her health.

Lastly, contrary to the assumption that women are by nature good readers of body language, we find Mrs. Holman's indifference to her own daughter's signs and Phillis's failure to interpret Holdsworth corporeal and verbal language. The impossibility to interpret Holdsworth's language on a logical basis provokes her breakdown. The correlation between the awakening of her sexuality, her love disappointment and her sudden illness implies taking to the extreme the ability of the heroine's body to communicate her feelings; external signs cannot be more explicit. This way, finally, the protagonist offers her own diseased body as an unambiguous text, impossible to ignore, forcing those around her to read it.



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# Chapter 3. Thousand cranes. Representations of nuclear impact on the life and death of Japanese people

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## **Abstract**

It is clearly assessed that stressful life events have influence on human illness. It is essential to know the impact these events had on the representation of health/illness and life/death dichotomies in the collective memory and their importance in the setting in motion strategies of health promotion. The study of these representations might help us to understand the impact on the idea of health/illness.

The aim of this paper is to analyse the representations of the process of falling ill or dying caused by two stressful life events occurred in Japan: The atomic bombings in Hiroshima/Nagasaki and the nuclear accident occurred in Fukushima. With a lapse of 60 years between them, both episodes are characterized by the nuclear impact on human health and social life. We propose a comparison of the representations of the concept of falling ill/dying through literary texts written by both Japanese and foreign authors.

We will assess the cultural differences that exist in the fear of suffering: In the representations from Japanese people we find open-minded expressions of suffering as a path to acquire social knowledge, while in those from other countries, much of the focus is given to the heroism of others' suffering.

**Keywords:** stressful-life-events, representations, human health, literature.

## **Theoretical background**

### **1-1-. Stressful life events**

A stressful life event is any unexpected event that produces a strong impact. In clinical psychiatry its effects are related to symptoms of depression,

anxiety or distress. A stressful life event could be an individual experience or a collective one. In the latter, the effects are still evident in the collective memory and have an influence on social, cultural and symbolic processes. However, we must also take into consideration the strong influence that stressful life events have on global human illness, bearing in mind the biological, psychological and social aspects (Gómez, 2004).

Thus, it is essential to know the impact that these stressful life events had on the representation of health/illness and life/death dichotomies in the collective memory, and their importance in the setting in motion of strategies of health promotion. The study of these representations, evident in many expressions, might help us to understand the psychological and social impact on the idea of health/illness.

### **1-2-. Literatureas a way of expression**

We must consider the importance of literature as a way of expression of human feelings. In this sense, much of the events that have had impact on human life generates the need to write about it in one way or another. For centuries, literature and health-related sciences have run in parallel somehow. Health workers want to express their experiences, and even patients choose to write about them. But another person's illnesses or fictions experiences have also appeared in literary texts (Montiel, 1999). The issues related to human suffering offer dramatic quality and give versatility to stories.

When we pay attention to stressful life events, it is necessary to analyse the works written by the collective who suffered the event (including health workers), apart from the texts of other authors who use the event as a literary resource to construct their stories.

### **1-3-. Atomic impacts in Japan**

We are going to focus on two stressful life events occurred in Japan: the atomic bombings in Hiroshima and Nagasaki (1945), and the nuclear accident occurred in Fukushima (2011). With a lapse of 60 years between them, both episodes are characterized by the nuclear impact on the human health and the social life.

The history of Sadako Sasaki has become a symbol of the impact of nuclear war. Sadako died at the age of 12 due to the effects of the radioactive dust, ten years after the atomic weapons exploded in Hiroshima. A statue of Sadako was built in the Hiroshima Peace Memorial Park, and also in other locations as the Peace Park in Seattle (USA).

Sadako devoted her time to fold origami cranes because there is an ancient Japanese legend that promises that anyone who folds a thousand origami cranes will be granted a wish, such as long life or recovery from illness. We take the title of our paper from this legend, which has become popular by Sadako not only in Japan, but also all over the world.

This is an example of how a stressful life event causes a representative and symbolic production in a society.

### **Method / Description of the experience**

The aim of this paper is to analyse the representations of the process of falling ill or dying caused by the atomic impacts occurred in Japan. We are going to study the representations made specifically through literary texts, proposing a comparison through literary texts written by both Japanese and foreign people.

We will focus on questions such as:

- The number of literary works and accessibility to them.
- The connection between the author and the event.
- The kind of literary account.
- The style and content.

We have only selected printed books due to the large number of digital texts which are quite difficult to analyse right now.

We also carried out some interviews to Japanese persons about these matters.

## Results

### 3.1. Japanese texts

#### 3.1.1. *Impact on society: atomic bomb literature (原爆文学 - genbaku bungaku).*

When we analyze Japanese texts, one of the most important questions to bear in mind is the existence of a literary subgenre called “atomic bomb literature” (原爆文学 - genbaku bungaku). This shows the great importance that the atomic impact had on Japanese people.

Many authors of this subgenre were hibakusha (被爆者). Hibakusha is the Japanese word for the surviving victims of the atomic bombings. The word literally translates as "explosion-affected people". Most of the hibakusha were exposed to radiation from the bombings. It is highly significant to see that there was a need to create a specific word to refer to this group.

Other authors were medical practitioners or soldiers who were in care of the victims. Sometimes, they were hibakusha, too. An example is the doctor Michihiko Hachiya, who wrote Hiroshima diary (1955). Although they did not live the experience themselves, some professionals of letters had direct knowledge about the events. An example is the Nobel Prize novelist, Kenzaburo Oe (1965), who visited Hiroshima for years to write his report Hiroshima notes. The prologue starts with these words: "Perhaps it is improper to begin a book like this with a reference to one's personal experience" (p. 13).

There is not a single literary category which could unify the "atomic bomb literature". We can find diaries, reports, poetry (for example haiku), theatre, tales, novels, manga works and fiction stories that focus their subjects on the moment of the nuclear disaster and on its effects and subsequent consequences. Generally, it is easier to find printed books about the nuclear impacts on Hiroshima than those about Nagasaki or Fukushima.

Naturally, most of the works were written days after the event. Hachiya (1955) says: "*I wrote whenever I could find time after August 8th, 1945*" (p. 231). The movement was censored between 1945 and 1950, especially by the North American authorities of the occupation. However, from nineteen sixty the movement was reappraised owing to the publication of some works of national prestigious authors as Oe and Masuji.

The Fukushima nuclear disaster in March of 2011 revived the movement of *genbaku bungaku*. However, since there are some differences in this movement when compared with that of atomic bombs we cannot still talk about a particular movement (only six years after the event):

-The number of people affected was lower. All Japan was feeling affected by the nuclear impacts of Hiroshima and Nagasaki because it was a military confrontation.

-The cause was a natural disaster. When we ask Japanese people about this question, they consider that the bombs generated more impact than the accident of Fukushima: "In my opinion, the use of atomic bombs in Hiroshima and Nagasaki was a 'slaughter', whatever their justification might be. Far from it, Fukushima was a sad accident. It gives us a lesson about the use of nuclear power stations, but the accident wasn't caused deliberately" (Japanese person born in Hiroshima<sup>1</sup>).

-Most of the works related to Fukushima are published in social networks or in websites, accompanied by visual resources as photographs and videos.

### *3.1.2. Representations of life, death and illness.*

How are life, death, and illness represented in Japanese texts? We shall summarize the essential features below.

**-Expression of feelings.** Some authors consider that *genbaku bungaku* is a written thoughtful response to the need to express themselves after this stressful life event. However, we have to take into consideration that the Japanese society is not used to do it publicly (Benedict, 1946).

The feelings expressed tend to be harsh as one can easily imagine. The authors talk about the impact of the destruction produced by the radiation from the bombings in material goods and people.

Nonetheless, they do not take advantage of rhetoric: The expressions tend to be plain, open and explicit. Only some metaphorical comparisons reinforce

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<sup>1</sup> We don't mention the names because of privacy matters.

the descriptions. Comparing with other sentimentalists' works, these expressions could be seen as plain and objective, but they are full of emotion.

**-Treatment of the affected people.** Victims are never praised as heroes. They are treated as normal people who suffer the consequences of the event. The suffering is presented from an image of not-ghoulish harshness. Authors try to narrate what they see, what they think about the things they see and how they feel when they see them: "My second brother pulled off Fumihiko's fingernails [his son], took his belt too as a memento, attached a name tag and left. It was an encounter beyond tears." (Hara, 2011, p. 89).

**-Representation of illness.** Ignorance, depression and lack of understanding are the main feelings that the authors transmit to us. During this process, the fear from the unknown and the uncertainty regarding this new disease appears. Nor the victims neither the medical practitioners know anything about symptoms and prognosis. The disease is shown as a process of unnecessary suffering that in most cases leads to death. After the fifties, with the pathological processes already known, the representation of the disease in the literature comes together with the fear of deformity and of the social stigma.

The expressions of anguish due to personal and non-physical issues do not fall apart. The main subjects are the family or the fear to have physical handicap that could prevent him/her from working in case of staying alive. Other subjects that often appear are the anxiety about Japan's surrender and the American occupation, which increases the panic in the victims.

**-Representation of life and death:** in the case of the hibakusha, the most important aspect is the gratitude for life. It used to be expressed through Buddhist concepts. Hachiya (1955) writes:



*"I have lost my home and my wealth, and I was wounded, but disregarding this, I consider it fortunate my wife and I are alive. I am grateful for this even though there was someone to die in every home in my neighbourhood." (p. 229)*

As for the death, the reflections appear constantly, especially when they are referred to the uncertainty of the future, its imminent arrival and the need (or not) of suffering before dying.

The general consideration about the effects of radiation is that this is an avoidable harm. Thus, it not only opens a path to political and social discussion, but also enhances the activation of health promotion activities and the avoidance of behavioural risks. Every book we have read makes an appeal for the need to learn from the experience.

### **3.2. Non-Japanese Texts**

*Genbaku-bungaku* was a quite unknown subgenre in the West, so there is no response by other countries' authors. Furthermore, these authors do not have direct experience with the events. In contrast, in Europe we can find a great number of books concerning the Holocaust or, in the Spanish case, about the Spanish Civil War.

The "atomic bomb literature" arrives to *the Western culture* quite late. To be precise, in Spain we had only indirect translations from English until a few years ago. Nevertheless, we can find great number of works about the Fukushima disaster in only five years.

On the whole, in the non-Japanese works the atomic events are used as a context for melodramatic stories, although novels used to have a happy ending. Suffering and death caused by the nuclear impacts give sentimentalism to the plots, but they are not usually the central theme.

Furthermore, in many cases, the authors have no experience with Japanese culture, and sometimes the characters of the stories express feelings in a way which is unnatural in Japanese society. In these stories, the victims are praised as heroes who are fighting for survival.

## Discussion

*"Tomorrow is August, the 6th, and here in Hiroshima we have a ceremony in the Peace Park at quarter past eight, the time when the bomb exploded. There are lots of television programmes these days. But please, don't believe that whole Japan is interested in this event, but rather there is too little interest outside of Hiroshima and Nagasaki." (An interviewee born in Hiroshima; August, 5th, 2016).*

In conclusion, we have tried to assess the cultural differences that exist in the fear from suffering: In the representations from Japanese people we find open-minded expressions of despair and suffering as a path to social knowledge, while the representations in other countries focus on the heroism of others' suffering.

We must consider that the narrative aims are different: Whereas Japanese authors try to express the experience looking for a learning process, "foreign" works are fictional stories in which stressful life events provide not only a contextual plot but also dramatic episodes.

We should highlight that in Japanese works the expression of suffering is a way to learn about the needs of care of the people, not only their biological needs, but also social, psychological, cultural or political needs.

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# Chapter 4. Intercorporeality: connectedness and creative collaboration in the embodied practice of dance

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## **Abstract**

Dance plays a role in healing rituals across a number of cultures and is also recognised to promote social bonding. This, of course, includes contemporary Western medicine, in which dance is used in psychotherapeutic contexts in the form of dance/movement therapy (DMT). As a contribution to the burgeoning field of health humanities, this paper seeks to explore the power of dance to mitigate human suffering and reacquaint us with what it means to be human through bringing the embodied practice of dance into dialogue with the work of the French philosopher Maurice Merleau-Ponty. The promise of the health humanities is of a broader and richer understanding of what is healthful and therapeutic through exploration of and insight into the human condition. As such, it celebrates the uses of arts and humanities within traditional healthcare settings, practices and training, but also calls for a reimagining of the boundaries of health and healing, so that our intellectual and therapeutic focus might escape the physical and, perhaps more importantly, the epistemological constraints of the clinical. In this spirit, this paper presents an alternative understanding of dance as therapeutic, which is based in philosophy rather than in the psy-disciplines or the neuroscientific insights that currently dominate the literature of DMT as a clinical practice.

**Keywords:** intersubjectivity, intercorporeality, dance.

## **Theoretical background**

For Merleau-Ponty (2002) the primary sense of self is not understood in the Cartesian dualist sense which separates and privileges mind over body, subject over object, but rather through the non-dualist notion of body-subjectivity. Prior to Descartes' cogito – 'I think therefore I am' – there is the

'tacit cogito' - 'I can' - the feel we have of our body and how it connects us to the world. Merleau-Ponty also denotes this pre-reflective feel that we have for our body's positioning and possibilities for action with the term corporeal schema. My corporeal schema is thus my primary sense of self or 'I', in the sense of the 'I can'.

While the Cartesian tradition has struggled with the problem of intersubjectivity, also known as the problem of 'other minds', Merleau-Ponty's rethinking of self as situated and embodied opens up the possibility for rethinking self-other relations. Merleau-Ponty shifts the focus from the private, invisible experience of thought to the lived body through his redefinition of human being in terms of embodiment and behaviour, these being visible and publicly available. The Cartesian problem of solipsism is in fact dissolved in Merleau-Ponty's framework as my existence as a self comes into being and comes to my awareness in the same shared world where other selves are coming into being and to my awareness.

Intersubjectivity, for Merleau-Ponty (1964), is therefore based in a mutual awareness, which is understood as a reciprocity of perception. This reciprocity is captured in the term reversibility, which is primarily conceptualised through the basic model of one of my hands touching the other where the hand that touches can also be touched by the hand that was originally touched but is now touching. Indeed being able to touch anything requires that the toucher is also touchable, as to touch a thing is to feel the thing touching me.

This perspective dissolves any clear distinction between touching and touched, sentient and sensible, and thus between the body as subject and the body as object. I do not experience my body as either wholly Cartesian

subject – in which case it would be invisible – nor as wholly object – in which case it would not be able to serve my intentions. Rather I understand and inhabit my body as simultaneously part of my intentional subjectivity and as an object in the world – an awareness that Merleau-Ponty calls corporeal reflexivity.

This corporeal reflexivity allows that there is overlap, not only between my body as subject and my body as object, but also between my experience of my (visible and touchable) body and my experience of other bodies. It is this reflexive overlap between the outer look of the body and the inner experience of the body that explains the possibility of imitating the behaviour of the Other despite the fact that the outer look of the behaviour is not the same as the inner feel of the behaviour.

Thus there is a reversibility to intersubjective relations which relies on my own sensibility as well as my sentience: the other and I are mutually available to each other through our perception of each other. The corporeal schema, my primary, embodied sense of self, is not a private, inner realm, but rather is visibly and tangibly manifest in my embodied behaviour, and as embodied, sentient and sensible beings open to a shared world, we experience each other in what Merleau-Ponty terms carnal intersubjectivity or intercorporeality. This intercorporeal connection with the Other is referred to as transfer of corporeal schema, and it is through this process that we recognise other human beings as like ourselves, making it the grounds of intersubjectivity.

## **Method / Description of the experience**

This paper will proceed by elaborating aspects of Merleau-Ponty's thought related to subjectivity and specifically intersubjectivity, before exploring how these phenomena play out in the embodied practice of dance. In order to attend to the experience and the potential of dance, this study draws on in-depth qualitative interview accounts of sixteen professional contemporary dancers from UK repertory companies. In-keeping with the aims of Health Humanities to broaden our understanding of the healthful dimensions of the Arts and to democratise our approach to the Arts in health- (and self- care) beyond the clinical setting, this is not, therefore a study of DMT therapists and patients, rather it is a study of individuals for whom dance forms a central part of their lives. Professional dancers, in particular, were chosen for this study because their daily engagement with dance as reflexive practitioners gives them a heightened awareness of their own embodiment and that of other dancers.

## **Results**

The process of joint movement, of dancing with someone else, is particularly interesting for rethinking intersubjectivity in Merleau-Pontian terms as it involves a form of connection or communication which is achieved without words and through the medium of bodily contact. As Louisa suggests, openness to such bodily communication is part of an overall tacit or pre-reflective awareness that the dancer has of their embodiment and situation within the immediate context of the dance:

*If you're in the moment and you're on stage and you're aware – you're in the moment and you're in your body, you're in that part of the piece, but you also have to be super-aware in the way that you're*

*ready to accept anything, and that's like that communication that happens which is not, you don't talk you just know, you, you even feel it in, you feel inside and you just react – that's the strange thing and that's really exciting when you just have that, when it's in sync like that. [Louisa]*

Here, the dancers are not consciously formulating thoughts or reflecting on the situation but are reacting to each other – to each other's bodies – at a pre-reflective level. Thus dance grounds us in our own body-subjectivity or bodily intentionality and also orients us to or opens us towards the body-subjectivity or bodily intentionality of the other dancer. The analogy with conversation used by many of the dancers is significant because this notion of a (tacit or unspoken) dialogical interaction emphasises a two-way process between two mutually engaged beings. Dancing together thus involves a reciprocal openness or awareness allowing this type of tacit bodily communication to occur:

*There's this like different kind of awareness that you have to have, just because you have to be able to move together.... you have to talk with your bodies so you have to kind of listen to each other – you can't always do it your way, you have to find the way. [Anna]*

The awareness of and connection with other dancers achieved in this way is not, therefore, limited to understanding the materiality of their bodies in terms of weight and position in space, but also includes an understanding of them as intentional beings who want to do things in certain ways that may be different to what you want. The dancers are able to recognise each other through their bodily interaction not only as other physical objects in the world but also as other body-subjects:

*you can kind of listen to each other through your bodies. You can become quite close to people – you have to be prepared to work very closely with people physically, but because you're so close physically*



*you, it opens up something mentally as well, there's some connection there. [Tara]*

This can be understood in terms of the Merleau-Pontian notion of transfer of corporeal schema where we can come to know people's thoughts, feelings and intentions through tuning in to the intercorporeal overlap between their bodies and ours. Dance training and practice, with their emphasis on mirroring and adapting to others' movements, open us up to this reversibility inherent in intercorporeal relations, and Tara's comments suggest that the intercorporeal identification involved in learning dance also makes the dancer more open to those dimensions of the Other's existence that she describes as mental.

Through moving with each other and attending to the corporeal schema of the other dancer, dancers can come to understand and experience a kind of physical and emotional or mental synchrony or kinaesthetic empathy with the dancer with whom they are moving. Dancing with another person thus returns us to a recognition of our shared humanity and our capacity for mutual openness and connection.

Indeed my interviewees emphasised that dance is characterised by mutual openness in the sense of both awareness and honesty:

*if you're really invested into the moment and invested in this connection then you have to let those masks and those barriers fall down so that you can feel one another, be with one another and experience this thing with one another. [Steven]*

For Merleau-Ponty it is this direct openness to others and to a shared world which characterises intercorporeality. Steven describes this as an interconnection or communion of the two dancers' souls as well as their bodies:

*I think that you get to know people incredibly well through dancing – incredibly, incredibly well in a way which is really quite beautiful actually, really quite beautiful because it, because, because it, because of the context of it, it allows space for you to... almost for like your, when it, for your souls to interconnect in many senses ... it's just simply about being with someone in the space and connecting with someone and that is such a beautiful sensation. ... it gets to a place where you're communicating, you're operating on a level of sensation and connection and it's almost like you're, you're having a conversation of sensation but there's no attachments or connotations of anything else really – it's really quite beautiful, really something quite special.[Steven]*

The context of dance as creative collaboration opens up the possibility for us to transcend our individual ego-centric concerns and feel that we are genuinely in touch with the other in a direct and open process of co-creation and co-expression. It was this ability to come out of ourselves and experience mutual connection with the other which my interviewees talked about as making the experience of dancing with someone else particularly 'special' or 'beautiful'.

In a continuation of the passage quoted above, Steven further explains:

*You do get to know a lot about people when you dance with them because you're working with them all the time and you sweat – you sweat with one another for goodness sake – you know when you sweat with someone you get to know everything about them ... it kind of is so, such a close-knit thing and you have to be so co-dependent, you know, it's so, you know, it's impossible for you not to get to know someone really well. [Steven]*

Steven's words here evoke a sense of vulnerability. What is special about the relationship formed when we dance with another person is therefore that it develops in us a capacity for openness towards the other which may feel too dangerous in alternative situations where it doesn't arise pre-reflectively from mutual trust being slowly built up in the process of joint movement. It

provides a context in which mutual openness (and its attendant vulnerability) develops between embodied beings, and thus returns us to an understanding of our basic potential to connect with the other and the world and thus with our own humanity.

## **Discussion**

In a world where negative feelings of detachment, fracture and alienation have consistently been identified by psycho-social theorists as ‘symptoms’ of modern living, it becomes increasingly important that any understanding of health engages with issues of groundedness and connectedness. In the spirit of the health humanities, this paper has offered the philosophy of Merleau-Ponty as a basis from which we might begin to make sense of our being-in-the-world as body-subjectivity and also of our connection to others as embodied and as borne of our mutual situatedness in a shared world, thus opening up a different kind of conversation about the therapeutic value of dance from those generally found in the psy- and sci-informed disciplines with their Cartesian underpinnings.

Importantly, it is dance as an end in itself that is brought centre-stage in this discussion, and the focus on the experiences of those who engage in dance as creative practice rather than those who subsume dance into their broader (psycho-) therapeutic practice is significant for re-adjusting the way we think about dance (and all creative arts) as healing and life-enhancing. This move out of the clinical setting is also significant in the context of the aims of the Health Humanities to democratise the practice of healing arts beyond professions such as DMT and to extend their reach beyond patient populations.

As has been shown in the discussion above, dance stimulates a particular kind of awareness that not only helps us to experience ourselves in a more holistic way as embodied beings by grounding us ‘in the moment’ and ‘in your body’, but also opens us to a direct connection with the embodied other. Here, dance allows us to experience a form of communication or dialogue with the other characterised a mutual openness and a transcendent state where self and other are both drawn out of themselves into the ongoing communicative and creative experience of co-expression. Through this Merleau-Pontian framework we can therefore come to appreciate the true potential of dance as a positive and deeply humanising experience, thus demonstrating how expressive arts practice understood through the lens of philosophical theory can open up new dimensions of understanding and experience in relation to well-being and self- (and other-) care.

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## **Section 2. Creative practices, social inclusion and well- being**

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# Chapter 5. Patchwork Stories: an arts project that celebrates and weaves our connections together

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## **Abstract**

*Patchwork Stories* is inspired by the tradition of using story as a response to people asking for advice and guidance. Our research project gathers personal stories and experiences to offer each other; stories that without advice or direct answers, tell us what it may take to turn towards one another.

Founded in 2012 by researchers from the Universities of UT Austin and Exeter UK, *Patchwork Stories* explores the potential of storytelling in building community connections. Through an interactive storytelling process with community participants, an aural patchwork of personal stories and experiences is created and shared. Through a participatory installation, the process of weaving provides a physical representation of the interconnectedness between strangers and friends.

This paper introduces 'storytravelling', a flexible term to describe intentional acts of giving and receiving stories. Both project facilitators and project participants are 'storytravellers'; the facilitating 'storytravellers' create conditions in which individual contributions are nurtured and valued and the participating 'storytravellers' contribute through sharing their own stories and actively listening to others.

This paper outlines the process of storytravelling; engaging with simple acts of reciprocity that validate connection and community; making possible social inclusion and healing

**Keywords:**community, story, connection, weaving.



## Theoretical background

We associate community with meeting our need to belong. In his book *Community: seeking safety in an insecure world*, Baumann identifies the longing for community being driven by a thirst for safety. He describes a 'peg community' as one created with the purpose of finding safety with others and yet necessarily fails 'to quench the thirst for security' because it doesn't address the great insecurity we experience in these changing times'. (Blackshaw, 2005, p.104).

Arts practitioners are familiar with the process of creating a community with each new project; beginning the process knowing that the end of it will signify loss for many members of this new community. This loss is far from an expression of a failed community but is instead an affective response to an experience of belonging.

Amiee Carrillo Rowe's work 'aims to render transparent the political conditions and effects of our belonging' and explores how we respond to the command to 'Be Longing'. (Rowe, 2005, p.16). Discovering the various ways in which we can, and do create ties and connections is part of the work of bringing our attention to 'the politics at stake in our belonging, and to envision an alternative.' (Rowe, 2005, p.16).

In *Patchwork Stories*, individuals not only exchange stories from their lives and experiences, they see and hear their stories in relationship to others as part of an audio clip or as words and images on fabric that are woven into a single piece of material. These artistic exchanges, as both literal and metaphorical intersections, create an opportunity for seeing and understanding our experiences as part of something larger than ourselves, as part of a community of experiences.

This project demonstrates how in listening to the words of those we live and walk amongst, we find the threads that connect us. The acts of sharing and weaving remind us that creating connections requires each of us to do something; actions of weaving, building and imagining; an act of turning towards, instead of away.

### **Description of the experience**

3 years ago I was 49, working in a University, feeling trapped by the position I had found myself in, with teaching and administrative responsibilities increasingly removing me from my artist and facilitator practice. During this time I found myself returning to an image in my head; a group of women are sitting around a table, sewing and talking about their lives; stories of hope, betrayal, gratitude.

I spoke about this image with my artist daughter, Carina Ripley. Her conviction that the image could translate into a socially engaged artist project provided necessary stimulus. Through dialogue with Megan Alrutz, a dear friend and colleague, this image became the seed for a practical research project. Together we imagined an interactive installation, the audience wearing headphones, tuning in to the women's conversations, finding hope and help in what they heard.

From these beginnings Patchwork Stories was born; a project that uses aural and visual material to create patchworks both of sound and image, spanning communities in Devon, UK and Austin, Texas, USA.

At the heart of Patchwork Stories is this vital question for our times...

'What does it take to turn towards one another?'

The answer is simple and yet vast; it requires that we make connections with each other. A simple and powerful way we make connections is through the act of giving, through being heard and the experience of being needed.

Patchwork Stories is an arts-based journey to find stories that, without advice or direct answers, tells us what it may take to 'turn towards one another'.

Answers to this vital question are around us all the time, demonstrated every day by people as they go about their lives, and yet, because these answers come from everyday experiences of ordinary people they are too little appreciated as guidance and profound wisdom. Patchwork Stories seeks these demonstrations of everyday answers to the question, finds them in the stories of those we live and walk amongst, records them and shares them with others through an aesthetically and socially engaged frame.

The heartbeat of Patchwork Stories are the 'storytravellers'; a group of individuals, often artists or people deeply engaged with their communities, who help to gather and share people's everyday stories, embedded wisdom.

The Storytraveller, carrying a sound recorder, visits places both familiar and unknown, meeting with strangers and friends, gathering stories from those they live and walk amongst. The Storytraveller creates a dialogue within an interview setting, sharing personal stories and using story prompts to facilitate others to share theirs. As the storytraveller listens, they are seeking answers to the deep questions they carry in their own hearts. The recorded stories are collated, edited into short aural patchworks with the stories of other people, and presented in an immersive performance environment in which visitors are invited to listen and reflect on what they've heard. Guided by project Storytravellers, visitors sit at a table and illustrate strips

of material with images, words or marks that express their responses to what they heard. Visitors then weave these strips of fabric together to create one large piece of material, a physical patchwork that mirrors the aural.

Storytravelling is a deep listening, inspired by belief in the power of story and narrative to be meaningful. The story traveller understands that stories, whether ancient myth or personal narratives, are the tools humans have developed to guide us and support us as we walk through the extraordinary experience of being here on this earth. As humans we are able to both be in the world and observe our place in it at the same time. In observation we are able to reflect, plan, judge and make decisions. The storytraveller rejoices in this unique ability to observe and pay attention to who we are and how, and to help others begin to do the same.

Last year, running the project in Austin, Texas, one of the storytravelling team members, seeking advice about what it takes to provide support to others had asked for responses to this story prompt...

'A time when someone I love stood by me even though it was probably difficult'.

A visitor to the installation recorded this personal response to the prompt:

*I was mad at my mom. I was 16.*

*She turned my Dad over to the police. She was mad at him and wanted him to know she was serious. So he was arrested.*

*I took a small bag and moved to my uncle's.*

*He let me live there and be a teenager, and stay up late, and leave takeaway leftovers everywhere. I wrecked his car and ran up his phone bill.*

*He never said anything mean about me.*

*He never said anything mean about my parents.*

*He helped me with my homework He gave me money to see movies with my friends. He did my laundry. He woke me up for school.*

*I stole some money from him. He let me think he didn't know.*

*I was driving his car and my girlfriend thought I was gonna hit some pigeons. I sped up, she covered her eyes. The birds flew off but I smacked the window from the inside so it would feel like we hit a bird. I broke the window. She screamed. We laughed. I lied to my uncle about it.*

*My Dad had a drug problem.*

*I woke up one morning and decided to go back home.*

*I don't think I thanked my uncle for a decade.*

Retrieved from: <http://www.patchworkstories.net/stood-by.html> (30 January 2017).

To the team member who posed that story prompt, the response she heard was a reminder of the bigger picture, the landscape of trust and hope that often is available if we choose.

For others, this story stimulated a conversation about the kind of uncles or aunts we are, of the extent to which we would support a nephew or niece, the capacity we have to offer safe haven to someone, no questions asked. The story invites us all to see where we place ourselves on the spectrum of unconditional support and brings us face to face with the ways in which we may have turned away, or have wanted to, or the times when we too have stood by someone we love, even though it was difficult.

The storytravelling process is without judgment. Everyone has an experience, a story of a time when as supporter or supported, someone has stepped up for a person in need. The sharing of these experiences generates connections, the recorded and edited stories in response to the prompt create an aural patchwork, a testimony of the untapped wisdom that lives within us.

Brother David, a Franciscan monk describes this beautifully:

*'Some insights of our human heart are so deep that only a story can help bring them home to ourselves and share them with others.'*

## **Results**

One of the project participants, Lucy, had an experience that further illustrates the concept of making connection through the act of giving and the experience of being needed.

The story prompt Lucy responded to was 'A time in your life when someone was there for you'.

Lucy told about an old friend who had travelled back from India before the end of her holiday on hearing of Lucy's sudden loss of her mother. As she told the story her face softened, her eyes shone. She wanted to talk about this friend, about the times they'd shared, about their adventures and those small moments that make up a friendship. She told of a holiday dare, when together they agreed to jump into the sea off a big cliff. Her friend went first and Lucy followed, but after the exhilaration of the jump, she was shaking with fear and couldn't get back up the cliff. Her friend at the top of the cliff shouted encouragement and told her exactly where to put her hands and feet. It took an hour, but Lucy made it to the top. It was a moment in her life

she'd not thought about for many years; a small experience within the bigger picture of her eventful life.

When she later visited the Patchwork Stories installation, she put headphones on and heard her own voice telling that story back to her, now edited alongside other stories of people taking risks, needing help, being there for each other.

After experiencing the installation and other visitors' response to it, Lucy was surprised and overwhelmed to discover that the small moment she had described could offer guidance and inspiration for others. She commented later that she finally understood the Patchwork Stories project, she understood that she could be like 'an elder', a wise one, and that if someone was wondering whether they should dare to take a risk or not, they might find an answer in her story.

Through this process, Lucy was both giving to others and experiencing being needed. Whether or not she meets those who listen to her story, she is connected to the aural patchwork, and the impact of her stories are woven into the fabric created, literally, physically, and metaphorically.

Patchwork Stories installations challenge Baumann's notion that 'peg communities' fail to meet their promise. A PS installation facilitates a flow of power; the guided can become guides, visitors become participants. The shifting dynamics invite deep reflection about how we build connections and shape our past and future stories.

The long-term value of this is not dependent on the future existence of that particular grouping of people or the location itself; the short-term PS community shares more than being in the same place at the same time. Values, hopes and experiences are shared with a focus on support and

appreciation of each person's contribution. The quality of connection generated can continue beyond the duration of the installation; experiencing both needing and being needed in the same moment can have lasting impacts on if and how we turn toward one another.

## **Discussion**

The experiences described demonstrate two things born from 'storytravelling':

- personal insights emerge through placing stories in conversation with each other
- a quality of connection between strangers and friends that grows from seeing ourselves in each other or in each other's experiences

Let's return to the story about the young man and his uncle; hearing this within the context of Patchwork Stories, we are invited to respond to it more deeply than solely as a well-constructed and moving story. The storytravelling framework enables listeners to reflect on their own responses to the story, and enter into critical conversations with others. The process of listening and reflecting builds connections through discovery both of what we share and of the uniqueness of our own experiences. We may respond very differently to situations requiring support, but we all appreciate the necessity of giving and receiving support in our lives, regardless of our circumstances.

Moreover, Lucy's story demonstrates how seeing and hearing your own personal story framed in an artistic setting, helps us value our own experiences as wisdom, as something critical or important to others. It



relocates or shifts perceptions of knowledge, value, and wisdom. We discover that even during those times when we have felt small or powerless, our actions offer guidance to others and that there is deep wisdom to be found in our experiences. We are invited to reclaim ourselves as authors of a life that is valued by and valuable to others. We discover that the arts might in fact help us connect to ourselves and to each other in critical and healing ways.

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## Chapter 6. Experiencing wellbeing at La Ruche d'Art: methods and materials of an art hive

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### **Abstract**

Involvement in the creative arts has a sustained and positive impact on mental and social wellbeing. Adding a third space for arts-based social inclusion, community engagement, and service learning for university students, provides a powerful vehicle for civic exchange across diverse demographics. Over time, a community art studio, aka Art Hive, provides a platform for participatory practice research leading to social innovation. This workshop recreated in part, *La Ruche d'Art* (The Art Hive), a university storefront classroom and a public home place for residents in a low wealth neighbourhood in Montreal. A public home place is a protected safe space, both psychologically and physically, which invites community members to share their skills and develop their unique voices. The workshop introduced theories, methods, and materials used in the Art Hive. Attendees assembled small visual journals based on creative reuse principles while sharing stories related to the relevance and scope of these special third spaces. Concordia University's Art Hive launched in 2011 hosts a network of 100 Art Hives across North America and Europe. This workshop encouraged participants to consider developing an Art Hive in their workplace or community

**Keywords:** arts-based social inclusion, public home place, social innovation.

### **Theoretical background**

Citizens are becoming acutely aware that "while the wealthiest human beings on earth are increasingly preoccupied with entertainment and living creative and expressive lives, nearly one billion other human beings are living in poverty and several billion more are barely making ends meet" (Rifkin, 2000, p. 231). Broadening personal wellbeing to include effective responses to urgent global dilemmas such as: consequences of climate

change, aging populations, diminished housing, and scarcity of clean air and water, is necessary. Watkins and Shulman expands Martín-Baró's (1994) suggestion to radically re-visioning psychology by stating, "To transform and humanize repressive or failing human institutions, all of the people who participate in them must also be transformed and humanized through participatory dialogue and creative imagination about alternatives." (2008, p. 27).

Art Hives provide one response to these escalating trends by inviting and empowering citizens to set up small and sustainable neighbourhood spaces located outside the market place. These free public home places welcome isolated seniors, marginalized youth, young families, immigrant newcomers, and other vulnerable individuals living on the margins of communities, and provide lively spaces to re-engage issues that matters to those participating. In Belenky, Bond and Weinstock's words:

*Public home places are places where people support each other's development and where everyone is expected to participate in developing the home place. Using the home place as a model, the members go on working to make the whole society more inclusive, nurturing, and responsive to the developmental needs of all people - but most especially of those who have been excluded and silenced. (1997, p.13)*

These complex social spaces "provide the ideological and material conditions necessary to educate a citizenry in the dynamics of critical literacy and civic courage, and these constitute the basis for functioning as active citizens in a democratic society" (Giroux, 1988, p. xxxii).

Liberation psychology provides another important theoretical lens underpinning the Art Hives incorporating principles of Freire's (1989) critical education and Martín-Baró's (1994) liberation theology. Liberation

psychology calls for contextualizing individual psychological suffering within social and cultural experiences of hegemony and oppression (Watkins & Shulman 2008, p. 26). While involvement in the creative arts have been shown to have a positive effect on wellbeing (Bolwerk, Mack-Andrick, Lang, Dörfler, & Maihöfner, 2014), Watkins and Shulman (2008) describe the necessity of the creative arts in social transformation:

*The arts have played a crucial role in assisting communities to resignify and resymbolize their experiences and environments. Cultural activists have been brilliantly inventive in adapting art forms to local conditions to awaken new sensibilities and develop collaborative methodologies that allow people with no arts training to participate. These experiences can be life changing. (p.264)*

Extending the university into the community as a “democratic public sphere” (Giroux, 1988, p. xxxii) has deep roots in Spain. My husband and I were honoured to be guests at the *Residencia de Estudiantes* in Madrid in order to study *Las Misiones Pedagógicas*, an energetic Spanish educational project that took place between 1931 and 1936, prior to the Spanish Civil War (Urtaza, 2006). Our historical research involved understanding social movements that may inspire the growth of the Art Hives Network, and learn in part, what worked, what didn’t, and perhaps, why.

The Spanish educational missions were a part of a vibrant, short-lived, cultural movement that involved a proactive group of university students, teachers, writers, musicians, and painters of Spain’s Second Republic. *Misiones Pedagógicas*, much like the U.S. Federal Arts Project’s (1935-1942) response to the Great Depression, brought the creative arts to thousands of people. Both projects ended abruptly due to war, but provide remarkable examples of what can happen when students and teachers prepare, plan, and push past academic walls. By way of trains, buses, pick-up trucks and

even mules, the *Misiones* students travelled into remote and isolated villages with musical instruments, puppets, costumes, wood to build outdoor stages and thousands of books. They set up puppet theatres, temporary galleries of famous oil painting reproductions from the Prado Museum, projected films in community squares, played music on gramophones, led children in dance and play, sparked community choirs, and set up 5,000 libraries with an average of 100 books per library. While supplying a utopian vision of education, *Misiones Pedagógicas* also believed that building relationships across divides and exchanging cultures was an important aspect of building an equitable and just society (Urtaza, 2006). Belenky, Bond and Weinstock (1997) call these poorly recognized, short lived and often forgotten collaborative creative learning environments, “a tradition that has no name” (p.11).

### **Method / Description of the experience**

This experiential workshop recreated in part, the methods and materials practiced by the community at La Ruche d’Art (The Art Hive). Located in a working class neighbourhood in St Henri, Montreal, La Ruche d’ Art is a lively and welcoming space, inviting everyone as an artist, especially those who are isolated or economically vulnerable, to create and develop their own public conversations, cultural events, and non-juried art exhibits. The community art studio is opened two days a week and other creative art therapies studios are held the rest of the week for groups, such as: a seniors group, cancer patient support group, street artist studio and young indigenous parents group.

Ideally, setting up a pop-up Art Hive for the duration of a conference brings forward conversations in a relaxed, experiential way. We have hosted Art Hives where mixing the public and conference participants added another layer of valuable exchange to the conference. Being limited by time, and access to creative reuse materials, inspired a more directive approach. For this workshop we offered small journal-making kits, prepared in Canada that combined the important elements of the studio: interesting recyclable materials, informal skill share (a particular binding method), and the freedom to develop or deviate from the project suggested

## **Results**

There is a great need today, to collaboratively innovate new ways to inspire, develop and practice methods of community–university partnerships. In Montreal, the Art Hives Network (<http://www.arthives.org>) developed at Concordia University has played a role in helping outline the role universities and other institutions play in society today. For example, it has provided evidence of the importance of service learning within classroom learning for university students (Timm-Bottos & Reilly 2015). It has also provided a model for the development of university “third space.” Like the Misiones Pedagógicas, La Ruche d’Art in St Henri is physically located between private space (home) and public space (work, university and other institutions), but we now know through sustained practice research, that third spaces can also be located at the edges of formal institutions. Soja (1996) expands the definition of third space by drawing on Lefebvre and Foucault, describing “first space” as that which can be mapped, “second space” as that which can be imagined, and “third space” containing both the real and the imagined. Third space invites seeing with a spatial imagination

(p.11). For Foucault, these “heterotopias,” represented, “the space in which we live, that draws us out of ourselves,” (Foucault, 1984, p. 48), requiring acceptance of ambiguity and vulnerability (Arhar, Niesz, Brossmann, Koebley, O’Brien, Loe & Black, 2013), in order to open oneself to different ways of seeing.

Conference workshops become another place to act out “third space.” As workshop participants entered the space, my husband Leo and I, greeted each participant and invited them to paint right away at a spontaneous painting wall and/or start with the journal-making materials. The group settled in to an hour of art making and storytelling with projected images of *La Ruche d’Art*. Participants expressed excitement and seemed to have been inspired by the lively conversation and art making that was interspersed through the visual presentation. Participants used the journal making materials to practice a new binding technique, or true to third space, developed novel ways (i.e. one journal became a hanging mobile of new possibilities) to achieve completely different innovative results.

## **Discussion**

It is often the creative reuse of discarded materials, rather than the purchase of new, traditional art materials, that leads to the spontaneous art making experiences. Materials offer a lot in developing the imaginative methods used in the space. Practically speaking, reusing partially used paints, glues, brushes, clay, fabrics, as well as other household donations, not only provide an endless supply of interesting materials, but contribute to the sustainability of the project.

At La Ruche d'Art, as donations began overwhelming the studio, students and staff set up the "Honey Pot," a household creative reuse depot. Materials are reorganized for reuse, and supply the 30 Art Hives in Montreal, helping to significantly reduce expenses. Increasing awareness about hyper-consumerism and environmental impact of consumer products has become an important topic for discussion and creative re-purposing has inspired other related community activities, including a university-wide institutional creative reuse depot.

Importantly, there is a personal and psychological process that accompanies the participant's use of discarded consumer goods, beautifully expressed by Oliver (2002) in the following quote.

*This process of distorting and deconstructing is the way in which "I" make the clichés of culture mine; it is a way of belonging that counteracts alienation from meaning and dominant culture. These distortions can be playful or angry, subversive or conservative, conscious or unconscious, but they must be creative and born from passion. They are ways of finding or creating the loving social space that can support an open psychic space. (p. 57)*

Opening to the inner spaces of learning about oneself and the world of relationships around us is implicit in the life of the community studio and university students play an important role in enlivening these processes. The service-learning component (Timm-Bottos & Reilly, 2015) is matched with the skills and fresh perspectives of engaged students. This exchange, involving spontaneous art making, skill sharing, and conversations with the community, sets up a non-hierarchical environment for everyone to be teachers and students for each other. In addition to formal course work, we practice, "Each One, Teach One," a method developed by African slaves who were not permitted education in the United States. These important



traditions of African American women's leadership have been devoted to lifting up entire communities and Art Hives welcome these and other diverse ways of knowing from all traditions, such as, street artists' survival practices, differing abilities ways of knowing, and indigenous science.

Over the past two years we have been exploring community engagement as a threshold concept for social innovation, which has evolved to include western and indigenous scientists expanding our perspectives through a series of interactive public conversations called, "The Science Shop." As art communities gather over time, we notice that we have begun to create a culture of "what works" to support meaningful and healthy community life. This practice has also begun to expand ideas about western scientific research as described by Arhar et al (2013):

*Research is seen here as a cultural space of multiple perspectives and demanding work on the part of the researcher(s) to examine and reshape his or her formal, course-based knowledge in light of a process that is often open-ended and unbounded. (p. 231)*

In third space, like at the Art Hive, "what seem to be oppositional categories can actually work together to generate new knowledges, new discourses, and new forms of literacy" (Moje, Ciechanowski, Kramer, Ellis, Carrillo, & Collazo, 2004, p. 42). A participatory research practice that proposes to reorient experts to "learning from organic histories with local participants" (Watkins and Shulman, 2008, p. 27) may lead to what Freire describes as "a world in which it will be easier to love" (1989, p. 24) and may hold hope for a grassroots vision of a more just and peaceful world.

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# Chapter 7. Take a photo a day and call me in the morning: exploring photography projects and well-being

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## **Abstract**

The practice of taking a photo every day and sharing it online has increased in popularity across social media and image-sharing websites. This paper explores the potential well-being benefits of participating in this practice, examining the different social and creative ways in which participants use it.

We interviewed sixteen people who currently participate in photo-a-day projects, and identified with the concept that participation in these projects had positive well-being benefits. Data were analysed using a grounded and iterative approach. Analysis focused on how participants derived well-being benefits in photo-a-day projects.

Photo-a-day projects enabled participants to look differently at the world. There was something satisfying to participants about noticing the world around them more, perhaps giving a sense of being more alive because they were more aware. The negative impacts on well-being mainly centred around the rules and constraints of the projects, including feeling obliged to respond to comments. Nevertheless, photo-a-day projects gave a sense of agency and choice, focused around a pleasant goal. Sharing photos could enhance social connections and lead to new relationships. The structure of taking one photo every day encouraged reminiscence, looking back on positive experiences and negative experiences overcome.

**Keywords:** photography, well-being, mental health.

## **Theoretical background**

Taking digital photographs and sharing them via social media sites like flickr, Facebook and Instagram is a common practice. This paper focuses on

a particular aspect of photo-sharing in the online environment: taking and sharing digital photos as part of a daily project. In a photo-a-day projects, also known as 365 projects, people commit to taking and sharing one photo online, every day, for a year. Often, people continue this practice after the initial year, recording daily life on a longer-term basis. These projects can become a personal photo diary or journal, but there is a lot of variation in how people use them. Some people choose to have a theme for their project, others treat it very much like a diary or daily record, or to practice and improve their photography. It is difficult to establish numbers of users and purposes of conducting photo-a-day projects, but the dedicated photo-a-day website blipfoto is estimated to have around four thousand users, and two significant Flickr groups (project\_365 and project365) have approximately 37,000 members internationally.

Online photo-a-day projects are part of a new infrastructure for sociality and creativity (Dijck, 2013) and may be said to contribute to an 'increasing visualisation of everyday life' (Hand, 2012). Previous research on photo-a-day projects has focused on them as creative and reflexive projects (Piper-Wright, 2013) or learning experiences (Barton, 2012). Both these framings of photo-a-day projects give insight into why people might conduct them. But our research has shown, building on a tradition of therapeutic photography, that these projects are more than this: they make a defined contribution to improving well-being.

Therapeutic photography takes many forms, including the photovoice method (Guell & Ogilvie, 2015) and its use in psychotherapy. The general principles are that those involved either take or select images that resonate with them and express an emotional state (Loewenthal, 2009). In photo-a-day projects, the predominant aim is not always to express or improve an

emotional state. Instead we theorise that the process of taking a photograph, selecting it, uploading and sharing it online – along with the processes of commenting on others’ photos and receiving feedback on photographs – has a positive impact on well-being.

Photo-a-day projects share some commonalities with interventions in Positive Psychology. Positive Psychology aims to have a beneficial impact on well-being by recommending small behavioural interventions such as gratitude letters or journaling (Seligman & Csikszentmihalyi, 2000). Emerging evidence suggests that these interventions are effective, but Positive Psychology assumes that they can be administered in a defined ‘dose’ to improve well-being. This ignores the complexity of the intervention itself, and its interpretation in everyday life.

By focusing on existing online photo-sharing practices, we provide evidence about the activities that people choose to engage in and explore how people enhance their well-being by weaving these practices into their daily lives. We take Cieslik’s (2014) view of well-being as a ‘social, processual and biographical phenomenon’ to develop an understanding of these perceptions and interpretations of well-being. Instead of using survey-based methods to quantify well-being levels, our focus is on how well-being may appear in vernacular accounts and popular narratives that reflect a complex picture of competing discourses.

The aim of this paper is to explore photo-a-day projects in the complex context of everyday life, focusing on their impact on well-being and the affordances of choice and action they present as part of changing daily routines.

## Method

Because our aim was to understand how participants themselves perceived photo-a-day, we used an interpretive methodology based on qualitative data collection. A semi-structured interview schedule was designed, which sought to explicate the participants' personal understanding of well-being and its connection to photo-a-day practices. It included questions on motivations for conducting photo-a-day projects, the value of the projects and the concrete processes of taking and sharing photographs. We recruited participants via an open online invitation, which outlined our interest in the potential connection between conducting photo-a-day projects and well-being.

Sixteen semi-structured interviews were conducted in 2015. Eleven of the participants were female, with five male. All were aged between their mid-30s and mid-70s, and had been conducting photo-a-day projects for over a year. The majority (ten) shared their photos on the blipfoto, with cross-posting to other platforms including Facebook and Flickr. Smartphone cameras, tablet computers and digital SLRs were all employed as tools for capturing photographs, depending on availability and circumstances.

Interviews were audio-recorded and fully transcribed, and all participants gave written consent. A research assistant conducted most interviews over the telephone or via skype, with one of the authors conducting one interview face-to-face. Ethical approval for the study was given by two University Research Ethics Committees.

Data were analysed using an iterative constant comparative approach (Charmaz, 2006), initially looking across the interview transcripts for

themes. Open codes grounded in the data were reviewed and organised into categories, then supplemented with themes generated from the literature.

## **Results and discussion**

Interview participants reported positive benefits to taking part in photo-a-day projects. Participants discussed how taking part in photo-a-day helped them to keep noticing and encountering the world. It encouraged them to engage with other people – both online and offline – and it created a narrative of identity in which glimpses of the self could be seen, rather than a conscious portrayal or biography. However, photo-a-day was not entirely a benign intervention: sometimes people found it difficult to fall in line with the ‘rules’ of the projects. And while these projects were often a positive experience, they were rarely simple.

### *Positive benefits*

Research participants spoke about how photo-a-day helped them when they were in difficult situations in life. For example, when one participant had lost his job, it was something that he could still do.

*It stopped me thinking negatively if you see what I mean. I could do something positive every day, although I was having trouble finding another job.*

Others found it changed their routines, giving them something to talk about and something to focus on.

*It actually keeps me ticking over... and I drive home and I am looking - I will sometimes stop at the side of the road if I have got my camera with me. [My friends] do notice a change in me. Because I will talk about photos, I will get excited about what I am doing.*



These aspects of photo-a-day projects resemble the interventions recommended in Positive Psychology. Undertaking a new activity every day and building it into a routine is a common feature of such interventions, but where Positive Psychology views these projects as a simple intervention, photo-a-day was a more complex set of activities. The activity of searching for a photo took people outside of their existing routines.

### *Encountering the world*

In its nature, photo-a-day is closely tied to everyday experience; but for some participants it subtly reshaped their daily practices. Participants adapted their routines looking for new things to photograph and some spent the day with their 'eyes open' searching for photos. Seeking different images became an enjoyable occupation, with one participant stating that this *'transforms how I look at the world.'*

*I notice all sorts I never would have noticed before. You are kind of scanning around all the time you are outside. Noticing things.*

Sometimes, people had deliberately adopted photo-a-day because it was seen as a challenge to complete. Participants spoke about changing their usual activity to seek out an interesting photo opportunity. This breaking of existing routines was seen as something positive: leaving the desk at lunchtime, driving a different way home, or going on a walk to look for photos.

*So it was really a way of getting myself away from my desk and out taking a lunchtime. [...] You know it is still quite a good way of forcing myself to think about something else other than work.*

This seeking and searching for photographs added positive interest to the whole day. It was not simply a one-off act. Participants also spoke about the

way that other aspects of the project, such as editing photos and adding text, further elaborated enjoyment.

### *Engaging with others*

Photo-a-day was 'social' in ways that would typically be expected from sharing material on a social networking site. Family and friends could be subjects for photographs, and often viewed and commented on the photos. But photo-a-day projects could also provide a connection with people that the participants did not know outside the online environment. Participants enjoyed the insight into other lives, and many clearly had a sincere interest in others' lives and photos. They felt the way that they conducted themselves in relation to followers was a part of the ethic of photo-a-day. These relationships felt significant.

*It is just an interest and almost a privilege if you like to be able to eavesdrop in on their lives and see what they are doing.*

Because photos were usually of pleasant things, sharing photos was seen in itself to be giving something nice to others.

*I have had several people say to me that my photos make them feel better when they see them in their day.*

Participants felt that those they followed on blipfoto or other social networking site formed a community because of the shared sense of concern shown to people. One participant talked about how he felt supported to discuss online how his illness had affected his life.

*It is an odd thing to say but I have got to know people without meeting them... You get to know bits about their life which are sometimes quite intimate. People ask me about my illness... it can be fairly heavy stuff really and through that you do get a sense of mutual support. People are concerned for you, and you are concerned for them.*

Photo-a-day projects became meaningful as a deeply social practice. Although the initial aim was the simple act of taking and sharing a photo, one of the main draws of photo-a-day became this creation and mutual reinforcement of a community.

### *Glimpsing the self*

Participants felt that the photo-day was representative of, and affected by, what else was occurring in their lives. However, these revelations of the self were not coherent or complete. A narrative of identity emerged through choices of photo over time; the story was not complete and the ending was not known.

*It is not a diary. It is much more, and it is what takes me.*

Photographs sometimes had a very private meaning, not appreciated by the audience. Photos also retrospectively acquired meaning through time and association, with a sense of emergence of knowledge experienced by the person undertaking the project. This meant that when looking back over photo-a-day projects, their multiple meanings and role as a record of lived experience could encourage reflection.

*It has become a valuable sort-of history of my life. [...] Some photographs that I take are very important to me in terms of memory, but the memory that I know they will evoke is completely private. So I might write no words at all because I have nothing that I want to say in public, even though I know the photograph will evoke something for me in the future.*

However, this history was predominantly written without artistry. It was not the aim to construct a definitive biography of the self or fashion a self-portrait. Any revelations emerged from the series of photographs and the text around them.

### ***Rules and responding***

Photo-a-day was not a universally positive activity; the negative impacts on well-being mainly centred around the rules and constraints of the projects. People felt under pressure to find a good image every day, and feeling obliged to respond to comments.

*I used to get really stressed if I missed a day [before], because there was a group leader who would say you have not posted a photo and it felt a bit of a chore.*

*I don't get myself upset that I can't possibly comment on everybody's photograph... Recently there was a spate of people leaving [the group] because they felt under pressure and they couldn't commit to commenting on everybody's photograph.*

Both participants commented that they had made changes to their practice following these negative experiences, showing that they still had agency and choice in action.

### **Conclusion**

Our aim was to try to capture the complexity of experience in photo-a-day projects, considering their effect on well-being and the diverse ways in which they could contribute to personal identity and memory. Taking the stance that well-being is a complicated 'social, processual and biographical phenomenon'<sup>8</sup> we have presented the lived experience of undertaking these projects and started to reflect on their role. Participants who were recruited to the research identified a connection between our view that photo-a-day projects impacted on their well-being and their own experience of conducting these projects. Although this was a small pilot study, further work in progress has confirmed that this is not an isolated phenomenon

among those who conduct photo-a-day projects, with many viewing them as beneficial to their well-being.

The photo-a-day projects themselves were a form of documentation of daily life, but also opened up a dialogue with others. Sharing photos could enhance social connections and lead to new relationships. The structure of taking a photo-a-day encouraged reminiscence, looking back on positive experiences and negative experiences overcome.

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## Chapter 8. The body, the creative arts, and inclusion: a certified program experience “Find your own voice”

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### **Abstract**

The exploration and construction of creative spaces are essential for human beings, and allow for flexible individual and collective encounters in which the value of an individual's experience is not predetermined. The experiences and modes of expression of the participants are appraised in an environment in which the borders and paradigms of what one “should” do or how one “should” act are open. The creation of spaces where difference is valued and validated becomes a privileged pretext for the goal of inclusion, through which all of the participants can find, develop, and express themselves.

This process has been conceived as a certificate program with the purpose of developing spaces of inclusion and encounter by placing the creative, sensitive exploration of the body at the centre. The creative arts allow us to be open to living experience and to the joy of the diversity.

There have been two cohorts in the program, with a total of fifteen students, women, with ages between 20 and 35 years, from different backgrounds such as anthropology, preschool and special education, psychology, social and political studies, and the arts. We use methods such as DanceAbility, Biodanza, dance improvisation, music improvisation with the body, and voice and musical instruments, as well as storytelling and photography.

The participants draw on their learning processes as a different way of understanding inclusion. They become better able to recognize their own creative nature and to apply their experience in their everyday work.

**Keywords:** pedagogy, presence, inclusion, art, body.



## Theoretical background

We started by reflecting on several authors and proposals that we had encountered in different moments of our personal and professional lives. We also took suggestions from participants in the diploma program, with the knowledge that every experience adds something valuable to the path we walk together. We share with authors such as Estanislao Antero, Fernando Barcena the concept of the “pedagogy of the presence,” (2003; s.f), which also takes inspiration from Hanna Arendt. Barcena’s concept questions the way we live and see this world and the capacity we have to transform it “with help from everybody else, or simply some others, through necessary mediations” (Barcena, sf; p.2), and through the possibilities that the arts offer for us to understand, interpret, and transform, and to find our own voices.

We also consider the proposal of Carlos Skliar in which he invites us to think and create a “pedagogy of difference” (Skliar, 2002, 200814), in a continual reflection on how we see ourselves, others, and how we have been seen. From Humberto Maturana, we take meditations on the sense of being human (Maturana, 2002), which allow us to question both that sense and ourselves from a position of otherness, and to challenge the individual forms of being in this world that make diversity a problematic and exclusionary subject, as well as the necessity of transforming the many institutional spaces where this exclusion happens. These transformations can only be possible if they begin with what we are capable of creating ourselves in our daily lives.

We take the body as a foundation, keeping in mind that our bodies are constructed socially, that society is incarnated in the body and that our

bodies reflect the mechanisms of power of the social order we inhabit (Butler, 2001). In considering the agency we have as bodies to transform our exclusionary social environment, we find that it is possible to manifest that agency through our personal explorations and changes as well as through collective action and growth (Pizza, 2005; Butler, 2001).

We believe that inclusion in different social contexts is always permeated by the living experience of bodies. We engage in the exploration and construction of creative spaces as a vital expression of the human being, making that experience a locus of permanent growth and research that approaches Denzin and Lincoln's proposal for the emergence of research-action-critique and of participation in the social sciences, especially those based in the arts. This approach constitutes a new theoretical and methodological genre of qualitative research, with the objective of "[creating] research processes oriented towards actions that are useful inside the local communities where they originate" (Denzin & Lincoln, 2015).

### **Method / Description of the experience**

Our starting point is the fact that all of the people that come to the course have their own backgrounds and experiences, and have an interest in the subject of inclusion, related in most cases to their work performance, their areas of training and in some cases with personal histories. We ask how they can develop that interest through the arts, mediating their experiences through the body. That is to say that each participant enters this field, implicitly or explicitly, because the theme of inclusion occurs in their daily lives and they experience relationships of otherness with those that have

been socially excluded or labeled, such as people with disabilities, people in vulnerable conditions, or others.

The journey begins with the premise of the encounter— all of the participants have the opportunity to have this encounter with themselves and their own questions, with the other participants, and with the teachers. As instructors, we take on the task of unpacking those experiences. We all take part in this journey, and we are there to share what we know, what we believe, and who we are.

We take elements from the methodologies of contemporary dance, in particular DanceAbility (Alessi, 1987), the Biocentric pedagogy, (Cavalcante, 2004) and experiential methodology such as sensory exploration (Rodari, 1983), music workshops, and visual arts tools. We make use of the communicative and interactive possibilities of these forms as well as written and oral communication.

The generative “detonating” experiences emerge from each of our backgrounds, from the proposals we use as source material, and from the professional and life experience of the teachers. The course employs three lines of techniques that correspond to three different embodied paths in the arts: movement and dance, words and visual expression, and sound and voice.

The course is structured around five modules called The Sensitive Body, Feeling, Being in Time, Being in Space, and Creation. This guide concepts are inspired from the principles of improvisation proposed by Alito Alessi in DanceAbility methodology, that help us to understand how is the exclusion made by the parameters that society created to normalize how we

should sense our body, experience our relations, the time and the space. (Alessi, 2010)

In *The Sensitive Body* we interrogate the senses to search and recognize ourselves in who we are, what we do, and what defines our corporality (Wainwright & Turner, 2003). From there we can comprehend and question normality and abnormality, and identify and deconstruct stereotypes and prejudices.

In *The Feeling Body* we explore ways of transforming and being transformed, we recognize the limits that are created and imposed on us (Pinkola, 2000; Pearson, 1992), and find ways to work together to challenge ourselves to affectively put our individual and collective possibilities into action.

In *Being and Time* we take on the task of comprehending the vertiginous nature of modernity, identifying its traps, and exploring its possibilities and the diversity of its temporalities (Kapra, 2000; Ende, 2007).

In *Being in Space* we ask ourselves about the social construction of space, and explore our ways of being in the world and the possibilities of creating and recreating our spaces, as well as the value of the diversity in that process.

The last one is *Creation*. We put the results of our journey on the stage, and take the risk of proposing, exposing, experimenting, rehearsing, living, and encountering each other.

## Results

The course is conceived as a living experience process that nourishes during the process and from the embodiment of new learning's that detonate in the participants' creative possibilities to engage the inclusion in each of the daily spaces they work in. The results that are shown tell us about a systematic reflexive process they have during the course and its impact in time through a conversational meeting made with them, one year later.

Participating in this course was like being on a journey. In the words of Jana (All names used correspond to pseudonyms that the participants chose as part of the process of the course), "It was like entering into a trance state". The participants allowed us to lead them through the proposals and the activities in that space.

As a consequence of the experience that we built during the course, some of the students felt the need to rethink the possibilities of what they can do and what they can be.

Some initiated important processes of personal growth, as the course brought us to discover and recognize the presence of memories in our bodies that impact our daily lives. For example, Eliska made an "epithelial self-portrait" in which she used drawings and photographs of segments of her body projected together with some writing to have a long-postponed conversation with her mother. Through her work she was able to reveal who she is and what she wants to do in the world, and how that is different from the person that she felt she had been molded to become, pushed to conform to the desires of others that she didn't share.

Others described the experience as a way of "finding their own voice". It was something that emerged from discussing and reflecting on the

detonating experiences that allowed us to listen to ourselves through our bodies, through music, and through the stories we created together.

For Filovera, finding her own voice meant being in tune with her own being and letting it speak, so that her voice or her intuition could lead her.

Collective exercises allow us to explore our natural instincts: to identify ourselves with animals, establish relations between smells and sensations, dreams and desires, colors and vibrations, music and emotional states, and give us the ability to share our otherness and also our disagreements when we converse. They help us see ourselves through the mirror of the other, sometimes being mirrors for others, sometimes for ourselves.

Jimpu appreciates how we created the encounter through conversation, and wove into it the feminine, the practice of observing and valuing diversity, and the possibility of connecting with the experience of others.

Jana describes it as “...an experience that you miss, that you feel the lack of.”

## **Discussion**

The experience is, at the beginning, destabilizing for the participants' canons about what is expected and pre-conceived in an education program, since it places them in a need to work from an intimate exploration of their own prejudices and real relationships with that that inclusion implies.

The body is usually abandoned in our daily life routines, and recognized it as the axis and place of knowledge and relationship with the world, it is one of the central proposals in the certification, and this is only possible to afford gradually because, in some circumstances, it means to confront itself with the unknown.

The confidence the participants build through the sensible experiences, allowed them to explore those dimensions that sometimes brings up pains and scars from deep past experiences, despite the fact that in the beginning the group feels misplaced, that allowed us to partner and join the process with who evidences it and had decided to transit the confrontation in a creative way.

## Conclusions

For us as guides, being able to go through the course, seeing the class as a sensitive space for sharing, where knowledge is constructed and permeated by the living experience of each person, it is a fundamental tool for the pedagogical encounter.

As teachers, this allow us to develop a means of constructing knowledge in which the sensitive and unique humanity of every person is validated, and which, step by step, we can lead by our own example.

We consider that to bet for experiences of education through the arts and bodies, allow us to empower the creativity we all have, to trust in the richness of diversity and explore different ways to be together and push forward in the construction of more inclusive environments.

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# Chapter 9. The use of group vocal improvisation as a music therapy technique in a mental health setting

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## **Abstract**

Although group work and the use of voice and of improvisation techniques are three common features in music therapy practices, a systematic review of the literature has shown that the combination of these elements has been overlooked in the research. This review also showed an association between using pre-composed material when working with the voice and, on the other hand, using instruments when improvising. This polarisation of instruments versus voice when addressing production and reproduction techniques in music therapy is not made explicit in the literature and therefore the clinical reasoning behind it might respond to decisions other than clinically orientated. Instead, these implicit assumptions appear to have become established practices in the music therapy discipline.

The present research project addresses the use of group vocal improvisation as a specific music therapy technique and attempts to look at the differences in therapeutic processes between this specific technique and a standard use of group music therapy, mainly making use of instruments. The workshop will demonstrate some of the techniques and will attempt to demonstrate their accessibility whilst uncovering the clinical reasoning behind the use of group vocal improvisation.

**Keywords:** music therapy, voice, improvisation, mental health, group work.

This workshop was organised in four stages: an introduction and contextualisation of the research topic, a presentation of the theoretical model and literature review, a practical session of group singing with some discussion with the participants and a clinical vignette at the end.

## **Introduction**

There is extensive evidence (Carr et al., 2013; Grocke et al., 2014; Tague, 2013) about the benefits of music therapy in mental health settings, both in individual and group formats. Group work offers benefits from a cost-

efficiency perspective and is also a platform to explore interpersonal struggles or difficulties, which are be very relevant for the everyday functioning and wellbeing of people suffering from a mental health illness.

The established use of group music therapy in mental health settings consists mainly in improvising with a range of available instruments. In the last decade there has been an increasing interest to address the voice as an important element in music therapy, especially in community choirs (Clift et al., 2008). However, the combination of improvisation and voicework in a group setting has been overlooked in previous research.

Applying group vocal improvisation within a National Health Service (NHS) outpatient clinic has involved in the presented study adopting an initially directive approach that aims to come across as non-threatening, accessible and not orientated towards vocal technique but more focused on the exploration of creative sounds. The main aim of the sessions is to provide an experience of being in a group, sharing something intimate about one's identity and acknowledging one's one voice within the group's voice.

This emphasis on the relational dimension within an intersubjective non-verbal medium that is strongly linked with emotional expression and sense of self aims to tackle some of the key difficulties that mental health service users encounter in their recovery journey. This is argued from an attachment theory perspective, where the agentive Self starts to develop in early years through safe and playful interactions with an emotionally attuned and empathic caregiver. This leads to the integration of primitive modes of experiencing internal reality (Bowlby, 1969).

Using the voice as a means for musical expression facilitates the emergence of an environment where a focus towards these early modes of interaction

can be revisited and experienced in a playful and aesthetic context. This provides the service users to begin to experience themselves and their self in relation to others from a new perspective with the potential for them to shift their perception of these patterns towards healthier and more accessible relationships.

### **Theoretical Model**

The uniqueness of the voice as a central instrument in music therapy can be looked at from different angles (Austin, 2008; Baker and Uhlig, 2011; Warnock, 2011):

- Physicality: when singing, the body undergoes physiological changes ranging from the breath to heart rate, from activation of particular neural regions to physical vibration and resonance.
- Embodiment: the voice is the only instance where instrument and instrumentalist are experienced at the same time. Therefore, this provides an experience as both object and subject.
- Universality: everyone who can speak can sing, all cultures sing. This means that everyone is naturally skilled in using the modulation of the voice in order to communicate emotions and to interact socially.
- Primal: both from a psychological and anthropological point of view, the non-verbal modulation of the voice is a primal instrument. It is the first means of communication for every baby with its environment in a similar way as it was for the first humans in prehistory.

The importance of the voice within music therapy has seen a recent increase in interest that has been reflected in the literature, especially in the area of the benefits of choral singing, as the literature review shows (Figure 1). Since the research in group vocal improvisation as a specific technique was almost inexistent, the literature review for the current PhD research project was organised around the different immediately neighbouring areas as the different categories of articles (A, B, C and D) reflect. Each category encapsulates 3 of the 4 distinctive elements of GVI: group work, use of voice, improvisation and music therapy.

Category A, for example, brings together articles focusing on therapeutic group singing but without improvisation; category B instead shifts the focus towards vocal improvisation in individual music therapy, losing therefore the element of group work; category C has to do with GVI outside the field of music therapy, therefore dealing with a performance and artistic practice of a minor genre such as group vocal improvisation; finally, category D accounts for articles on the music of group improvisation in music therapy but mainly dealing with instruments.

## Group singing activity

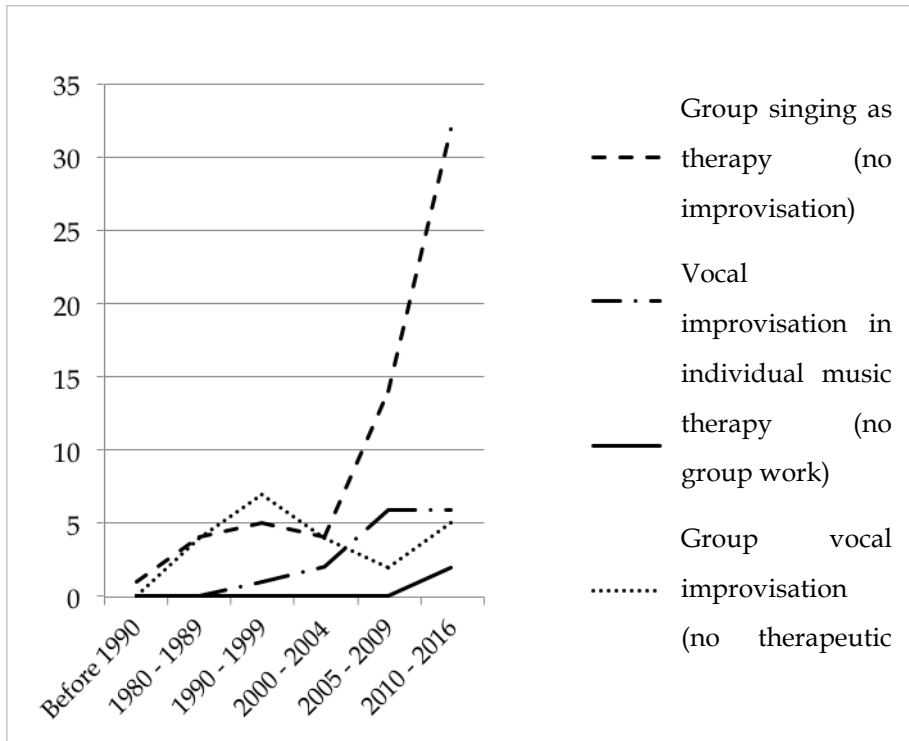


Figure 1. Results of literature review in categories

The  $y$  axis represents the number of results obtained for each category through a systematic research of the literature. The Healthcare Database Advanced Search (HDAS) was used to search five databases from the National Institute for Health and Care Excellence (NICE): Embase, PsychInfo, MedLine, CINAHL and AMED, The search was completed in November 2016.

During the workshop, participants were asked to say how comfortable they feel in using their voice in front of others in a dynamic way, by positioning themselves in a continuum from “never” to “all the time”. Having shared their experiences of group singing, the participants engaged in a gentle physical and vocal warm up, including stretching, breathing exercises and

vocalisations. The main activities of the workshop involved doing short improvisations with the sounds of each participant's name in a call and response dynamic. The practical section of the workshop ended with everyone learning a short "circle song" in harmonic parts and then introducing the possibility of adding improvisation on top of it.

After this, the participants were encouraged to share their comments about the experience and what they thought a similar kind of activity could provide in a mental health setting. The feedback was positive, with people visibly smiling and some individuals surprised at the resulting sound of the group. Some participants also shared how at the beginning they found it a little exposing to sing in front of others and how they found the different activities helpful in overcoming this sense of insecurity.

These comments were linked to the previous theoretical presentation and they were categorised in the following broad categories:

- Synchronisation: rhythmical entrainment, "being together" in the music.
- Socialisation: feeling closer to one another, perceiving others more positively.
- Energising: uplifting feeling, awakening sensation in the body and alertness.
- Shared experience: feeling part of a group, collective endeavour.
- Interactive communication: intersubjective experience of dialogue with others.
- Emotional expression: strong emotional connection and experience.

- Creativity: feeling that one could improvise easily, willingness to “try things out”.
- Preverbal dynamics: implicit affect attunement, *vitality affects*.

### **Clinical vignette**

The workshop finished with a case study from one of the groups included in this current PhD research project. The clinical vignette focused in a single session towards the beginning of the formation of a closed group where there were only two attendees. The two male participants (one in his 30s and one in his 50s), both suffering from depression, engaged in conversation about songs that they liked.

This apparent superficial way of getting to know each other was interpreted by the therapist as an attempt to define a common identity for the group and an effort to work out together what the group “was about”. After some discussion, the therapist pointed out at this and suggested to write down the titles of the songs that they had listed and to use those as lyrics for an improvisation.

The titles were: “I’m changing”, “Summertime”, “I’m feeling good”, “At last”, “A house is not a home”.

The therapist moved to the piano and started playing a few chords for the patients to chose which ones they felt would be better for the piece. Once they gave an orientation of the mood they wanted and chose the two chords the therapist started playing them in alternation.

The improvisation lasted for about 10 minutes, during which they used the mentioned titles and also started to change them to, for example: “I’m not



feeling good”, “Summertime, blue skies”. The patients provided positive feedback afterwards and they appeared to have gained a more robust sense of group and trust.

### **Final thoughts**

Bringing together the first hand workshop experience along with the clinical vignette and the initial theoretical presentation afforded a rich reflection of the different factors influencing and shaping the use of group improvised singing as a means for therapeutic change.

The workshop proposed an organic way of working with the human voice in an accessible way in order to explore emotions, relationships and creativity. The initial findings presented from the literature search and form the preliminary clinical work show good potential for the use of group vocal improvisation as a powerful music therapy technique. At the end of the present PhD research more data will be available to reflect further on the clinical implications, strengths and limitations of this new technique.

This technique links organically with the development of music therapy as a young academic and clinical discipline. Group vocal improvisation is situated within a continuation with the foundational music therapy literature describing the clinical use of improvisation (Wigram, 2004; Bruscia, 1987) and attempts to make a contribution to a new area of research involving the use of voice and improvisation in mental health settings.

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# Chapter 10. Birth professionals make art. Using participatory arts to think about being a birthing professional

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## **Abstract**

In The Birth Project we are exploring women's experience of childbirth and the transition to motherhood using the arts and then presenting the research findings in films and exhibitions. Our overarching research question wishes to explore what role arts engagement might have to play in antenatal and postnatal provision, especially where post-birth trauma is being translated into bodily symptoms or depression. The Birth Project is also interested in investigating to what extent clinically-related birth practices are implicated in iatrogenic outcomes, especially post-natal distress. Furthermore, the research is also concerned to explore the birth experience from the perspective of the birth professionals involved. A suite of films has been produced and several shared at the conference.

**Keywords:** birth and art; participatory art and occupational stress; arts and health; health humanities; birth professionals.

## **Theoretical background**

Midwifery and obstetric practices, within a period of austerity for the NHS, amid litigation fears and pressure from the media, have an effect on the experience of all those involved: women giving birth and birthing professionals. In *The Birth Project* the arts are being used to interrogate this complex topic, using the arts as a qualitative research method. Obstetricians, midwives, and new mothers have been given the opportunity to explore their experiences of compassion fatigue, stress, birth suffering and post-natal

readjustments using the arts. These different groups have joined together in 'mutual recovery' events in which perspectives have been shared, primarily through elucidation of the art works produced and captured using documentary filmmaking. The *raison d'être* of this project is to create dialogue between different communities of interest and experience, to use the arts to interrogate discourses, to challenge embedded assumptions, and in this process, to stimulate mutual recovery between all those who experience and are affected by birth. We situate this endeavour in the context of an emerging practice of health humanities (Crawford, Brown, Baker, Tischler, & Abrams, 2014).

All those witnessing birth face seeing or being actively involved in traumatic events. Stressors and satisfaction for midwives have been noted to be multifaceted, involving issues such as supervisor support, work pressure, clarity of roles, and levels of autonomy (Carlisle et al., 1994). Secondary traumatic stress in midwifery is an acknowledged phenomenon that may contribute to midwives leaving the profession and which has potentially harmful effects on midwives' ability to care effectively and compassionately (Leinweber and Rowe, 2008). Trauma from dealing with difficult births can have long-term consequences (Halperin et al., 2011). Increasing fear of litigation may also be a contributory factor to midwifery stress in the UK and elsewhere (Hood et al., 2010). A series of workshops with birth professionals, including professional doulas, who may have experienced vicarious trauma, whose traumatising experience is often overlooked, have used the arts to explore their experiences. This film narrates their concerns and reveals their artistic engagement.

## **Method / Description of the experience**

The filming by Sheffield Vision has been used as a research method and as a documentation of the research process. The aim of the filming is four-fold.

1. Firstly, as a method to capture the research, which will be used to develop new thinking on contemporary birth experience and practice (it is research data).
2. Secondly, the footage is being edited to produce short films which address the research questions. Thus the films are a research output.
3. Thirdly, the short films themselves will also function as teaching and training resources and will be made available for this.
4. Lastly, a documentary film of the entire process is being made to be shown to a public audience. This aims to highlight some of the issues raised throughout the process and also to reach a broader audience with key issues.

The birth professionals group will be discussed here. The facilitator, Debra Gibson, used a participatory art approach, drawing on techniques from art therapy. Although the workshop series was led by a Health & Care Professions Council, UK (HCPC) registered art therapist, all participants had signed a consent form stating that they understood this was not art therapy. However, art therapists are practiced in facilitating group work, including handling interpersonal tensions and are skilled in containing strong emotions, so lend a high-level of expertise to the process of facilitating group work. It was

for these reasons that an experienced HCPC registered art therapy practitioner was selected to run this workshop series. Participants were invited to reflect on that it feels like to be a midwife, (or other birthing professional). This group was non-directive in emphasis, so specific themes were not suggested, nor instructions given. Rather participants were able to reflect on the conversation with which sessions started and then make art work which may or may not elaborate or explore a point of that discussion. It was made clear by the facilitator that participants were free to explore any topic they chose, in relation to their practice and their personal experience of their practice.

## **Results**

### *Issues Arising*

Some of the participants perceived that midwives were not always viewed favourably by the general public, and it was felt that this may be because of women having had bad birth experiences. Putting the birthing women at the centre and the difficulty of this was articulated. There was a definite acknowledgment and wish expressed that it should be a positive event for women, though acknowledging the pain and possibilities for complications. One experienced midwife worried that some women left the ward feeling “assaulted mentally”. She wanted to make women feel she was one their side.

In one image, shown in the film, the midwife places a placticine figure of the birthing women in the centre of the piece and herself unobtrusive, and “not interfering”, at the side, “hopefully she’s at the centre”, she says. The mother is depicted upright (though on the bed). The midwife depicts herself as brick-like shape, “confident and solid” and “making it feel safe”. There is also a big presence of the medical nature of the birthing room symbolised by the symbol of the red cross. This medical expertise was acknowledged as amazing and life-saving, but not always necessary and that it shouldn’t be what “dominates and guides” the midwife and all the practice. However, an underlying anxiety was also acknowledged. One trainee midwife noted regarding the possibility of emergencies, “We were trained to recognise every eventuality and you can’t unknow that...”. It seemed that the possibility for trauma coloured the entire thing. Certainly the medical symbol dominates the art work.

The pace of work was also acknowledged as having risen, as birthing professionals are now managing more people, with the same resources as previously. The example of a piece of equipment breaking and then having to be shared with a larger number of people was given; this could interfere with the flow of work and complicate the midwife’s use of her time. The consequence of this greater workload is having to spend more time prioritising where to spend one’s time, she said. One hospital midwife put it like this, “I don’t feel I can *be* with women because I’m *doing* midwifery... being



a midwife is about connecting with the person while you are carrying out physical care” and that is what was felt was being lost, because of having to rush from one person to another. With more than one woman in active labour in a labour suite, the midwife noted that she completed one observation, and then wrote it up and then had to “run” to the next women, as observations should be completed every fifteen minutes. This prevented her from *being* with any of the women in a meaningful way, she felt. This left the midwife feeling guilty and angry.

One area which was highlighted as particularly problematic was breast-feeding support. One midwife described new mothers on a drip, having had an unwanted Caesarean-section, as exhausted, and frightened, but also as feeling under pressure to breast-feed, and feeling that they’ll be a “bad mum” if they don’t. The midwife wanted more time to give *emotional care*.

Another midwife was very explicit about feeling constrained in her practice by hospital policies, with the fear of litigation always at the back of her mind, and actually “doing things as a precautionary measure”, when it was felt that it would be better not to intervene. She described this as a culture of intervention, in which midwives felt that it was better to feel they were doing something rather than nothing, when not intervening would be better. She felt that hospital environments carried with them the expectation of management, and noted concepts such as “bed blocking” - that a women taking up a

bed for longer that the hospital protocol might be seen as blocking it for the next person. This added pressure to make unnecessary interventions, such as offering to break the waters, when if progressing normally, there should be no need for this.

She was unequivocal that she could not practice in the way she would like to do because of temporal pressures and policies. Her art work shows a mask suffocated with a layer of cling-film and with a red-cross over the mouth, indicating that it cannot speak. It is an uncomfortable piece to view. The same midwife suggested that home births were preferable because that's where the women is likely to feel more comfortable, able to eat and drink as she chooses, have visitors, "and hugs" interjected a hypnotherapy specialist. There seemed to be a consensus that more homebirths would improve the quality of experience for women experiencing normal labours.

Not articulating 'negative' feelings in the workplace was also discussed, and a suggestion that if one did see ones supervisor too often that ones professional capability might be brought into question. A "let's get on with it" culture meant that emotions tended not to be shared. Furthermore, burnout and bullying were recognised as reasons why midwives leave the profession. Acknowledging that one is not coping with ones workload, can lead to harrying rather than supportive responses. Being able to discuss issues and make images to express different layers of experience was articulated as useful.

## Discussion

### *Complex Art Work*

Some of the artwork produced was very complex. One midwife created a double faced mask-like sculptural piece. On one side was a mass of snake-like pipe-cleaners representing a tangle of thoughts, but also the different paths of birth experiences, including one that had ended in a fatality. This was shown with a black blockage or full-stop.

On the other side is the midwife who is calm and reassuring and positive. Her demeanour can help to relax the women in labour “so that everything can happen more naturally”. This midwife persona is surrounded by images of positive or ideal childbirth, such as a man kissing his new-born baby, or a woman at home in front of her fire with her cat. These are images of what people hope for. She acknowledged the importance of the birthing event and expressed sadness that sometimes it can be “a horrible experience” for a couple and that this “can’t be put right”. However, she hoped she might be able to influence how they felt about it.

Another image, made by a hypnotherapy practitioner, was a picture of a party scene with a woman in bed holding her new baby, but this was covered in layers of plastic, so barely visible – “blurred”. The piece is entitled ‘Celebration of Life’ and she articulated how childbirth should be celebrated, but has become a medical condition fraught with anxiety and fear. She wanted to see it celebrated in the home with friends and family and a party atmosphere and regarded as special, but it is hard to see that because of the pervasive nature of the medical model (represented by the plastic overlaying the entire image).

It is intended that the film will be used as a teaching aid with trainee midwives, health visitors, trainee therapists and others and that it will stimulate critical debate about key issues.

Film: *Birth Professionals Make Art. Using Participatory Arts to Think About Being a Birthing Professional*. Executive Producer: Susan Hogan. Running time 30 minutes. Available at: <http://www.derby.ac.uk/health-and-social-care/research/birth-project/films/>

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**Section 3. Professional  
competences: integrating  
creative practices and health**

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# Chapter 11. Workshop ‘Art therapy for an art therapist’

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## **Abstract**

‘Art Therapy for an Art Therapist’ was an experiential workshop presented at the 5<sup>th</sup> International Health Humanities Conference, Arts and Humanities for improving Social Inclusion, Education and Health: creative practice and mutuality – hold in Seville (Spain), from September 15<sup>th</sup> to 17<sup>th</sup>, 2016.

The main enquiry proposed to the audience was how to conduct an art therapy workshop for an art therapist. This key question addressed an important role in our teaching model, since it was designed to promote an autonomous and critical thinking among the participants to an almost Socratic style and to some more committed conjunctures according to Bain theory (2005: 118) and following the Experiential Learning (Kolb, Boyatzis & Mainemelis, 2000).

The method used involved different phases and techniques, as a gymkhana or an art exhibition. The results pointed out the vision and thoughts of the ideal art therapists and the descriptions of the main capacities and abilities needed.

**Keywords:** art-therapy, game, roles, workshop.

## **Theoretical background**

According to the Spanish Professional Association of Art Therapy, ‘art therapy’ is a profession that uses artistic creation as a tool to facilitate the expression and resolution of emotions and emotional or psychological conflicts. This is practiced in individual or group sessions with varied populations and objectives, from the treatment of mental illnesses such as depression and anxiety, to the promotion of emotional intelligence and self-



esteem (Esteban & Garrido, 2013). The main element of this type of therapy appears in the relationship between the agents: (a) the patient / user, who use Art as an alternative and complementary type of communication to the word, (b) the image or artistic object, which is created during the session and (c) the therapist, who guides and facilitates the creative process as a function of the therapeutic goals.

The basic skills that practitioners of art therapy must develop, according to Izuel & Vallès (2012), are summarized in eight blocks: (1) Artistic & therapeutic competence (i.e. understanding the need to establish and maintain the artistic & therapeutic relationship as a creative process within a holder and safety frame; Knowing the own capacities and limits), (2) Artistic competence (i.e. Developing production activities in any form of Art), (3) Cultural competence (i.e. Being aware that therapeutic artwork can be affected by culture, age, origin, gender, religious beliefs, etc.), (4) Critical competence (i.e. Ability to exercise the profession in a critical, self-critical and reflective way), (5) Ethical competence (i.e. Understanding of art therapy as a process to be developed 'with' the patient and not 'for' the patient); (6) Communicative competence (i.e. Communicative ability both verbal and not verbal, through images or other forms of representation, that allow an adequate communication for the development of the task); (7) Creative competence (i.e. Ability to promote and evaluate creative processes at individual and collective level through the development of non-stereotypical perceptions and divergent thinking); and (8) Research competence (i.e. Ability to properly use the art therapeutic framework in research, as well as the application of the most appropriate methods to allow advance in the knowledge and studies to be performed).

For its development, art therapists must permanently revise their practice, their theoretical, technical and methodological formation. In this sense, we consider that developing artistic activities as users will facilitate art therapists own training as well as professional and personal growth. Also, experiencing as participants the activities they develop as therapists, put themselves in the place of their users, increasing the empathy and identifying their own reactions to therapeutic proposals. We are, therefore, faced with a process of Experiential Learning Theory that provides a "holistic model of the learning process and a multilinear model of adult development, both of which are consistent with what we know about how people learn, grow, and develop" (Kolb, Boyatzis & Mainemelis, 2000). In this sense, there is an increasing number of manuals where there are techniques that are directed to a multitude of groups, where health care professionals also begin to have a space for attention (Domínguez & Esteban, 2014).

In this document we present an experience in this direction carried out at the *5<sup>th</sup> International Health Humanities Conference* with health professionals from different contexts and countries. Below is the methodology carried out, the main results, some lessons learned and conclusions.

### **Method / Description of the experience**

Goals pursued to participants were as follows:

- To reflect on creative techniques currently used at work with vulnerable populations.
- To change the position of the art therapist in order to adopt the role of "patient" and feel as such in a given context.

- To generate open, collective and/or multidisciplinary spaces for innovation in this field.
- To encourage the incorporation of new teaching and artistic methods for improving health and social inclusion.
- To promote the use of alternative creative tools for improving health and social inclusion.

To facilitate these goals, we organized the experience using *flipped classroom* (Sanmartín, 2015), a kind of conceptual workshop based on constructivist methodologies oriented to action (Arroyo, 2014). This type of workshop allows participants to solve for themselves the challenges they face by working in groups (Finkel, 2008: 167-170). So the workshop lasted 50 minutes, distributed in four phases:

Table 1. Description of the workshop phases

Phase	Time	Description of the activity
A	5 min	Presentation of the workshop (Figure 1).
B	35 min	<i>Gymkhana</i> developed by teams composed by slightly different numbers of members. Through different clues provided in six trials, participants unravelled different concepts, tools, ideas and materials that responded to the question posed at the beginning of the workshop (i.e., characteristics of the ideal ‘art therapist’). So, the objective was to discover how to make an art therapy workshop for an art therapist. The key was that if they really wanted to know the answer, then they had to obtain it through a somewhat peculiar way - deciphering the clues. Once the teams found and analysed everything, we all met again, gathering all the collected parts to give the solution to the enigma.

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C	10 min	From this point we proceed to a discussion through the sixth and final trial, taking into account the paradox that participants had already done unconsciously an art therapy workshop for an art therapist through the previous phase. So, the challenge was maintaining the generated expectation all the time.
D	No time restriction	Art exhibition with the pieces resulted in the workshop and made by participants were shown in the hall of the conference's host institution afterwards.

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The audience of this workshop involved 10 participants in total. Materials were delivered to them in order to develop the activities: such as paper, crayons, markers, glue, scissors, cardboard or ropes. The room provided by the organization of the conference was a standard room with mobile tables and chairs and also a screen and speakers for the audio-visual material and *PowerPoint's* presentation displayed in this workshop, in which the six trials below already mentioned in phase B were described to participants as it follows:

Table 2. Description of the six trial in phase B

Trial N°	Time	Description of the activity
1	3 min	To make groups finding other participants with the same colour.
2	8 min	To take an envelope (per group), looking for materials outside the classroom and putting them on a specific target table provided in the classroom (Figure 1).
3	4 min	To select the materials more interesting for the group and taking them to its own space.
4	15 min	With those materials, to debate in the group which are the main characteristics of the ideal 'Art Therapist' and creatively represent it from the attributes defined (Figure 2).
5	5 min	To imagine the room as an art gallery and to exhibit the artwork produced in the group (in 1 minute) explaining it to the rest of groups (1 minute per each one).
6	10 min	Sharing session asking the next key questions proposed: What common characteristics would you highlight from these representations? What have you learned from this experience? How could change the ideal art therapist role in the future?

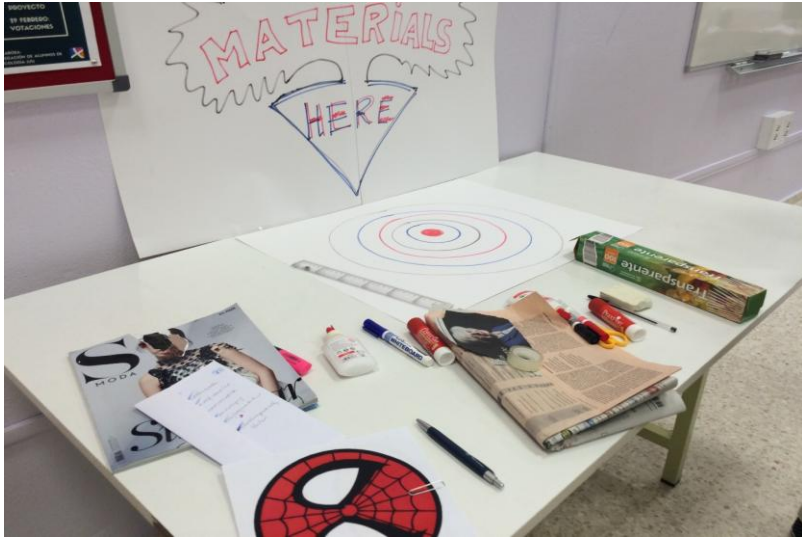


Figure 1. Materials founded by participants and displayed on a specific target provided. *Source: own collection, 2016.*



Figure 2. Participants doing the trial No. 4 during the workshop. *Source: own collection, 2016.*

## Results

As a result of this whole process of learning, the evidence led the realization of four works of art produced by the four groups formed in the workshop respectively. Each work symbolized the ideal 'Art Therapist', according to the group that represented it, generating knowledge through their own emotions experienced during the workshop (Mayer y Salovey, 1997: 10; Kolb, Boyatzis & Mainemelis, 2000). The following four works are analysed below.

The first group performed a work, which was titled "Art is below" and it was given the price of \$50,000. It consisted of a hard platform as a base, taken from a magazine, a glass, human beings made of play dough, a kid's tambourine, a layer of silver paper and many portraits of people cut-out from newspapers (Figure 3).



Figure 3. Artwork made by group 1. *Source: own collection, 2016.*

They tried to portray how these people, who might well be art therapists, tried to climb the 'fragile' glass, to finally break the last layer of silver and enter a world full of different people and personalities. The kid's tambourine gave stiffness but also rhythm to the composition.

The second work was made of play dough, an open magazine, glasses, and a battery-operated toy that played a melody if you pressed a button. On this occasion, what they tried to represent in the figure of the ideal art therapist was the exaltation of all the senses of a human being. They pointed out the head as something big and an open book is trying to emphasize that to be a good tool as art therapist, who also would need the best sight, touch, smell, taste and especially, ears.

The third group made a piece of cardboard, a silver paper, a bit of play dough and many cut-outs from magazines. In this case, with each cut of magazine, which constituted a symbolic image, they wanted to represent the skills that every ideal art therapist should have. Among others, they indicated enthusiasm, attention, calm, courage, communication, self-awareness and openness.

Finally, the fourth group used mostly blank paper and cut-outs with superhero logo prints to create it (Figure 4).





Figure 4. Artwork made by group 4. *Source: own collection, 2016.*

As can be appreciated, they attempted a general balance of weights in which we must know how to measure very well what is best for the ideal art therapist depending on the situation depending on the patient to be treated. In this work appeared the icon of 'superman' as a strong superhero and out of the ordinary human, but also with a powerful heart from which to be feed.

## Discussion

With all these pieces produced by the participants it was conducted an exhibition at the end of the workshop. A productive debate was generated in which each one shared the own vision of what a good art therapist should represent as well as the vision of all this experience during that workshop.

It was expressed, among other things that the art therapist works from a transparent layer that separates it from the rest of people. Also it is

necessary to separate what it means to be an 'art therapist' or to be an artist who works to improve the health of the people. Every professional should find their own ways of working in which to be identified and find the own limits.

Finally, and as an extraordinary closing ceremony of the workshop, all the works were settled at the congress reception entrance, enabling a temporary and original exhibition aimed at the enjoyment of all attendees.

Additionally, participants expressed that the methodology based on learning by doing was very interesting, because it allowed them to think in a critically way and to use subjective strategies to share with the rest of the group, facilitating a warm atmosphere where to express their thoughts.

Consequently, we conclude that art therapy workshops are useful methodologies to include in the training of art therapist and providers of healthcare, based on the premises of the experiential learning models (Kolb, Boyatzis & Mainemelis, 2000).

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# Chapter 12. Medicine and the muse: opportunities for connection through education, research and shared experience

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## **Abstract**

**Introduction:** The Stanford Medicine and the Muse: Medical Humanities and the Arts Program is based at a research intensive medical school, which trains physician-scientists and lauds bench and translational scientific endeavours. However, traits which lead to scientific excellence, such as curiosity and interest in interdisciplinary work, are also traits necessary for innovation in health humanities. The Program began over 15 years ago as a bud of a research grant program for Stanford medical students. Initial emphasis on arts and humanities scholarly work as a track in medical education led to a multi-pronged Program with education, research, community-building and outreach missions.

**Methodology:** Three of the multiple components of the Program will be examined. 1. The Biomedical Ethics and Medical Humanities Scholarly Concentration which has supported over 120 medical student projects. A qualitative study of alumni of the Scholarly Concentration is currently being analysed 2. Cross-disciplinary elective courses such as The Art of Observation, held in the University's art museums with peer-peer interactions between medical and art history graduate students. 3. Community-building through creative writing and literature discussion groups for medical students, health professionals, and the support of Pegasus Physician Writers.

**Discussion:** By initiating the Stanford Medicine and the Muse Program as part of the research mission at the medical school, the Program gained traction in the local culture. Networking across the University and beyond enables meaningful exchange and new opportunities. Program expansion, including writing and literature groups, respond to needs for community building and wellness experiences.

**Keywords:** medical education, humanities, arts.

## Theoretical background

Stanford University, founded in 1891 in Palo Alto, California, is a premier research and educational institution. It houses seven schools, only one of which is health-related, and over seven hundred major buildings, including two art museums and multiple gallery and art installations. Although the majority of undergraduate majors are in science, technology and engineering, stellar resources exist for scholarly engagement at the intersections of the sciences and arts/humanities. As a University, Stanford has more graduate than undergraduate students. Similarly, the School of Medicine has more graduate (PhD/MS) than professional (MD) students, and places emphasis on student involvement in research and scholarly endeavours no matter what degree is pursued.

For a health humanities program to thrive, cohere and gain respect in this environment, opportunities for students to engage in scholarly activity would be critical. Although in the 1990s elective courses and individual events, such as physician-author readings were offered, it was not until recognition of the scholarly potential in the area of health humanities that an actual program developed. The model of a bud on a tree, that is, growing a new program as a branch from an existing structure, even though that existing structure had no element akin to the bud, is presented as a means to integrate a new, interdisciplinary program into a largely science-based school. This practical method facilitates visibility, community building, and collaborations.

Philosophically, the program exists in four overlapping domains. These domains are central to the purpose of a Health Humanities program, that is, 1.) improve health; 2.) encourage inquiry; 3.) promote wellness and

community building; and 4.) provide a structure for better understanding of who and why we are.

This paper focuses on three of the multiple components of the Stanford Medicine and the Muse: Medical Humanities and the Arts Program: biomedical ethics and medical humanities scholarly concentration, the development of collaborations across disciplines through courses, and the evolution to emphasize writing and literature based on interests of the community served.

### **Method / Description of the experience**

This paper provides an overview of program development at one medical school.

### **Results**

#### Biomedical Ethics and Medical Humanities Scholarly Concentration

Stanford medical students are encouraged to engage in research during their educational years, indeed, the majority of students will add a year to their medical education in order to pursue research. Each MD-only student at the Stanford University School of Medicine must choose an area of scholarly concentration (SC) as a graduation requirement. Each concentration must offer core courses required for concentrators, elective courses, project mentorship, and facilitation of project presentations. The SC program was initiated as part of broad medical curricular reform in 2003, although the medical scholars program, which provides grants and academic credit for students doing research at the medical school began many years before

(Meites, Bein, & Shafer, 2003). Currently there are 15 SCs; some students choose to concentrate in two separate areas. Each student develops a course and project plan approved by the concentration director (Shafer, 2016).

The two core courses required for the Biomedical Ethics and Medical Humanities (BEMH) scholarly concentration are introductory seminars, one in ethics and the other in medical humanities and the arts. Elective courses are offered by faculty associated with bioethics or medical humanities, but students are also encouraged to explore the vast course offerings across the University campus which are related to a variety of topics such as health and society, comparative literature, global health, design thinking, and studio art.

Extracurricular opportunities include early clinical experiences, for example, participating in hospital ethics consultations and utilizing observations skills training in the operating suite. Student-initiated activities are supported. Additionally, students organize and lead the annual spring symposium entitled *Medicine and the Muse*, which features student presentations and a keynote speaker, and attracts hundreds of attendees.

Scholarly projects can be funded by a competitive proposal process through the medical scholars program. Of the 135 BEMH funded projects from 2000-2016, nearly one-third (43) were creative writing projects. Outcomes include published books, articles, essays, poems, and web-based resources, and are updated on the *Stanford Medicine and the Muse* website (The Stanford Medicine and the Muse website, 2017). Students present their projects at local, national and international conferences.

Currently, a qualitative study is underway of graduates of the BEMH SC (from 2007 - the first year of graduates, through 2014) in order to evaluate

longer term impact of the SC. Using structured interviews and a data saturation model, a codebook of responses was created. Thematic analysis is ongoing to examine domains such as impact on clinical practice, wellness, community building, and professional identity formation.

#### Cross-disciplinary Courses

A hallmark of biomedical ethics and medical humanities is the cross-disciplinary nature of the fields. That is, not only is the content of multiple disciplines, such as history, literary studies, and anthropology, incorporated into courses aimed at providing a context to medical care and illness, but the methodologies and critical lenses are also used to broaden thinking and provide tools to examine the cultures of medicine.

Numerous courses both at the medical school and across the University utilize this cross-disciplinary approach, but the focus here will be on two. The first, *The Art of Observation: Enhancing Clinical Skills Through Observation*, is taught at the two art museums on campus, Cantor Arts Center and the Anderson Collection at Stanford. Art history PhD graduate students facilitate the development of observation skills of preselected works in the galleries, enable participants to articulate observations, encourage students to back up any interpretive statement with the data (the work) before them, and allow ambiguity to be tolerated - and even celebrated. After the gallery observation and discussion sessions, students gather in a conference room in the museum, and hear a clinical correlations interactive presentation by a medical school faculty member. Session themes have included narrative (family medicine), childhood (pediatrics), brain and body (neurology), and death (pathology). Medical students are encouraged to practice their observation and interpretation skills in their clinical work.



The second course is one of the core BEMH courses, *Medical Humanities and the Arts*. The course begins in the Stanford Medical History Center of the medical library, where students can see, learn about, and even touch some of the historical book holdings, such as *De humani corporis fabrica libri septem* by Andreas Vesalius (1543), Arabic texts by Ibn al-Nafis (13th century), and *Motu cordis* by William Harvey (1639). Other sessions focus on topics such as global health and close reading techniques in fiction, medical anthropology and cultural assumptions, film and health, play-back theatre, and posttraumatic stress disorder. A major component of the course is the development and presentation of student projects in medical humanities. The feedback from the class on works-in-progress help students hone their ideas and sharpen their project focus. All courses are open to non-concentrators as well, but limited in enrollment to facilitate the intrinsic seminar nature.

#### Writing, Literature & Medicine, and Pegasus Physician Writers

As can be deduced from the significant number of writing projects, narrative-based endeavors are of major interest to the community of health care providers and learners at Stanford. This interest reflects the historical roots in the United States of medical humanities as the study of literature and medicine. Writing opportunities and literature discussion series offered by Stanford Medicine and the Muse are thus a response to the basic yet ever-growing interest in these areas.

Writing opportunities include: a creative writing for medical students course, writing workshops open to anyone with an affiliation to Stanford Medicine (e.g., social workers, staff, physicians, trainees, alumni, nurses, volunteers), writing contests, writers forums with readings, writing

embedded in events (for instance, the keynote speaker at the Medicine and the Muse symposium has included writers, such as Khaled Hosseini, Anne Lamott, Malcolm Gladwell, Anne Fadiman, Abraham Verghese, Perri Klass, Rafael Campo, Stephen Bergman (Samuel Shem), and Sheri Fink), a writer-in-residence (Laurel Braitman, PhD), a student journal: H&P, and in-depth writing projects both in the funded medical scholars framework and outside. In particular, students and physicians-in-training are encouraged to hone communication skills through writing, storytelling, and the spoken word.

Housestaff are also encouraged to attend drop-in literature discussion sessions held at the hospital. The sessions, sponsored by the Stanford Wellness Center, are facilitated by the assistant director of the Medicine and the Muse Program, Jacqueline Genovese, MA, and cover topics such as the patient experience, discrimination and prejudice, burn-out and compassion. Separate sessions are held for physician faculty, who read brief pieces of literature prior to the session for discussion. Evaluations of participants have indicated increased empathy for one's colleagues, which can lead to a stronger sense of community (Gavi, Genovese, Trockel, & Murphy, 2017).

Pegasus Physician Writers, established in 2008 and directed by child psychiatrist Hans Steiner, MD, serves almost 100 physicians and medical students. Although some meet only virtually, approximately 60 members meet monthly in 5 separate groups of 10-12 members per group. Each group meeting is used to workshop nascent writing pre-circulated to one's group. A series of Stanford Bookstore readings celebrate the publication of physician authored books, and a separate collaboration of the poets and the ensemble-in-residence at Stanford, the St. Lawrence String Quartet, leads to an annual concert and poetry reading open to the community. Numerous books, essays and poems which have been workshopped through Pegasus

Physician Writers have been published and presented at readings, local and abroad. (The Pegasus Physician Writers at Stanford, 2017).

## **Discussion**

In sum, the Stanford Medicine and the Muse Program provides a home for anyone interested in the multiple intersections between the arts, humanities, qualitative social sciences, and medicine. Originally developed as an offshoot of a grant program designed to encourage Stanford medical students to pursue research studies, the Medicine and the Muse Program has grown to encompass a wider audience, establish collaborations across the University and beyond, and provide curricular and extracurricular offerings.

By providing resources and structure, yet remaining responsive to changing interests and needs of the Stanford community, the Program seeks to nurture curiosity in and empathy for others (such as patients and co-workers), foster the search for the complex contexts of illness and caregiving, promote scholarship, and encourage broad as well as in-depth knowledge, understanding and learning. Explorations of wellness and community-building through the arts, in particular, enable the externalization and sharing of experiences, actualize the benefits of expression, and nurture a changed perception of the world with the goal of enhanced engagement. By teaching the tools and skill sets from cross-disciplinary methodologies, the Medicine and the Muse Program ultimately hopes to encourage meaning making and meaning discovery in health care. With a deeper understanding of the human nature of health, illness and healthcare, the Program aims to value the integration of various facets of

one's life such that fragmentation is diminished. In this way, health care is incorporated more into one's concept of self rather than in conflict with other aspects of life.

Health humanities programs exist or develop in a myriad of ways. One way, as exemplified by the Stanford Medicine and the Muse Program, is to examine the local culture of the school and its mission, and to bud from an existing program or curricular reform movement. Flexibility, inclusion and the provision of resources enable growth by nurturing cross-disciplinarity and connection.

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# Chapter 13. Professional interpreters and their critical role in ensuring communication with other-language speaking patients

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## **Abstract**

In our current societies, people from different backgrounds and cultures who speak different languages live together. This rich mixture of cultures and languages also implies some challenges for the functioning of and access to public services, including healthcare, as people who do not speak the official language of the place they live in have the right to access public services in the same conditions as native speakers. The barriers raised by linguistic and cultural disparity become even more obvious when healthcare is considered from a humanistic perspective, as language barriers in healthcare very frequently lead to a lower quality in health services, worse patient health outcomes and greater treatment costs. It has already been proved, however, that the best remedy to overcome these language and culture-based communicative problems is to resort to professional interpreters. This contribution describes a set of case studies that have been extracted from a corpus of real conversations recorded from medical consultations with patients who did not speak the language of healthcare providers. Our aim is to discuss how healthcare interpreters work (and how they should work) in order for communication to be improved and assistance to be enhanced through the intervention of professional interpreters.

**Keywords:** interpreting, other-language patients.

## **Theoretical background**

The world is witnessing an unprecedented human mobility both within and across national borders. According to the United Nations, “about 1 billion persons, or one in seven, currently live outside their country or region of

origin" (UN System Task Team, 2012: 3), and yet these estimates are rather conservative as they do not consider migration on a temporary or seasonal basis. And it is not only international migration but also mass tourism and supranational political integration (see the European Union, for instance) that are playing a key role in this mobility of people across borders. Subsequently, current societies are no longer monocultural and monolingual entities (if they ever were), but complex multicultural and multilingual assemblages.

This reality is posing unquestionable challenges for public service providers, as public services must cater for all users, regardless of their linguistic, cultural or ethnic background. One of the domains where these challenges are particularly conspicuous and have farther-reaching consequences is healthcare, since "everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care", as enshrined in Article 25 of the Universal Declaration of Human Rights. These challenges, obviously, are related to the intercultural and interlinguistic communicative needs encountered by both healthcare professionals and healthcare users when they do not speak the same language. Whereas overcoming these language barriers is way beyond the abilities and qualification of the former, not addressing them may easily jeopardize the medical assistance for the latter.

Subsequently, interpreting plays a "pivotal and responsible role where there is not a shared language" (Corsellis, 2008: 85). Face-to-face (on site) interpreting still seems to be the preferred option by academics and practitioners regarding quality, as it takes account of both verbal and non-verbal communication and allows for an immediate environment of trust and professionalism. Nevertheless, there are also other modalities that are

gaining ground, especially the so called remote interpreting, in which interpreting is provided through telephone or video-conference, with clear advantages in terms of availability (interpreters are always ready to step in whenever needed and it is easier to find an interpreter for a language of lesser diffusion) and cost-efficiency (no travelling expenses must be covered) (Navaza, Estévez & Serrano, 2009).

The provision of healthcare interpreting varies much from country to country. Some have long-established professional frameworks, like Australia and Canada. But much to our regret, most healthcare interpreting is still undertaken by the so called *ad hoc* interpreters, including friends and relatives of the users or healthcare professionals who are somewhat familiar with the user's language, which normally results in a deficient interpreting service and hence a poorer (and more costly on the long run) healthcare assistance. Evidently, these amateur interpreters have not been specifically trained in the ins and outs of the trade, they do not follow any code of professional conduct and no accountability can be claimed. Therefore, it seems to be critical that the interpretation be performed by a qualified professional, who holds specific training and can be taken accountable by peers and society in general.

In this contribution we examine the critical role played by interpreters in healthcare settings. By depicting two real (and archetypal) cases in which no or poor interpreting took place in medical settings, we purport to highlight how important it is that interpretations are carried out by duly trained and qualified professional interpreters in order to efficiently meet current language needs.



## Method / Description of the experience

In order to illustrate the communication problems which arise from the lack of professional interpreters, we present two extracts from recorded real conversations. These two conversations were recorded at the Emergency Department of the Guadalajara University Hospital and a healthcare center in the same town, located in the central area of Spain, close to Madrid. They belong to an open corpus of recorded medical conversations which is being compiled from 1998 by the FITISPos-UAH Research Group. Permission for recording was granted from all the participants in the conversation through informed consents and an agreement was signed by the healthcare authorities to carry out the study. Digital audio recorders operated by the researcher were used to register the conversations.

## Results

*Example 1. A Polish patient (40) has gone to the Emergency Department with what might be appendicitis. He is assisted by a doctor (50), a Medicine student (30) and a nurse (40). [...]*

1. D2: *¿Si le aprieto aquí le duele en algún sitio? ¿Si le suelto?, ahí sí, ¿verdad? ¿Cómo le duele más? [Does it hurt somewhere if I press here? And when I let go? When does it hurt the most?]*

2. P: *Aquí [here]*

3. D2: *¿Así? [like this]*

4. P: *Sí [yes]*

5. D2: *¿O cuando suelto? [or is it when I let go?]*

6. P: *Sí [yes]*

7. D2: *Bueno pues hay que operarle ¿eh?* [Well then, you will have to have an operation]

8. P: *Vale (xxx)* [ok]

[...]

9. D2: *Bueno, pues vamos a hablar con el anestesista, ¿eh?* [Then, let's see the anesthetist]

10. P: *¿Anestesista?* [anesthetist?]

11. D2: *Sí, claro, porque habrá que dormirle* [Sure, we'll have to put you to sleep]

12. P: *Oh, no, (xxx) yo no dormir poco* [Oh, no, I don't sleep little]

13. D2: *No, no, no. Para operarle. No, ¿eh? Para operarle hay que dormirle* [Just for the operation, we'll have to put you to sleep]

14. P: *(xxx) Yo dormiré ya como siempre dormir, no* [I will sleep as usual, sleep, no]

15. D2: *¿Eh?* [huh]

16. P: *(xxx) Mucho duele [¿no?] [it hurts much, right?]*

17. D2: *[bueno] Hombre, es que si le operamos en vivo sí le va a doler mucho, ¿eh?* [If we operate you live, it is going to hurt very much]

In this fragment a Polish patient visits the Emergency Department with a sharp pain in the lower part of his stomach. He is extremely nervous and has serious problems to communicate effectively in the Spanish language. He arrives at the hospital on his own and there are not interpreters available for his language.

As we can see in Example 1, in the first turn the doctor asks where the patient feels pain and whether he feels it more with or without pressure. We

can see how he needs to ask several times until he finally has an answer from the patient. In fact, the second question he utters is a reformulation of the first one and, as he does not receive an answer, he responds on behalf of the patient. Then the doctor asks a different question, but the answer the patient gives in the second turn corresponds to the very first question the doctor asked.

In the third turn the doctor repeats this last question about when the patient feels the pain. This time he applies pressure and asks whether it hurts. The patient answers affirmatively. Then the doctor relieves the pressure and asks again, and the patient also answers affirmatively, but does not indicate whether he feels more pain this time. The doctor has to deduce this from his body language.

In the seventh turn the doctor announces to the patient that he has to undergo an operation, and the patient agrees. However, the patient seems surprised when short time later the doctor tells him that it is necessary to talk to the anesthetist. In the eleventh turn the doctor explains to the patient that it is important that he is asleep during the intervention. However, the patient does not understand and replies that he does not sleep much. This misunderstanding continues during the following two turns, until turn 16, when the patient asks whether the intervention hurts. The doctor then explains again that it will hurt if he is not asleep under anesthetics when the operation takes place.

After 17 turns, though, we cannot be sure that the patient has understood that he has to undergo surgery and that he needs general anesthesia. This is particularly serious because the patient will have to give his consent about the procedure and there surely will not be consent forms available in his

language or someone who can explain it to him. If he does not get operated soon, his condition will worsen seriously.

With the intervention of a professional interpreter this piece of communication would have been much more fluent and effective. The patient would have known what was happening to him and the treatment he was going to receive. He would have also been able to ask whatever question he might have had and his level of anxiety would not have been so high. The doctor would have been able to communicate the information in a faster way. He could have gathered consent from his patient and would not have felt insecure and frustrated because of the lack of communication.

In the following conversation there was an interpreter present, although, unfortunately, she was an *ad hoc interpreter* (to wit, a neighbor of the patient).

***Example 2. A Moroccan patient in her 70s is appointed to a pediatric consultation. The pediatrician, in her 50s, is treating her patients' relatives after suspicion of TB. The patient wants to know the results of a Mantoux test and visits the consultation together with her neighbor, in her 20s.***

1. D: *¿Sabe, si ella ha estado, o ha tenido contacto con la tuberculosis y al darle (xxx) (corte en la grabación)... tuberculosis y para saber si está enferma, le tenemos que hacer una placa de pecho [Do you know whether she has been or has had contact with TB and when given (xxx) (cut)... TB and to know whether she is ill, we have to examine her chest with X-ray]*

2. I: *Sí (xxx) [Yes (xxx)]*

3. D: *¿Ya se lo sabe ella? [Does she already know?]*

4. I: *Sí [yes]*

5. D: *Pues explíqueselo, por favor [Then explain it to her, please]*

6. I: *Sí, pe... pero ella ha venido par que lo haga a... [Yes, but she has come so that you do...]*

7. D: *Ya, ya, pero (xxx) que se lo explique [OK, OK, but (xxx) you explain it to her]*

8. I: *Ah, bueno [Alright]*

In this example the patient is accompanied by an *ad hoc*, non-professional interpreter: her neighbor. The doctor, in her first turn, utters a long explanation about the tests the patient has to undergo and the treatment she will receive. The interpreter, instead of explaining it to the patient, nods. The doctor, highly surprised, inquires about the reason why the interpreter has not rendered her words and asks whether the patient already knows what the treatment is about. The interpreter only answers 'yes', without further explanation. The doctor is not convinced about this and asks the interpreter to explain the treatment to the patient. The interpreter tries to reply that the patient has only come to the consultation for the results of the tests. The doctor immediately interrupts the interpreter and insists on her explaining the content of her first utterance to the patient. The interpreter finally agrees.

It takes up to eight turns until the interpreter renders the message to the patient. The interpreter not only does not transfer the content of the doctor's words to the patient, but also demands information from her without the patient having asked anything. The interpreter here is speaking with her own voice and the patient is completely left apart. The conversation is not fluent at all and this creates an environment of mistrust. A professional interpreter would have strictly followed her code of ethics and would have rendered everything and no more that the doctor had said, complying with the principle of accuracy.

## Discussion

Nowadays, healthcare professionals must provide assistance to an ever increasing number of other-language speaking patients who, for their part, have the same right to medical assistance as the speakers of the language of healthcare providers. As illustrated above with real cases, the lack of linguistic and cultural assistance or the inadequate provision of interpreting may lead to also inadequate medical assistance, with the well known consequences this can entail, not only in terms of health outcomes (including death) but also in economic terms (more and more lawsuits against healthcare providers for inadequate assistance due to linguistic problems).

Professional interpreting does not only protect healthcare users and professionals, but also safeguards the standards of the interpreter profession. As noted by Corsellis (2008: 85), “the medical and legal professions, for example, would quite rightly oppose pressures for doctors and lawyers to be allowed to practise with lower standards in order to increase their numbers quickly or to provide a cheaper service”.

Thus, it is cardinal for anyone involved in healthcare settings to become aware of the central role played by the interpreter in ensuring the adequate medical assistance when the users are not fluent in the language used by healthcare professionals and demand that interpretations be carried out by professional interpreters who have been trained and tested to pursue this professional activity and belong to a professional group that monitors their members’ performance (and, if need be, can sanction a member’s negligent practice). It is only with the recognition of the importance of professional interpreting by both the users and the other professionals (doctors, nurses, healthcare managers, etc.) that current language barriers can be effectively

overcome and proper medical assistance can be provided to other-language speaking patients.

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## **Section 4. Creating spaces for well-being**

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## Chapter 14. Under the microscope

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### **Abstract**

*Under the Microscope* is an arts research project conceived and led by artist Sofie Layton in partnership with GOSH Arts and the NIHR Biomedical Research Centre at Great Ormond Street Hospital for Children NHS Foundation Trust and University College London.

Over 12 months Sofie explored how children and families interpret medical information and understand disease. Working with clinicians, researchers, patients and their families to understand the issues she developed artwork in response to these conversations, and created imagery and representations of disease, as well as the experience of treatment.

The project culminated in a series of installations exhibited at the hospital and the Institute of Child Health. Artworks included 3D medical heart prints, interpretive heart sculptures, soundscapes, embroidered and embossed hearts made by Sofie and participants, and a sensory installation, which explored the visual landscape and intricacies of the immune system, and the experiential reality of a young patient undergoing gene therapy. Audiences were invited to 'scrub up' and enter an interactive isolation tent with an accompanying soundtrack.

Patients and hospital staff were invited to attend the exhibition and discuss the issues raised. The exhibits were also open to the public on bookable tours guided by young people from our Young Persons Advisory Group. Feedback was gathered from all participants and the public were also given the opportunity to comment. There was a highly positive response from both patients and clinicians, and the general public.

**Keywords:** art, PPI, imagery, narrative, children's hospital, 3D printing.

## Description of Experience

The project ran over 12 months and was broken down into the following phases;

1. Interviews / discussion with clinicians, researchers and biomedical engineers at GOSH and ICH as part of the research phase
2. Workshops with patients and families at Great Ormond Street Hospital on Bear (Cardiac), Fox (Bone Marrow and Stem Cell transplant) and Robin (Immune and Isolation) wards
3. Workshops with a specific group of Young People with Congenital Heart Disease (CHD) exploring the notion of uniqueness
4. Public Exhibitions



Figure 1. Young people with Congenital Heart Disease taking part in a creative body mapping exercise (Stephen King, 2015)

The three public exhibition outcomes were as follows;

*Unique*, Main Entrance, Great Ormond Street Hospital Exhibition documenting artist - led participatory workshops involving young people living with cardiac conditions and congenital heart disease and related artworks. Including group work made by participants with the artist, and work by the artist.



Figure 2. Collaborative art piece made by artist and project participants using embossing techniques and quotes from patients and families (Stephen King, 2015)

*Making the Invisible Visible*, Gallery, Institute of Child Health  
A series of multi-disciplinary artworks about the heart including textile panels, 3D medical heart prints, and sculptures that translate some medical aspects of cardiology. Created in conversation with the cardiovascular imaging team, clinicians, parents and patients on Bear Cardiac Ward and young adults attending transition clinics and their parents.



Figure 3. 3D printed heart models on display as part of exhibition *Making the Invisible Visible* (Stephen King, 2015)

*In Isolation*, Friends' Roof Garden, Great Ormond Street Hospital  
A sensory installation, which explored the visual landscape and intricacies of the immune system, and the experiential reality of a young patient undergoing gene therapy. Participants were asked to 'scrub up' (i.e. put on hospital gloves, apron and mask) before entering a replicated isolation tent, and sit on a hospital bed whilst listening to a specially edited sound track of patient testimony and gathered sounds.



Figure 4. Participants listening to sound track inside sensory installation *In Isolation* (Stephen King, 2015)

Reponses from participants were gathered throughout the project and in specific interviews led by evaluator Anna Ledgard at the end of the project.

During the workshop process young people commented that the creative process had helped them visualise their heart in a particular form, and gave powerful metaphors.

*My heart is a Rubick's cube, a puzzle, a patch work that cannot be fixed! Patient*

*My heart is a soldier; it's been through the wars, I am really proud of it. Patient*

Participants also articulated how taking part in the project had been a useful and cathartic experience.

*I am no different from everyone else and everyone's heart is different including those considered 'normal'. Without the 3D printing and*

*Sofie taking it upon herself to have an MRI scan, I would never have known that there is no such thing as a 'perfect' heart. Patient*

*It is wonderful seeing our opinions and reflections brought to life in amazing art work. I am very pleased with the outcome, and proud to have been involved. Patient*

Staff involved in the project also commented on how the artistic process allowed patients to express complicated feelings about their conditions;

*Young people who have struggled to articulate their feelings about their heart for years have been able to express it in other ways Clinical Nurse Specialist*

*Giving insight through art to invisible processes and structures is very important for learning, patient experience and patient outcomes. Artistic imagery can be very powerful and more memorable to the non-scientist than scientific images and this stimulates interest and awareness. The work helps to make science more tangible and something to be embraced rather than feared for the non-scientist, conveying that science is not just for scientists but is for all of us. Health Psychologist*

## Results

The project brought together an artist with a strong vision and practice, and an established hospital arts programme. Working in partnership and over a longer time period than usually viable, enabled the artist to really embed herself into the life of the hospital and take time to make relationships and explore avenues of interest. Longer term artist-in-residence interventions can allow sensitive topics to be explored and deeper outcomes to develop (Caulfield, 2014).

The workshops, particularly the focused sessions with young people with CHD, allowed patients to explore the uniqueness of their condition in depth,

and work in a supportive environment with a multidisciplinary team (Layton et al, 2016).

The project also allowed the arts team to develop a strand of work that broadened their reach from specific delivery of creative activities to patients and their families, to a wider audience of clinicians, researchers and the general public. This public facing work, whilst not altering the programme's core purpose of arts activities for children at their specific hospital, allowed GOSH Arts to raise its profile and develop practice (Ledgard, 2016).

Embedding the work within the existing arts programme also meant the artist was properly supported, and could build upon the existing relationships and positive reputation of the arts programme within the hospital to make initial approaches to staff and patients. Arts in health projects can involve many diverse partners who can be difficult to bring together (Raw et al, 2012) without the support of an established figure in the hospital. It also meant all procedures and logistics regarding hospital guidelines such as infection control, safeguarding etc would be adhered to. The uniqueness of the setting and particular guidelines can be difficult and confusing for an artist to navigate on their own (Noble, 2012). The programme also offered the artist additional opportunities to engage with patients and staff, and to share practice with other artists from all art forms working in the programme.

The project reached a much greater number of participants than originally expected. Over 200 direct participants, approximately 1400 exhibition attendees, plus additional numbers viewing online and engaging through social media and twitter. Of particular interest was the number of clinicians and researchers reached who might not normally engage with the GOSH



Arts programme. Staff contact with the exhibition had some profound effects, with many staff commenting that they hadn't considered the patient perspective in this way before.

*The installation reminds staff that there is a person behind that heart, scan or medical image and staff should consider the whole person and how that person feels about their heart* Clinical Nurse Specialist.

The location of the exhibition *Making the Invisible Visible*, in the gallery corridor which links Great Ormond Street Hospital and Institute of Child Health, was particularly significant both symbolically and in giving the work profile and status with staff at both institutions.

In the final evaluation report, Ledgard (2016) explored the findings and wider implications of the project;

*'Under the Microscope met and, in some instances, exceeded its original objectives, producing high quality beautiful artworks, and was considered a model of good practice by all involved: clinicians, researchers, nursing staff, psychologists, patients and general audiences alike.'*

The aesthetic and 'beauty' of the final artworks, despite, or because of, their sensitive subject matter, was appreciated by many participants, and figured highly in narrative analysis of audience responses. Written feedback was gathered from 128 respondents through a 'Comments Book' situated in the exhibition and 'postcards' that could be filled in and returned.

*One of, if not THE most beautiful exhibition I have ever seen. The imaginations of artists, scientists, clinicians and patients in one place is mind-blowing. Visitor*

*This has been the most beautiful display so far. Visitor*

*The pictures are complex, bold and beautiful and in some ways they mirror the complexity and beauty of the subject matter. I found the use of the 3D printed hearts, the printed screen, the metal tables as well as the pictures all complementary which gave a really holistic feeling to the installation. Visitor*

The 'beauty' or quality of the artwork also gave it credibility with visitors, and this could lead to deeper engagement with the subject matter.

*Because it is so beautiful, I took the time to stay and read the information. Visitor*

## **Discussion**

For the arts programme in the hospital the project offered an opportunity to embed an artist over a longer period of time, and therefore explore issues that are complex or sensitive. The regular programme does not often directly address illness and disease in this way due to constraints of time and context, but working with an artist who gained the confidence of clinicians and support staff such as nurses and physiologists meant GOSH Arts felt confident in the integrity of the process and quality of the final outcome. The buy-in and proper support of staff is key to the success of this type of work (Charnock, 2006).

This can then lead to deep and effective collaboration between 'artists' and 'scientists/ 'clinicians', as Biomedical Engineer Dr Biglino comments in Ledgard, 2016;

*Working with an artist provides the scientist with a new avenue of research, paved in the artist's vision. [...] When working together, the artist is not just an outlet for a scientific concept, embellishing it or simplifying it in order to make it more accessible. Her work is complementary, adding form, colour, texture, and above all narrative to a concept, which is often abstract or technical. (Biglino in Ledgard, 2016)*

This project has led to further collaboration and an on-going relationship between the artist, the biomedical engineer and GOSH Arts, which has resulted in funding from The Wellcome Trust for a three year project specifically focusing on medical and poetic representations of the heart, please see <http://www.insidetheheart.org/> for further information on this project which will lead to a public exhibition and tour in 2018 in Newcastle, Bristol and London, UK. *The Heart of the Matter* hopes to explore and expand upon the narratives and positive outcomes outlined in the *Under the Microscope* project in this paper.

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# Chapter 15. Home and mental ill-health: twenty dimensions

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## Abstract

In the context of psychiatric rehabilitation and care, home is often associated with health. In the context of deinstitutionalization, however, home has increasingly become the primary site of psychiatric suffering. Drawing on a two-year ethnographic research project with a drama group for young adult mental healthcare service users living in supported housing facilities, this paper presents twenty dimensions of home through which mental ill-health can be approached as a bodily experienced, and discursively and medically structured form of being in the world. These dimensions are here offered as a framework for further exploration of the social, spatial, temporal, structural and embodied aspects of psychiatric suffering.

**Keywords:** applied theatre, mental health, housing.

## Theoretical background

Inhabiting a place is a human mode of being (Heidegger, 1962/1995). This mode of being is fundamentally affected by mental disturbances and the practices of the psychiatric healthcare services: Illness in general can be experienced as a state of homelessness (Honkasalo, 1998). Psychiatry has the power to remove its subjects from their home worlds (Goffman, 1960). Psychiatric problems contribute to homelessness, and homelessness can contribute to mental disorientation (Tischler, 2007). Social care services often look at the state of the home when assessing especially women's state of mind, and stigmatization leads to mental health care service users facing difficulties finding housing.

Using home to analyse and understand experiences of mental distress enables a reading that a) emphasizes the illness experience and centralizes the humanity of the suffering subject in terms of gender, class, ethics/ethnicity and age, and b) can combine phenomenological understanding of experience as a multi-sensory, bodily relation in/to time and space with the construction of subject positions through discursive and spatial orders (Jäntti, 2012). This is particularly important, as medical models of explanation may reduce e.g. clinician's empathy towards patients (Lebowitz & Woo-kyoung, 2016).

### **Method / Description of the experience**

This project engaged a drama group of around thirty 21-35-year-old participants in a search for the meanings of home in a housing facility in a large Finnish town in 2014-2015. The drama group, although led by a professional theatre director, and part of the participants' weekly programme and thus of their rehabilitation, had no therapeutic aims. We focused on artistic work and shared research on the meanings of home and homelessness. The method used was "devising" (Govan, Nicholson and Normington, 2007) where, without a script, a group explores a chosen topic to produce a performance. To explore the subject, we used drama exercises such as improvisation, but also e.g. writing, drawings, recordings and animation. In addition, I carried out interviews with voluntary participants, and the group interviewed two of its own members. During the production of two performances we discovered the twenty dimensions of home presented below. They are here offered as a tool for further theoretical, theatrical and artistic exploration of the significance of and relationship between psychiatric suffering, housing, and belonging.

## **Results: Twenty Dimensions of Home**

1. *Relationality*. First and foremost, home is an affective relationship between a space and its inhabitant(s) (Johansson and Saarikangas, 2009). Change in either affects this relationship.

2. *CulturalIdea(l)s*. Cultural ideals of health, happiness and well-being are often associated with images of perfect homes in e.g. advertisements and life-style magazines. These cultural representations may comply with or conflict with our own idea(l)s. In any case, they form an interesting, useful, and potentially painful point of comparison to the actual homes of the service users.

3. *Identity*. Homes are intrinsically linked to identity both as points of (dis)identification and as grounds of social identity. How, where and with whom we live places us on a socio-geographical map where nation, region, town, district and neighbourhood all mark our identities. Inviting a friend to a place with the words “rehabilitation home” written on the wall reveals more of one’s identity than does an ordinary apartment - and more than is perhaps desired.

4. *Materiality*. Home can be conceptualized as a material extension of one’s identity. What distinguishes it from, for example, a hotel room or hospital is that through the everyday acts of living and bodily and material contact a home adapts to one’s personal needs, daily routines and routes around one’s home. In addition to purely functional objects, a home often includes belongings that represent important memories and attach their owner to a historical continuum (Young, 2005). Taking care of one’s home, engaging in the daily chores and deciding how one’s daily living environment is designed can be important for recovering one’s agency. The widely



recognized, dehumanizing effect of having one's belongings taken away when one is committed to a psychiatric hospital was reported in interviews. Not everyone, however, identifies with their physical environment; some people will find their home in social relations and activities.

5. *Activity*. For people suffering from severe mental health problems, the "self", tormented e.g. by abusive voices, can be an insupportable space. Engagement with activities can help to create an "inner home" (cf. Winnicott, 1973). An inner home is a creative state and can refer to an activity that is so engaging that it enables the subject to forget about him/herself. In our group, table tennis and singing were reported among such activities.

6. *Sociality*. Most interviewees associated home with people. Many also reported that moving into the housing unit had significantly reduced their sense of isolation, and they regarded this as the most important aspect of their current wellbeing. Home can be conceived as a social space - or a social space can count as a home.

7. *Spatiality*. Mental suffering and psychiatric treatments can significantly alter the geographies and spatial patterns of sufferers' daily lives. Depression, for example, can reduce this space to one's bed as in one of participant's drawing of his ordinary day. The maps the participants drew of their typical daily routes showed that recovery, with visits to clinics, healthcare and rehabilitation centres and therapists, often expands these geographies of everyday life.

8. *Multi-sitedness*. Like the important objects within one's home, spaces in one's wider living environment can be marked by important - positive and/or negative - memories or points of identification. Mapping these

spaces can recover one's sense of self and identity. For migrants, they are often transnational and reveal home and identity as layered and multi-sited.

9. *Temporality.* We do not simply inhabit a space, but we carry within us the spaces where we have lived before. Not all dwelling places count as homes. Personal histories narrated through previous homes often draw attention to the childhood home, which our participants often remembered with some nostalgia, though both happy and violent childhoods were recalled. Narratives of past homes can also reveal phases of homelessness in the participants' past.

10. *Homelessness.* The interviews and the discussions around the production of our second performance revealed that homelessness can be experienced as, and analytically broken down to, degrees of homelessness. Psychosis, for example, can be experienced as an existential crisis and the inability to tell whether one is dead or alive, and depression can be experienced as a sense of alienation and nowhere to go. The sense of isolation that often accompanies psychiatric suffering can also be conceived as a form of homelessness. Homelessness can thus refer to a psychological state, existential, spiritual and/or intellectual deprivation, and/or a concrete situation where one is physically deprived of a place to live.

11. *Communality.* The sense of home can be created in/through identification and the sharing of ideas and ideologies. The communities thus created can be found and maintained through various technologies that break down the (imagined) distinction between the private space of the home and the public space outside. The photos the participants took of important objects in their home frequently showed new technologies such as phones and computers. These also played an important role in the improvised scenes. Photos of

books can symbolize both identity and intellectual aspiration. Sharing one's thoughts and receiving positive responses can also take place through books and new technologies.

12. *Spirituality*. Religion or faith can both contribute to and diminish one's sense of safety and belonging. In the Finnish psychiatric context today, however, it is rarely addressed. In our project, religion was manifested both in the interviews and in passing references in the group to religious communities. In the first performance, one participant chose to play a "theologian". Her speech referred to the dual meaning of home in Christianity - heaven as the ultimate home, after life, and the human body as God's dwelling on Earth.

13. *Embodiment*. The body is intrinsically connected to our sense of self. Furthermore, whether we feel at home in our bodies, identify with it or not, as embodied beings we can only relate to the material world through our bodies. The physical aspect of home thus comprises not only the physical building and structure, but the body itself. Certain positions and postures, such as lying on a sofa or the floor, are culturally associated with private spaces and situations. In the rehearsals, we saw a great deal of these postures associated with relaxation and being at ease with ourselves and those around us. Doing nothing or having nothing to do was, however, for many a frustrating aspect of their lives. In their first performance, the participants presented the demand to have not only decent living conditions but also something to do. Home can only become a place for rest if there is somewhere to go in the outside world.

14. *Rhythm*. Home is a space of leaving and return. A space one cannot leave, due to physical or psychological restraint, becomes a prison. Daily routines

and rhythms of coming and going connect the spatiality of home to temporality and embodiment. Depression, for example, can be experienced as feeling out of step with others. In institutional settings it is important to consider whose rhythm is respected and how to reconcile communal functions and individual needs.

15. *Multi-Sensory spaces.* Through sounds, smells and tastes, space also enters us. Auditory hallucinations may invade the soundscape of our minds, and sounds, smells and tastes can help us transcend the spaces our bodies inhabit. Home is often associated with certain foods that are again associated with togetherness. In our performance, one participant associated home with enjoying a steak cooked by his stepmother when he returned from football training.

16. *Language.* Home can be found in language. Language allows us to formulate thoughts and experiences and connect with others. Moreover, through the materiality of its sounds and e.g. prosody it affectively connects us to communities. Rhythm and intonation, social, discursive and dialectal variations, mono- and multilingualism can include or exclude. Through its cultural associations language, or a desire to learn one, can also orient us towards our dreams and desires.

17. *Future.* Home can be conceived of as a space where we orient ourselves towards the future. As recovery has become the expected outcome for most psychiatric conditions, it is important to find ways to explore what counts as home for each of us individually; what will make a place to live that sufficiently supports our agency and being throughout our rehabilitation and recovery. However, many participants found difficult an exercise where

they had to choose pictures cut out from magazines to create their own ideal home.

18. *Autonomy*. Having money and a space of one's own were the two things that Virginia Woolf once defined as essential for women's independence in society. Both are essential for service users' independence as well. At the beginning of the project, keys, doors and thresholds played an important role in the scenes the participants created. An interview revealed that for those living in housing facilities, their rights as residents to decide, for example, if they had to let the staff in, were not always clear.

19. *Economy*. Both national economies and individual circumstances affect where people with psychiatric problems can afford to live. Psychiatric suffering is often accompanied by financial hardship and the encounters with bureaucracy involved in getting housing benefit can significantly contribute to the service users' suffering and lack of agency. Bureaucracies involved in housing benefits are often complex and labour intensive. In our second performance, the national social security office, bureaucratic procedures and endless forms played a significant role. Bureaucratic decisions can be consistent or conflict with rehabilitative needs. In our project, the staff repeatedly recalled an incident where a client, after years of institutionalization, had found somewhere she wanted to live. Paradoxically, however, the apartment did not meet the standards of the welfare office, and despite the staff's efforts, the client had to move to a more modern and expensive flat (!) that, for her, felt less like home.

20. *Architecture*. Apartments, houses, and residential areas are a mesh of architectural trends, socio-economic and political decision-making and the interests of the construction industry. They reflect the family ideologies and

standards of their time; but whether built environments are experienced as alienating or welcoming is affected also by cultural associations, and personal preferences and memories associated with them.

Personal preferences can only be discovered if we keep asking each other and ourselves what constitutes home.

## **Discussion**

Addressing the experience of psychiatric suffering through the notion of home centralizes the humanity of the suffering subject and locates him/her primarily in the context of the home-world. It thus offers a humane approach to experiences that in the current context of increasing medicalization are still imbued with stigmatization and suffering. As a framework, home allows the examination of both the phenomenological orientation and experience as a bodily, spatial and affective relation between a space and its inhabitant(s) and the socio-economic, architectural and bureaucratic structures that shape these experiences. This study addressed this relationship as a culturally, materially, socially, structurally and psychiatrically conditioned form of belonging, and it offers a framework for further exploration of the ways in which different forms of psychiatric suffering are shaped by their local conditions and by individual experiences and desires. To think these issues through the notion of home offers significant tools for understanding the needs and desires of sufferers and can help to enhance both the recovery of service users and housing facilities.

## Acknowledgements

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# Chapter 16. Architecture as a creative practice for improving living conditions and social welfare for Alzheimer's patients

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## **Abstract**

The purpose of this paper is to present a portion of the results obtained over the course of the work carried out as part of the "Designing tailored spaces for the absence of memory", research from the Healthy Architecture & City, Research Team at the University of Seville. The objective of this research is to determine the best physical environment for allowing Alzheimer's patients to carry out their daily life with the greatest possible safety, accessibility and independence. Here we share a variety of international buildings with architectural value that have contributed to the evolution and creation of a new type of arrangement for Alzheimer's patients. The principal contribution of this report is to define the characteristics of this new architectural typology.

**Keywords:** architecture, Alzheimer, health, welfare, humanities.

## **Theoretical background**

During the first half of the 20th century, the majority of Alzheimer's patients were treated at mental hospitals, 45% of these centers contained an area or health care wing focusing on people affected by Alzheimer's. The policy change that took place in the American health care system during the years 1955-1980 caused hospitals to lose 75% of dementia patients to so-called

"nursing homes" and new initiatives were undertaken in the interest of this system (Calkins, 1988).

New studies and research on planning and designing spaces for people with dementia began in 1985, producing manuals by Brawley, 1997; Calkins, 1988; Cohen and Day, 1993; Cohen and Weisman, 1991; Marshall, 2001. This resulted in the creation of architectural solutions designed to improve the physical environment of Alzheimer's patients and the recognition of their ability to directly aid people with dementia (Kristen, Carreon, and Stump, 2000). New specialized equipment has given rise to a new type of architecture as well as a series of architectural practices designed to improve the well-being and quality of life of this group.

## **Objective**

The aim is to demonstrate how the standard hospital model for this type of patient has changed since the advent of the first specialized centre, one that used a purely residential plan, up to the appearance of a new, residential-care model. The new healthcare paradigm has had a very important influence on the form and type of building, architectural practices, as well as on the design of healthy spaces designed for these patients. The objective is to define the characteristics and unique features of this new model for taking care of the needs of people affected by Alzheimer's.

## **Method**

The tool used to carry out this research has been the analysis of buildings designed for Alzheimer's patients. It begins with the first examples that appeared at the end of the 1980s and continues to today. The criteria for

their selection has been that these complexes have been built, contain long-term residential units, and are for exclusive use by this type of patient or contain an independent division in their formal and operational structure. By applying these criteria, we have obtained a sample of 37 complexes, distributed in the following manner: North America (35%), Europe (21%), Oceania Australia (6%) and Asia (3%).

The method used consisted in a comparative observational analysis of these structures, a standard methodology in the field of architecture. By understanding the main buildings and equipment designed for patients with memory problems, their structure and layout, we can obtain data in order to define what a building designed for this purpose must feature and contain. Identification files were created for each complex, including information on the following aspects, assessed and compared through visual representation:

- situation in the context of the site
- number of persons assisted
- surface area and dimension of rooms
- facilities and services provided
- places for social interaction
- places for contact with the outside or natural worlds
- use of materials
- use of light
- inclusion or integration of new technologies

## Results

The methodology that follows determines what elements are shared, as well as the main characteristics of this new typology. The elements that make up this new type of building style are:

### *1. Housing as the basic unit of spatial organization*

The first building, specially designed with Alzheimer's patients in mind, belongs to the Corinne Dolan Alzheimer Center, built in the year 1985 in Heather Hill (Cleveland). It is a rest home (replace with: nursing home) that emerged using a new architectural approach, combining medical care with the goal of determining what environmental and design characteristics would help to keep Alzheimer's patients relaxed, safe, independent, and active for as long as possible (Lewin, 1990). It was built using an organizational model whose main contribution was the elimination of long distances, using concentric hallways leading to the common areas and open spaces visible from the room of each resident each resident's room.

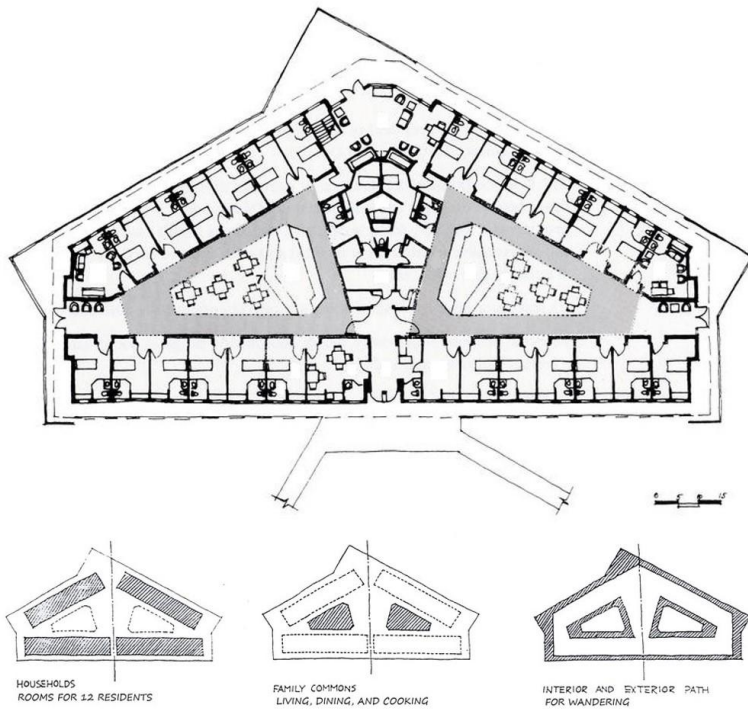


Figure 1. Floor plan and spaces and routes schemes from Corinne Dolan Alzheimer Center, Heather Hill (Cleveland), designed by Taliesin Associated Architects, 1985.

In 1991, the construction of Woodside Place in Pennsylvania led to the most significant advance in the theory of caring for the patient through architecture. The building was designed for 36 residents, using a spatial model that utilizes housing as the core unit of organization. It is a one-story building, made up of three modules, each containing twelve rooms. The floor plan is in the shape of a comb or an "E," with each arm containing one of the modules. The piece that brings everything together is the area where social interaction takes place. This plan proposes an expandable structure, allowing for an increase in the number of modules and the ability to care for any number of residents without neglecting their specific needs.

This complex also innovatively introduced the use of the environment as a therapeutic tool for the resident, proposing that space influences memory, incorporating decoration and the presence of personal furniture that allow patients to recall their homes. Another innovative element is the relationship and connection established by the outside areas, replacing isolation and control of the patient with the ability to spend time in garden areas included as part of the complex.

Many projects with a considerable formal similarity were later based on this model. These are architectural approaches based on creating pleasant spaces and designing a new habitat that counteracts the trauma created by the need to leave one's family home. This is in light of the fact that adjusting to a new location, as well as encountering strangers, may produce adverse reactions and behaviour in the elderly (Anthony, Procter, Silverman, and Murphy 1987).

## ***2. The limited residential scale and location***

The number of residents is an element that directly influences the design of buildings for people with Alzheimer's. Based on the results of research carried out at fifty-three special nursing homes or retirement homes in four states of the USA (Sloane et al., 1998), design guides proposed that units with a small number of residents reduced the over-stimulation of people with dementia, mainly due to control of noise. 73% of the total complexes analyzed in the research sample contained a residential population of less than one hundred people.

The first arrangements follow the North American tendency to live in houses located on extensive areas of land, giving rise to the so-called Green Houses, characterized by their location in rural or suburban areas and

limited number of residents. This is the solution proposed by White Oak Cottages in Colorado (2006), a building in direct contact with nature, outside of any urban areas, in which all the rooms are arranged around a central living area for social interaction.

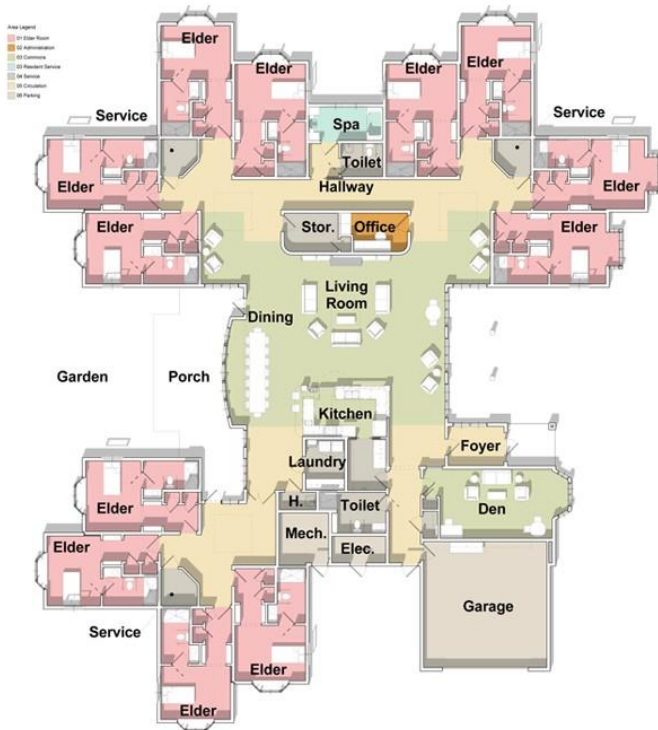


Figure 2. Floor plan of the project White Oak Cottages (Colorado), designed by EG Architects, 2006.

The models developed in North America were also adopted by the rest of the world, especially in Europe. One such example are the projects designed by Feddersen Architekteten, such as the Kompetenzzentrum Demenz in Nuremberg (2006); they are buildings that maintain an operational



organization based on housing as the core units, but which grow in height or generate green spaces within the complexes themselves, due to the fact that there is often a lack of available floor space.

### ***3. Incorporation of care services along with residential ones***

Over the last few decades, the spatial model for the care of dementia patients has undergone diverse structural changes, mainly conditioned by the need to provide spaces that are not only residential, but also include the specific care required by dementia. In this manner, there has been a transition from a purely residential model to a mixed one that includes care services in residential areas equipped to fit a domestic context. This change has been reflected in open architectural structures that contain areas or added modules with services such as areas for medical attention, special care, or sanitary needs. Some complexes also appear in which the architectural structure is a closed space with control over all the patient's daily activities, integrating all the services into daily life.

An example of the former structure is the Reina Sofia Foundation's Alzheimer center in Madrid (2007). It is a complex for 156 residents divided into six modules, each containing areas for care according to the different stages in the evolution of the disease. It also contains research areas, a day center, and a common area. It is located in an urban area, meaning that views to the outside are through interior patios located in each one of the rectangular modules. These elements allow for a space that helps to orientate the residents, incorporating natural light into all of the center's rooms.

The latter structure mentioned is a residential complex that creates a fictitious interior reality with the purpose of offering a living model that

appears normal, incorporating complimentary care and safety services for inhabitants. This is the case of Dementia Village in Hogeweyk (2009) in the Netherlands, a center for 150 residents with 23 housing units, each for six to eight inhabitants. It is an enclosed complex measuring one hectare (2.47 acres), containing an urban environment with supermarkets, pharmacies, shops, etc., with the goal of making the residents feel like they live in a recognizable environment, one that is similar to their original city or neighborhood.



Figure 3. Exterior spaces at Dementia Village complex in Hogeweyk, Wees (Holland), by Molenaar & Bol & VanDillen, 2009.

#### ***4. Integration of new technologies***

The spatial disorientation of these patients is created by the presence of an unrecognizable space, a confusion in regards to the time in which they live, aggravated by the loss of personal identity (Cohen and Weisman, 1991). A simple, clear organizational plan, with environmental information made explicit, helps the resident to properly orient themselves (Passini et al, 1998).

Some of the creative practices employed by architecture allow the patient to recognize spaces, and guide them around the facilities. At Woodside Place Pennsylvania or the Alzheimer's Respite Centre (2011) in Dublin, they use keepsakes, photographs of the rooms, or color coded doors 81% of the projects analyzed include home decoration with the goal of including recognizable elements and providing the patient with the memory of their

residence. Some buildings, such as Abe's Garden (2015) in Nashville, transcend the barrier of housing in order to create an outside space that allows for a landscape reading of the environment in which they have lived, making it possible to maintain a direct link with an environment that is familiar to them.

The most recent building proposals are also examples of contemporary architectural language. This is the case of Établissement d'hébergement pour les personnes âgées dépendantes (2012) in Paris, which includes prefabricated panels on the walls that allow for a dimming of the light according to the time of day or the needs of residents, or the Alzheimer Residence for the "Froyer la Grange" (2014) in Nantes, which innovatively employs exposed concrete and reinterprets the first models of this type, maintaining the same formal design but using a new approach to home decoration.



Figure 4. Interior spaces images from the Alzheimer Residence for the "Froyer la Grange" Center, Nantes (Francia), designed by Mabire Reich, 2014

The integration of new, emerging technologies is another of the most-used architectural practices in these complexes with the purpose of designing an environment that proactively interacts with the Alzheimer's patient. They use automatic mirrors that can turn opaque, or that include tasks, temperatures, times, activities, location sensors or sensors connected to light circuits, and bio-climatic facilities that provide warmth and comfort to the domestic environment. These techniques used in these new care spaces, have an important influence on elements such as the management of stress and anxiety.

## **Discussion**

The evolution of specialized architecture for Alzheimer's patients reflects the change in the model for collective residences. It has gone from one centered around hospital assistance in which the patient is a resident within the organizational structure of the complex to the development of new types of buildings and services, where the care and attention focuses exclusively on this type of patients. This new type of care arrangement is based on a reduced amount of residential space that is appropriately scaled, with a simple and organized layout tailored to the needs, symptoms and requirements of the patients. It incorporates spaces for direct interaction with the physical setting as a key element serving as reference points in time and space.

The basic unit of the layout is the residence, considered the optimal habitat for someone with Alzheimer's, considering that the scale and type of residence serve as a link between the patient and their environment, in addition to maintaining a constant and recognizable number of inhabitants

living together in the same space. The residential space requires personalization that is adapted and adaptable to the particular characteristics of each patient. Different architectural elements are used to achieve this objective: the use of natural light, the organization of space, the use of crossed visuals or warm-coloured materials. The main technique, however, is the integration of new, emerging technologies that can be used to gradually adapt the residence to the progress of the condition.

All the above are creative elements generated and organized by the discipline of architecture in order to provide a solution to the symptomatology and evolution of Alzheimer's disease, improving their quality of life.

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# Chapter 17. Mindfulness and design: creating spaces for well being

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## **Abstract**

What is the relationship between mindfulness therapy and the physical settings in which it is practiced? Mindfulness is defined as “paying attention to what’s happening in the present moment in the mind, body and external environment, with an attitude of curiosity and kindness” (MAPG, 2015: 5), however the qualities of the ‘external environment’ are rarely discussed in relation to mindfulness. As mindfulness based therapies increasingly applied in clinical and educational settings, this presents opportunities to explore how the design of a space – from the arrangement of furniture through to the qualities of a room, building, landscape, or wider spatial context – may influence mindfulness practice and its therapeutic benefits. In this workshop, a combination of research presentation and therapeutic practice was conducted. Literature from landscape architecture and architecture was presented, evidencing the effects of built environment design on mental health and well-being and emphasizing notions of ‘biophilic design’. Delegates were then invited to participate in guided mindfulness meditations, followed by facilitated group enquiry about the combined effects of formal mindfulness practice and the qualities of the physical space we were practicing within.

**Keywords:** mindfulness, built environment, design.

## **Theoretical background**

Increasing human health and wellbeing is an aim shared by mindfulness meditation practitioners and by many built environment designers, providing a potentially rich yet underexplored area for the cross-fertilization of ideas. A rapidly growing body of research is quantifying the effects of mindfulness on wellbeing (Williams and Kabat-Zinn, 2011: 2), including evidence from behavioral medicine, neuroscience and psychology.



Meanwhile, research within landscape architecture, architecture, urban design and environmental psychology illustrates the effects of indoor and outdoor settings on people's wellbeing (CABE, 2009; Landscape Institute, 2013), evidencing correlations between environmental qualities and mind / body responses. Despite these shared concerns, the study of mindfulness, and the study of environments and their design, remain discrete areas of knowledge. In this workshop we aimed to systematically bring this knowledge together by presenting theories about mindfulness and built environment design with a focus on healthcare and biophilic design, and by practicing mindfulness together.

### *Mindfulness*

Much has been written about mindfulness in recent years, and its application in healthcare settings is on the increase. Mindfulness has its origins in Buddhist epistemology, and, within this, the history of Buddhist meditation. It is typically cultivated by a range of meditation practices, which aim to bring a greater awareness of thinking, feeling and behaviour patterns, and to foster compassion. This leads to an expansion of choice and capacity in how to meet and respond to life's challenges, enabling practitioners to live with greater wellbeing, mental clarity and care for themselves and others. Mindfulness based applications as they are known in the West today, including 8 - week Mindfulness Based Stress Reduction (MBSR) and Mindfulness Based Cognitive Therapy (MBCT) courses, were developed within the context of behavioral medicine. Mindfulness is now a recognised therapeutic treatment for various conditions, from anxiety and depression to eating disorders. In 2015 the Mindfulness All-Party Parliamentary Group (MAPG) in the UK set out the efficacy of mindfulness practice in the treatment and prevention of mental illness. This report

focused on mindfulness in a variety of contexts including the health system, the corrections system, education and workplaces. While it recommended the promotion and implementation of quality programs and trainers across these different settings, the report made no mention of the actual physical spaces involved when conducting mindfulness therapies.

Mindfulness literature appears ambivalent toward physical space for a number of reasons. On the one hand, its spatial character may be explained by the inward-looking nature of meditation. Leading authority and developer of MBSR, Jon Kabat-Zinn, states that practitioners need not 'find someplace special to practice' (2004: 24), advising that the potential to mediate mindfully and revel the present moment exists wherever you are. On the other hand, formal mindfulness practices acknowledge and work with the external environment in several ways: When meditating practitioners are typically asked to find a comfortable space where they are unlikely to be disturbed; some practices directly involve noticing the sounds, temperature or light in the room; others involve mindful movement such as walking with a particular attitude or awareness. Historically, Buddhist monasteries created spaces with particular architectural and landscape qualities with the intention of enabling and embodying mindfulness, for example with cloisters for walking and the use of symbolic geometries and objects to focus the mind. Such specific settings have not been transferred to secular mindfulness therapy practice; instead the types of spaces people practice within can be divided into three categories. First, the notion of taking a retreat to a specific place away from usual daily activities forms a part of most mindfulness teacher training programs, taking place in urban or non-urban settings. Second, and most commonly, training for mindfulness takes place in regular meeting rooms or offices,

which may be adapted by the trainer to accommodate activities, for example by rearranging furnishings. This is often the case with hospitals, clinics, prisons, schools, workplaces and so on, where sessions are held in whatever space is available. (This was the case with our workshop, as discussed below.) Finally there are a few examples of contemporary custom designed interiors for mindfulness, where a space is set aside and configured for group or individual meditation. One recent experiment in custom-designed space is the individual 'meditation pod' which Oyler Wu collaborative created for Headspace, a company that designs mindfulness meditation apps and other mindfulness products. The Headspace meditation pod is a small cube-shaped booth manufactured of timber, which allows a user to sit in an intimate enclosed space and access guided mindfulness sessions on an inbuilt screen. Interestingly, the pod is designed to invite privacy while also allowing connection to the surrounding space (wherever the pod may be located), with the intention that 'users will enjoy a calming private space, but one that doesn't exclude the external environment, since sound and atmosphere are such an important tool in meditation' (Headspace, 2016).

### *Designed space and well being*

Despite the different settings in which mindfulness meditation occurs, little work has been done to test whether some spaces work better than others when seeking to attain the benefits of mindfulness therapies. Within the design professions, however, there is a growing interest in theorising, testing and measuring the effect of space and place on people's well being generally. For example, in the UK the Commission for Architecture and the Built Environment (CABE) published the 'Future Health' report in 2009, identifying a combination of physiological influences on environmental comfort for building and landscape occupants. These include thermal

comfort and air movement, acoustics, lighting, personal space (proxemics and territoriality), actual and perceived safety, legibility (being able to find one's way around a space), cognitive stimulation, and biophilia. The latter characteristic, biophilia, is defined as an innate need to connect with living structures in our environment. In 'Biophilia and Healing Environments', Nikos Salingaros (2015) describes eight biophilic qualities which he argues are part of any successful space, namely certain qualities of light, colour, gravity, fractals (patterns), curves, details (at a human scale), and the presence of water and finally life itself (plants and animals).

While such characteristics are deemed beneficial regardless of the type of building or activity, the in relation to the design of healthcare facilities such as hospitals and other clinical settings, where internal and external environments are intentionally designed to enhance the healing process. Hospitals and sanatoria reaching back to ancient Greece were set in natural surroundings, and part of successful medical treatment once typically included time spent in gardens and under trees and accessing fresh air. Modern healthcare based on pharmaceuticals treatments and sanitation tended moved away from those models, and hospitals became complex machines for curing patients, places where biophilia was absent. Therapeutic environments are now being shown to improve user outcomes for staff, family members and patients in terms of physical and mental well being. Roger Ulrich has led the evidence-based study of health care environments, with numerous studies illustrating how views of nature out of hospital windows, natural light, natural sounds and even images of nature (for example in waiting rooms) create 'positive distraction' which in turn reduces stress levels and improves health outcomes. This work has influenced the design of several healthcare environments, notably the

domestically-scaled 'Maggie Centres' now built for cancer patients and their families in locations worldwide (Jencks, 2015). Being directly immersed in multisensory outdoor environments also has the potential to contribute to well being. In the UK the professional body of landscape architects, the Landscape Institute, has published a position statement affirming five principles of healthy landscapes, including the assertion that healthy places are restorative, uplifting and healing for both physical and mental health conditions (Landscape Institute, 2013).

### **Description of the experience / Discussion**

In the workshop a small group of participants with a range of mindfulness experience and professional backgrounds (arts, psychology, and architecture) explored the relationship between mindfulness therapy and the physical settings in which it is practiced. This workshop was an invitation to discuss design and space for health, to experience guided mindfulness practices, and to enter discussions and enquiry following those practices with a focus on our shared experience of mindfulness *in the space we were working in* – a typical seminar room at the Department of Psychology, University of Sevilla (Figure 1). The workshop was lead by Nicole Porter, an academic with a background in architecture. The mindfulness practices themselves were led by trainer Dr Johanna Bramham, who prepared pre-recorded videos of guided meditations for the group to follow.



Figure 1. Seminar room where creative workshop was conducted.

The first ten minute practice, 'ARRIVAL', invited delegates to explore how we were feeling, in the moment, by focusing on our breath and our points of physical contact with the floor and chairs. This exercise was primarily about connecting to oneself. After this practice participants generally agreed we felt an increased awareness of own thoughts, and awareness of bodily sensations and posture. The exercise was generally perceived as being calming and relaxing. One participant with a background in psychology and no experience of mindfulness observed a similarity with gestalt theory and therapy, insofar as both encourage present-moment holistic awareness.

A follow up exercise involved considering the seminar room layout before offering the opportunity to modify it to create our optimal environmental setting. We were already seated in a semi-circular layout which allowed us to directly engage with each other through eye contact, while being generally oriented toward the front of the room where the audio-visual

presentation was being screened (this configuration was arranged by artists conducting a prior creative workshop session). It was collectively decided that this layout was already suitable for group meditation and discussion, noting that if the room had been in a lecture format, for example, we would have changed it.

The second practice focused on 'SOUNDS' in the room, inviting us to connect to ourselves and our environment. Ambient sounds in the room and building are out of anyone's control, and as the practice was pre-recorded there was not scope to respond to immediate sounds as part of the guidance, only in discussion afterwards. As it happened that day, the room had a noticeable white noise / buzz from the AV equipment which was noted by all, mostly with discomfort. It was noted by participants that this environmental noise, and others nearby such as people walking past etc, were not noticeable until attention was drawn to them through mediation. The potential for sounds to be helpful as well as distracting was discussed. This led to a general comparison of the current seminar space with some of the biophilic examples shown in the preceding 'theory' presentation.

A third practice, 'MOVEMENT' was planned to take place outdoors, taking the opportunity to leave the windowless room and go to a leafy sunny courtyard, where participants would have walked silently with the intention of connecting to themselves, the outdoor environment and (through negotiating movement through shared space) connecting with each other. Unfortunately due to time limitations this final practice did not take place, but the principle of walking and practising outdoors was discussed and endorsed by participants.

Final discussions highlighted two main considerations for mindfulness spaces. First are the pragmatic concerns associated with conducting a group meditation activity, ensuring basic functional needs are met such as having adequate room and an element of privacy from external activities. Secondary 'optional' spatial qualities, where biophilic design or other therapeutic qualities may promote well-being, are preferable but not essential for mindfulness to work. In short, space will support but not guarantee mindfulness. As noted with regard to other forms of health care, inadequate space makes it more difficult to attain a truly healing environment, although the elements of the caregiver and the care provided are even more critical than the physical place or space (Kreitzer & Zborowsky, 2013). In this case it was interesting to note that having a pre-recording of Dr Bramham was itself a limiting factor, as the ability to connect directly with the guide (the care giver) in a shared physical space was missing from this workshop. Given the widespread use of self-guided mindfulness programs and technologies, as well as the emphasis given to interrelationships and direct human connections and narratives which were raised throughout this conference, this is also an issue worthy of further exploration.

In summary, the workshop fruitfully explored the extent to which designed spaces can encourage connectedness – both to our surroundings and to each other. There is scope for the future application of mindfulness in a variety of settings, as already acknowledged in healthcare policy. As mindfulness based wellbeing programs are increasingly applied in diverse clinical settings, this presents opportunities to explore how the qualities of space – from the arrangement of furniture through to the design and layout of a room, building, landscape, or wider spatial context – may influence



mindfulness practice and its therapeutic benefits. In a time when mindfulness evidence-based therapies are being promoted and practiced in a range of institutional and professional contexts, the question of *where* such practices take place is significant for built environment designers and other creative practitioners, as well as healthcare professionals.

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## **Section 5. Art, coping with illness & aging**

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## Chapter 18. Community projects based on Art & Health: A collaboration between the Faculty of Fine Arts at the Complutense University of Madrid and Madrid city council's *Madrid Salud* Service

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### Abstract

In 2011 the Faculty of Fine Arts at the Complutense University of Madrid, and Madrid City Council's Health Promotion and Prevention Service (*Madrid Salud* Service) signed a collaboration agreement for developing joint projects and activities. This mutual collaboration agreement has generated an extremely active working network, in which university students supported by health service professionals plus Faculty academics and researchers have designed, and developed, community projects based on art and health with a number of groups (children, adolescents, women at risk, people with diversity, etc.). Across all these projects, both artistic creativity and art education have worked as mediators to offer significant experiences in promoting health.

These arts programs (painting, drawing, photography, textiles, dialogues, and art appreciation) have been designed and developed by students for these communities and groups. These community projects based on art and health emphasise the capacity for commitment and collaboration of the groups and communities involved. Students and participants create together and in an atmosphere of trust, with

awareness of their abilities and of the importance of art as a tool for changing their realities, in other words, as a tool for social transformation.

**Keywords:**community project, art, health, education.

## Theoretical background

The relationship between art and health has always existed, and has been very varied and complex, from art as an instrument for representing the healthy body and the diseased body, through to art as alternative therapy for the mentally sick and the use of well-known pictures and murals for decorating hospitals.

However, since the mid-20th century this relationship has been changing. This change has come at a time when art has begun experimenting in spaces and spheres where it was not normally seen up to now, enabling it to come up with arts projects linked to social contexts (public art, action art, participative art, etc.), thereby becoming a vehicle for interpreting and changing human and social reality. Similarly, the concept of health has also broadened to occupy a special place not only in the individual realm of the person but in their social realm too. It is this social realm that is shared by both fields, that of art and that of health, where interactions have been occurring in recent years. One of the keys to understand interactions in this social realm lies in the concept of *community project*. This concept shared by art and health enables us to gain an understanding of the meaning of the actions described in this text, carried out by two institutions that on the face of it seem to be so dissimilar, namely a Fine Arts Faculty and a health promotion and prevention service, *Madrid Salud Service*.

*Community based art projects have been described as “art in other places”, this means that art has left the museum to enter communities*

*and social institutions where it can have a direct and positive impact on people's lives, from the most personal aspects to the most political spheres of social life. (De Nobriga and Schwarzman, 1999).*

In other words, the community project has taken on the guise of the possibility of art to leave its legitimate space (the *museum*) and get out into social reality, but it also has the ability to influence social change:

*Art is a transformative practice that arises from people's struggles to make sense of the world. Art is a language and a form in which people express their deepest needs and beliefs, and in doing so, art lives for them. It is not something put in a building for which you pay to get a glimpse, but do not even receive an explanation. It is the set of practices concerning people's life choices. (Bains and Mesa-Brains, 2002, p. 193).*

However, having briefly described the approaches to the concept of *community project* from an artistic point of view, we should also include the specific definition given by the health promotion and community health sphere, for the interactions described above to be valid. According to the Ottawa Charter for Health Promotion (1986),

*Health promotion is the process of enabling people to increase control over, and to improve, their health. To reach a state of complete physical, mental and social well-being, an individual or group must be able to identify and to realize aspirations, to satisfy needs, and to change or cope with the environment. Community health is a care model aimed at empowering the population of a territory and takes into account the social and cultural context of the community and its risks and opportunities for health.*

This means, then, that the community project understood from a health point of view also implies social change.



## Method / Description of the experience

In 2011 *Madrid Salud* Service, run by Madrid City Council, signed a collaboration agreement with the Faculty of Fine Arts at the Complutense University of Madrid. Along these same theoretical lines, and with a view to working jointly in the area of Health Promotion and Prevention linked to Art, the job of *Madrid Salud* Service is to manage Madrid City Council municipal policy on Public Health Promotion and Prevention in the city of Madrid. They work in spheres such as improving environmental health, promoting healthy habits, and the integrated care of people with addictions. They do this work in the city's 16 health promotion and prevention centres (one for each district in the capital: Villaverde, Vallecas, Usera, Carabanchel, Hortaleza, etc.), and single purpose centres (cognitive decline, healthy habits).

The collaboration agreement signed between the Faculty of Fine Arts and this service was basically aimed at providing technical advice and putting in place art and health projects and practices, and was formalised in the following three kinds of collaborations:

1. Design, execution and evaluation of artistic creativity workshops in collaboration with *Madrid Salud* Promotion and Prevention Centres programmes.
2. Practical experience and tutoring for students on courses taught in the Faculty of Fine Arts (Degree, Master's, PhD, etc.).
3. Mutual technical advice and, if applicable, collaboration in any activities and projects on community health, health promotion and artistic expression that both sides may be interested in.

This collaboration generated a framework of action in which academics, researchers, health promotion professionals started working together on designing and developing community projects in the city of Madrid, in which health promotion and prevention, and the arts have converged. What this paper aims to describe is how interactions between these two institutions and all the agents involved have been made possible in terms of practice. To do this, four objectives have been set:

- To define artistic creativity, specifically art and visual creation, as a tool for use in health promotion, and prevention projects.
- To involve students studying on fine arts courses in social projects with real groups.
- To involve various social agents in community health projects.
- To reflect on the sustainability of this kind of project in the city of Madrid.

The first objective was achieved during the first year through working meetings, pilot experiences and collaboration groups made up of academics and researchers based at the Faculty of Fine Arts, and professionals from the Health Promotion and Prevention Service at *Madrid Salud* (Ávila et al, 2014). An area of common ground had to be identified in which the interests of all the professionals involved could converge, and the viability of these projects could be assessed with real groups (Segura, 2013). The first objective came out of this first phase, to define artistic creativity, specifically art and visual creation, as a tool for use in health promotion and prevention projects.

Once this objective had been defined and the potential of art in these health promotion and prevention contexts had been assessed, it was deemed

necessary to involve the various agents that would make this collaboration possible, leading to the following two objectives: To involve students studying on fine arts courses in social projects with real groups and, to involve various social agents in community health projects.

Involving students in this type of project was not a complex task bearing in mind the new Degree and Master's course structures, which enable university students to undertake the practical side of their academic studies in institutions that work together with the university. These practical placements have meant that in the last four years, more than thirty students (Degree and Master's) have worked on this kind of project in centres run by the *Madrid Salud* Health Promotion and Prevention Service.

Likewise, involving different social agents in these sorts of projects was made possible by making use of the collaborative network. The network of collaboration built through these projects is perhaps one of the most interesting objectives achieved, namely that the Faculty of Fine Arts would enable contacts to be made with museums and cultural institutions in the city of Madrid. This includes the following museums: Thyssen Museum, the National Museum of Romanticism, the national Museum of Decorative Arts, the Cerralbo Museum, the Lázaro Galdiano Museum, the National Museum of Anthropology, and the independent body *Madrid Salud*, with the network of associations with whom it normally works (the Tomillo Foundation's SEPI Prevention and Insertion Service, the Romí Sersení Association of Spanish Gypsy Women, ADISLI, etc.). This amalgam of cultural, social, and health agents have worked jointly on citizen participation projects, as can be seen in the Results section, as well as encouraging discussion between agents who had not previously interacted with each other (students, professors, art educators, health professionals, museums, and more).

Lastly, once these objectives have been achieved, it is essential to reflect on the sustainability of a collaboration of this kind by addressing this last objective, which is set out in the discussion section of this paper.

Developing these projects requires a huge coordination and cooperation effort between the two institutions involved and all the collaborating agents working in them, as can be seen in the following section. As pointed out in the description of the second objective, one of the advantages of incorporating university students as creators and executors of this type of project, as part of their practical placements, is the possibility of including an academic tutor (in this case from the Faculty of Fine Arts) and a placements manager (a professional from *Madrid Salud*). This structure has driven the projects and enabled them to be run taking several aspects into account at the same time, as well as facilitating a highly productive interdisciplinary dialogue (Ávila et al, 2016). Dialogues have focused on *health promotion and prevention aspects* (responding to the objectives of the *Madrid Salud* Health Promotion and Prevention Service), on *artistic aspects* (responding to students' creative and artistic interests), and on *social and community aspects* (responding to the needs of the groups and individuals taking part in the projects). Finally, we had a discussion around *academic and research aspects* that enabled monitoring reports to be produced, and projects to be documented, which students have been able to use as academic and research material.

## Results

The results obtained over the course of the last five years can be found on a special website produced jointly by both institutions:

<https://www.ucm.es/artesaludproyectos/>. This electronic resource contains the summaries and articles, publications and activities arising out of all the community projects based on art and health, as well as input from all the agents involved in each one of them.

## Discussion

Considering art as a tool for effecting social change through community projects seems to be a reality, confirmed by what has been achieved over more than 5 years of collaboration between these two institutions. The collaboration between the Faculty of Fine Arts at the Complutense University of Madrid and Madrid City Council's *Madrid Salud* Service has put in place a whole network of potential collaboration, in which cultural and arts agents, social agents, and health professionals, have been able to actively take part in *community projects based on art and health*, in which participants have shared experiences, time and knowledge. In all these projects, art has been a catalyst, a generator of experiences very different to those available in the normal social lives of many participants (access to cultural life in Madrid, museum visits, taking part in workshops on artistic techniques, dialogue through art, and so on).

We can find community projects based on art all around the world. *InspireArt*, for example, is a network dedicated to increasing awareness about community and activist art initiatives in Montreal, using creative expression to build healthy communities. The *National Endowment for the Arts* (in United States) is an independent agency that funds, promotes, and strengthens the creative capacity of communities by providing all the people with diverse opportunities for arts participation. And *Community Arts Network* (CAN) Project (in United State too) promotes art made as a voice

and a force within a specific community of place, spirit or tradition. But what undoubtedly makes these kinds of community projects meaningful is that the impetus or driving force comes not only from the university or from the cultural or health institutions, but also from the community actually taking part in the projects, from the group of people and individuals who form part of them and participate in them.

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# Chapter 19. *Tenemos cita con el arte*: a pilot project of visits and workshops with people affected by Alzheimer's disease in the Prado Museum, the Centro de Arte Reina Sofía Museum and the Faculty of Fine Arts at the Complutense University of Madrid

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## Abstract

GIMUPAI is a research group comprising teachers and researchers from the Faculty of Fine Arts (University Complutense of Madrid) and the Department of Social Psychology and Anthropology (Salamanca University) who have been working in art and health projects over the last thirteen years. Recently, we have carried out *Tenemos cita con el arte*, part of a national research project entitled "Art education in museums and other cultural institutions as a tool for increasing the wellbeing of people affected with Alzheimer" (Ministry of the Economy and Competitiveness-EDU2013-43253-R). The main objective of the program is to make the museum's artworks available to people with Alzheimer's and their caregivers, at the same time encouraging them to participate in artistic activities and artistic creation through art workshops. *Tenemos cita con el arte* has been designed as a program of visits of the Prado Museum and the Centro de Arte Reina Sofia Museum. The program also has included participation in workshops on visual arts and artistic creativity in the Faculty of Fine Arts. The program was undertaken between October and December 2015 with a group of 15 participants (Alzheimer's patients, caregivers, and other health and social workers).

**Keywords:** Alzheimer, dementia, art, museum, wellbeing.



## Theoretical background

Looking after the needs of people with dependencies is one of the great challenges for social policy in Spain. This circumstance is the result of the huge progress made by medicine over recent years, together with the combination of other demographic and social factors that have resulted in an ageing population. Against this background, this project falls into the European research and innovation framework of *Horizon 2020*, specifically the *Health, Demographic Change and Welfare* action plans, in which one of the main challenges is lifelong health and welfare for all. The approval of this national project, “Art education in museums and other cultural institutions as a tool for increasing the wellbeing of people affected with Alzheimer's” (Ministry of the Economy and Competitiveness-EDU2013-43253-R), implies the need and the priority that should be given to art and arts education in a society that is ageing but must prepare for an active and participative ageing process. In this context, it is a fact that there is a need to come up with meaningful experiences and alternative leisure and cultural programmes. The overall aim of this research project is to assess the ability of art education to be a resource for the wellbeing of people with early dementia, by designing and implementing arts activities in museums and cultural institutions. The specific objectives of the project are described below:

1. To ascertain the degree to which wellbeing is produced in people with early dementia by carrying out activities related to contemporary art within the specific context of museums and/or cultural institutions. To assess patients' level of connection with social reality and relationship with their surroundings, the extent of their sense of personal achievement and improvements in their cognitive and memory skills.

2. To assess the methodological advantages of the pedagogical model to be used to implement the activities to be undertaken with the sample and in the contexts described, evaluating the advantages of a collaborative pedagogical model that encourages creativity and involves the creation of knowledge.

3. To assess the benefits that the context of application (museums and cultural centres) provides for the two previous objectives, depending on patients' level of connection with social reality and relationship with their surroundings and on their degree of social acceptance.

This paper describes work carried out to date by the research team. This work has focused on collecting and reviewing similar projects both in Spain and abroad, briefly described below and in the set of papers on *Arte y Demencia* (Art and Dementia) in the academic journal of the Complutense University of Madrid, *Arte, Individuo y Sociedad*, to be published in 2017. The papers give an account of the most recent experiences on the project as well as interviews with a number of professionals involved in the study. The monographic also describes the design of *Tenemos cita con el arte*, a pilot programme of museum tours and creative arts workshops that aim to promote an artistic experience that can be shared by the people taking part and their caregivers.

In Spain, the inclusion of people with early onset dementia in the museum context has focused mainly on integrating these participants in activities along the lines of the ones being run by MoMA in New York since 2006. The New York Museum of Modern Art (MoMA) was one of the first museums to provide programmes aimed at improving access to the collection for people with Alzheimer's and their caregivers. The first programme was called *Meet me at MoMA* (Rosenberg, 2009) and offered work areas, an exhibition of the

museum's major works and discussion forums for evaluating, improving, sharing experiences and increasing both the museum's and society's understanding of the disease. The museum became a tool for better treatment of the disease, providing affection and understanding, for people in the early and intermediate stages of the disease, their caregivers and their families. The programme was a huge success and led to the MoMA Alzheimer's Project, which together with the MetLife Foundation is now in charge of devising resources such as publications, websites, lectures and study areas for people with the disease and to improve understanding of it. *Memories in the Making* developed in Cincinnati (Kinney & Rentz, 2005), and *Visiting the museum together* (McGuigan, Legget & Horsburgh 2015) set up by the Auckland Museum in New Zealand, have also served as precedents for producing the design protocol for the *Tenemos cita con el arte* programme. Other experiences carried out in Spain and which are shaping an interesting panorama of action over the last few years are the following:

In 2002 La Caixa Foundation developed a programme for Alzheimer's and other neurodegenerative diseases, aimed at promoting research, training and raising awareness of the condition. The programme included an interesting guide for patients and their caregivers, entitled *Recordar en los museos* whose purpose was to encourage Alzheimer's disease patients to remember their childhood and youth by stimulating their memory with a museum visit.

In 2006, the Xunta de Galicia regional government launched an initiative for using cultural heritage as a therapeutic resource for improving quality of life for patients and their families. This initiative, called *Lembrar no museo*, involved participants recreating their life history by making murals with themes based on tours of the Ethnological Museum in Ribadavia, the Museo

da Escola y de la Infancia (School and Childhood Museum) in Pobra de Trives and the Museo do Xoguete (Toy Museum) in Allariz.

In 2009, the Museum of Fine Arts in Murcia ran the Alzheimer's Project in the Museum of Fine Arts in partnership with the Alzheimer Foundation, the Caja Murcia Foundation and Murcia City Council.

In 2010, equally inspired by the MoMA experience, the CCCB (Contemporary Cultural Centre of Barcelona) also ran its own programme. Madrid's Thyssen Bornemisza Museum signed a collaboration agreement with Nintendo Spain to act as art education advisers for one of the company's new educational products: *Art Academy*. The project explored the potential of both the programme and the consoles for working with people with diversity, especially in terms of cognitive stimulation and psychomotor training for people with Alzheimer's disease. The Prado Museum, with its *El Prado para todos* programme, is undoubtedly at the forefront of this type of project, available to associations and centres working on inclusion issues with these groups. In addition to these initiatives, a number of other actions have also been carried out, such as the *Mental Health Days* at MUSAC in León; the *Memory Workshop* at the Picasso Museum in Malaga; the *Reminiscences. Art and Culture against Alzheimer's* project at MACA in Alicante; the *Art and Memory* workshop project at Sala Rekalde in Bilbao and the *Album of Life* project run by Visiona in Huesca.

### **Method / Description of the experience**

As this paper describes a pilot programme, it does not give a detailed description of the four museum visits (two visits of the Prado Museum and two of the Reina Sofía Museum) or a detailed account of the four artistic

creativity workshops. Instead, it provides a table with guidelines that serve as a protocol or guide, enabling the programme to be reproduced and tested.

In terms of the first protocol (designing the museum visits), the previously described experiences and recommendations have been taken into account but adapted to two specific museums, the Prado and the Reina Sofía

Table 1. Protocol for museum visit *Tenemos cita con el arte*

Items	Description
Works selected	5-6
Duration of the visit	Approximately 1 hour 30 minutes
Number of participants	10-12 (people affected by Alzheimer's and other dementias, caregivers and health professionals)
Educators	2 leading educators to present the works in two groups of 5-6 participants each 2 support educators to accompany the discussion in pairs or in small groups of 3
Schedule	Meeting point, welcome and general presentation of the visit Guided visit of the works following the pattern of a brief presentation and dialogue in accompanied pairs or small groups End of visit and farewells

List of works selected:

Prado Museum, tour 1:

1. *Las Meninas*. Velázquez, 1656
2. *Baltasar Carlos*. Velázquez, 1635
3. *The Spinners*. Velázquez, 1655 – 1660
4. *Apollo in the Forge of Vulcan*. Velázquez, 1630
5. *The Drinkers*. Velázquez, 1628 – 1629

Prado Museum, tour 2:

1. *The family of Carlos IV*. Goya, 1800
2. *The Clothed Maja*. Goya, 1800 – 1808
3. *The Naked Maja*. Goya, before 1800
4. *The Grape Harvest*. Goya, 1786
5. *The Kite*. Goya, 1777 – 1778
6. *The Parasol*. Goya, 1777

Reina Sofía Museum, tour 1:

1. *Girl at the Window*. Salvador Dalí, 1925
2. *Sailor with Guitar* (sculpture). Jacques Lipchitz, 1917
3. *Portrait of Josette Gris*. Juan Gris, 1916
4. *La bouteille d'anis*. Juan Gris, 1927
5. *Le moulin à café*. Juan Gris, 1920
6. *La fenêtre ouverte*. Juan Gris, 1921

Reina Sofía Museum, tour 2:

1. *Triadic Ballet*. Oskar Schlemmer, 1922
2. *Girondelle*. Miró, 1937
3. *Escargot, femme, fleur, étoile*. Miró, 1934

4. *Portrait*. Miró, 1938
5. *Tête de Femme (I, II, III, IV)*. Picasso, 1937
6. *Guernica*. Picasso, 1937

In respect of the second protocol, referring to the analysis and selection of activities and creative art tasks, attention was paid to leading studies in the field that discuss the positive effects gained from creative and artistic activities and processes (Camic, Tischler & Pearman, 2014). Previous experience gained by the research team was also invaluable, especially with activities carried out in the *Centro de Referencia Estatal de Atención a Personas con Enfermedad de Alzheimer y otras Demencias* (CRE Alzheimer) in Salamanca, using techniques such as collage, photo collage and cyanotype (Ullán, 2012; López Mendez, 2015).

Each workshop was based on participants producing their own work based on the dialogue with the original artworks during the museum visits. Although the four workshops undertaken in the pilot programme *Tenemos cita con el arte* did not offer a wide range of possibilities in terms of the techniques used, they did allow the focus to be centred on two in particular (cyanotype and collage), enabling the team to pinpoint and list the guidelines that any artistic technique should provide in a context and with participants with these characteristics. A detailed version of this list will be included in the article to be published in the monograph mentioned earlier.

Table 2. Protocol for *Tenemos cita con el arte* creative art workshops

Items	Description
Techniques selected	Collage Cyanotype
Workshop duration	Approximately 2 hours
Number of participants	10-12 (people affected by Alzheimer's and other dementias, caregivers and centre professionals)
Educators	1 leading educator to present the creative art task 2-3 support educators to accompany the creative process
Schedule	Welcome and reception Virtual tour of the works selected on the previous tour Presentation of the creative art task Individual work on the creative art task Sharing work produced Farewells

## Results

The artistic experience, whether it involves observing, discussing or making art, triggers intellectual and emotional stimuli to which people with dementia are more than capable of responding (Camic, Tischler & Pearman, 2014). Studies on people affected by Alzheimer's and other dementias taking part in artistic and creative activities and tasks have shown that they have both a social impact (in the way they



relate to others, to caregivers and in terms of interaction with the group) and an impact on certain cognitive skills (concentration, memory, persistence with the task and commitment to it, decision taking) and affective skills (pride in the results, pleasure, fun, etc.). Both in the visits and in the workshops, art becomes a perfect vehicle for personal expression and exchange of impressions. For the caregivers it also provides an opportunity for exploring their own artistic interests together with their relative in a setting where they can interact with other caregivers and feel supported. Undertaking a shared cultural activity improves communication and connection between the caregiver and the person with Alzheimer's. It places them both in a context that is different than their usual one to carry out a cultural and creative activity that could turn out to be interesting for any adult person. The pilot programme *Tenemos cita con el arte*, has produced results that emphasise the importance and positive outcomes of these experiences.

## Discussion

The awarding of this nationwide project implies the need and the priority that art and education should have in a society that is ageing but that must prepare for an active and participative ageing process. In view of this, it is undoubtedly our responsibility, as cultural agents and as a university research group, to investigate how to come up with meaningful experiences with this group of people and to assess alternative leisure and cultural programmes. With the cultural and artistic resources to hand, investment

needs to be made in the human resources (artists and educators) who can contribute new perspectives and views on this active ageing process, working with the idea of achieving wellbeing by ensuring cultural and artistic participation in the community (Ávila et al, 2016). Within the framework of wide-ranging research, the programme *Tenemos cita con el arte* seeks to be an accessible resource that is available to the community at large, replicable by any of the participants and professionals involved in the task of ensuring a healthy and active ageing process.

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## Chapter 20. *Tenemos cita con el arte*: visiting art museums with people living with Alzheimer's disease and their caregivers

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### **Abstract**

GIMUPAI is a research group constituted by teachers and researchers of the Faculty of Fine Arts (Complutense University of Madrid) and the Department of Social Psychology and Anthropology (Salamanca University). In answering to the growing necessity of developing museum programs for people living with Alzheimer's disease, we have designed, implemented and evaluated a set of museum visits and workshops under the name “Tenemos cita con el arte”. This initiative is part of the Spanish state-funded research project entitled “Art education un museums and other cultural institutions as a tool for increasing the wellbeing of people affected with Alzheimer” (Ministerio de Educación-EDU2013-43253-R). With this program we aim at making the museum accessible to people with Alzheimer and their caregivers. In doing so, we analyze the difficulties that a group of this characteristics encounters. This text offers an in-depth view of the museum itineraries carried out during the visits to the Museo del Prado and the Museo Nacional Centro de Arte Reina Sofia in Madrid. It includes information on the specific aims, methodology, contents, challenges and difficulties encountered while accompanying a group of people suffering from Alzheimer's disease and their caregivers to a museum setting.

**Key words:** Alzheimer, museum, education, art, itinerary.

### **Theoretical background**

This project is framed in the pedagogical philosophy of Social Reconstructionism that emphasizes the addressing of social questions in a quest to create a better society. In this case, this project addresses the situation of people living with Alzheimer's disease and their caregivers. We

analyse the potential for improving their wellbeing while visiting art museums. Social Reconstructionism as a philosophy has been applied to many fields of study. In the case of this project two fields are involved mainly: museum education and psychology.

In the field of museum education we find a reference from the beginnings of the profession that describes the work of the educator (formerly called “docent”) not “as guidance, but companionship “(Gilman, 1912, p.82). This early idea of being sensitive to the visitor’s interests and needs rather than the museum’s discourse has inspired this project. Developing a conducive atmosphere in which there is a free exchange of ideas based on the works of art guides the experience. In terms of the purposes of the interaction with the artwork, we find in art appreciation the approach that informs this project best. Art appreciation is the knowledge and understanding of the universal and timeless qualities that identify all great art. The more you appreciate and understand the art of different eras, movements, styles and techniques, the better you can develop, evaluate, and improve your own work. The creative potential of the participants in this project is enhanced by this approach to art education.

The aim of this project is improving the wellbeing of the participants: people living with dementia and their caregivers. To that end, this project studies the psychological needs of the participants that take part in the activities. So as to do that, Kitwood’s (1997) people-centered approach to dementia provides the key concepts to take into account when understanding people with dementia’s psychological needs: attachment, comfort, identity, occupation, inclusion, and love.

Attachment and connections are concepts applied in this project to make the participants feel part of the learning community constituted when visiting the museum together. Inclusion is manifested when making sure that the participant feels part of the group. Occupation when going to the museum and making a personal creative object produce a sentiment of personal value and purpose in life. Being in front of a work of art and analysing it also encourages a reflection on the identity of each participant. The idea of comfort is present in this project when designing the itineraries so as to answer to the need of freedom to move and have a bond with others. Finally, the core idea that boosts the activity carried out in this project is the sentiment of love throughout the whole design, implementation and evaluation of the project. In the following sections, we describe the experience, results and discussion in detail.

### **Method / Description of the experience**

The two-month program “Tenemos cita con el arte” has been developed through the elaboration of two “protocols”. The first one has been focused on the design and execution of guided and commented visits at Prado and Reina Sofía Museums. The two itineraries in the Prado Museum were dedicated to Velázquez and Goya respectively, while the two itineraries in Reina Sofía Museum were oriented to explain a group of modern artists from the 20th Century such as Picasso, Miró, Dalí or Juan Gris (1). These visits were designed in order to offer the participants a complete and deep experience with the artworks. This allowed them to have a wide and satisfactory vision of the artists included in the visit, their culture and ideas, as well as a personal experience with art pieces. Also the accessibility of the

places where the works were exhibited was taken into account so as to ensure the comfort of the participants.

From 5 to 6 artworks were selected in each visit. Each was discussed for ten or 15 minutes, making the tour last for approximately one hour and a half. Two educators had the main role in leading the conversation around the artworks. Each party consisted of two groups of five or six participants. However, there were four to five educators (depending on the availability) that acted as support by walking with the participants, taking part in the talks and creating more personalized dialogues between all the participants. The idea that these visits had a warm and friendly nature has been essential to get an enjoyable experience for both the people affected with Alzheimer and their caregivers. That is why we have worked in creating a likable and relaxing atmosphere that invited every participant to engage in creative and unique dialogue while expressing their personal opinions and experiences.

The second protocol of the project has consisted in designing and developing four workshops based on their corresponding visits in the museums. The duration of the workshops was also approximately one hour and a half. Each session started with a presentation of the artworks we visited the previous week in the museum to remember all together, both the artworks we saw and the conversations we had, the impressions we shared and the common experience at the museum. Once the presentation was done, the educators explained the participants how the artistic proposal they were going to do was, having always the images of the museum's visit as a central element. The artistic techniques that have been used in the workshops were mainly cyanotype and collages. The reason behind this choice is the suitability for developing their own creative work, making it

easier for them to maintain the attention on it and also allowing them to explain the process to the fellow participants.

During the workshops, the educators acted again as companions whose main goal was to create a good atmosphere and integrate all of the participants in the activity. All the participants created their own work, being able to make personal decisions based on their own opinions and tastes, but also having the possibility of sharing their experiences with the rest, producing a common involvement that emphasizes the collaborative character of creation.

## **Results**

The experience of approaching art is always connected to emotions, memories and reflections. Art represents the perfect vehicle for dialogue and interaction with other people. Observing, commenting, and creating, encourage both intellectual and emotional experiences in everybody.

This program has been quite successful for all: caregivers, people living with dementia and educators. Connecting people with art in a cultural activity at a museum setting has been engaging and interesting to the whole group. This has motivated opinions, aesthetic appreciations, memories and personal experiences. The fact alone of visiting a museum in a shared experience with a loved one or companion has meant a turning point in the daily routine in the immense majority of the cases. As it was pointed out to us by the participants, this activity's value lies in that it works beyond the person's limitations and understands individuals as creative beings. Carrying out this activity with a family member or trusted person means



enjoying a normalized and cultural activity in which all participants have enjoyed observing, commenting and creating.

A conducive atmosphere and an open and respectful environment has been favoured. Implementing the itinerary at the museum in small groups has enhanced communication and interaction amongst the participants.

Contemplating the authentic works of art has given the participant the chance to develop the emotions that that involves, both to those who had already seen the pieces and those that saw them for the first time at the museum. The meaning of this encounter became stronger considering that these pieces are part of our collective memory.

For the family members the fact that they could enjoy a shared cultural activity has been highly valued. We had the chance to observe the support and empathy developed amongst the caregivers. We created a safe space for sharing the emotions involved in living with the disease.

All participants were grateful and showed satisfaction when finishing the activity. In the case of the museum visits, some participants decided to go on with the visit once the tour was over. It was expressed that the feeling of seeing the art pieces over and over again gave them joy and excitement to go on seeing other works of art in the following sessions.

During the workshops in which art making inspired by what had been seen at the museum was the purpose. The easy-going environment helped in having a joyful mood, sharing personal experiences, jokes and different views on the works of art. Many family members shared the process of creating the artwork. This produced situations in which all parts were involved in collaboration towards a common goal: the artwork itself.

The last session was the most important in assessing the results of the experience. Each participant explained and showed their creations to rest of the group for the recognition of the collective work. Participants valued the experience in general considering it a success. With enthusiasm and emotion it was pointed out that the fact that all participants could spend time with their family members and caregivers in an activity that all of them could enjoy and in which all of them had learnt new things, established relationships and tighten bonds with their family members and people of their trust.

Most of the participants expressed their wish of returning to the program in a future edition given that the experience was considered valuable and important for their mood and well-being.

## **Discussion**

Due to the increasing ageing of the global population, the illness of Alzheimer and other kinds of dementia will have more and more importance in the social and health issues we will face in the future. Creating programs that help people with this disease and their caregivers to be integrated in the cultural life of their societies is a key part to help solving the problems of isolation they cope with in most cases. The “Tenemos Cita con el Arte” program offers them the possibility to participate in activities that not only help them to develop their creativity, giving value to their ideas, opinions and tastes but also make them part of a cultural heritage that belongs to all citizens.

The principal aim of these programs is to prevent the isolation of people with this disease and fight against the situation in which their illness means that they don't feel invited to participate in the cultural life.

During the activities, these participants enjoy talking with other people such as the caregivers and the educators. This allowed them to feel in a natural situation, fading their role of "patients" and being just participants of cultural activities of their community. The time they spend socializing and making activities has been demonstrated as beneficial for their state of mind diminishes the feeling of being segregated from the society (Ullán, 2012). That is why we believe in the relevance of the application of this kind of programs. Given the flexibility these programs have been created with, they can be applied in different situations and contexts using the particular cultural heritage and adapting the itineraries, visits and workshops.

Finally, based on our results and on other pieces of research about the same theme (Rosenberg, 2009, Kinney and Rentz, 2005, McGuigan, Legget, and Horsburgh 2015), our conclusion is that these projects can improve considerably the life of the people living with Alzheimer disease and make easier their inclusion in society and their enjoyment of the public cultural heritage.

## Notes

List of artworks visited in the itineraries:

Prado Museum, tour 1:

1. *Las Meninas*. Velázquez, 1656
2. *Baltasar Carlos*. Velázquez, 1635

3. *The Spinners*. Velázquez, 1655 – 1660
4. *Apollo in the Forge of Vulcan*. Velázquez, 1630
5. *The Drinkers*. Velázquez, 1628 – 1629

Prado Museum, tour 2:

1. *The family of Carlos IV*. Goya, 1800
2. *The Clothed Maja*. Goya, 1800 – 1808
3. *The Naked Maja*. Goya, before 1800
4. *The Grape Harvest*. Goya, 1786
5. *The Kite*. Goya, 1777 – 1778
6. *The Parasol*. Goya, 1777

Reina Sofía Museum, tour 1:

1. *Girl at the Window*. Salvador Dalí, 1925
2. *Sailor with Guitar* (sculpture). Jacques Lipchitz, 1917
3. *Portrait of Josette Gris*. Juan Gris, 1916
4. *La bouteille d'anis*. Juan Gris, 1927
5. *Le moulin à café*. Juan Gris, 1920
6. *La fenêtre ouverte*. Juan Gris, 1921

Reina Sofía Museum, tour 2:

1. *Triadic Ballet*. Oskar Schlemmer, 1922
2. *Girondelle*. Miró, 1937
3. *Escargot, femme, fleur, étoile*. Miró, 1934
4. *Portrait*. Miró, 1938
5. *Tête de Femme (I, II, III, IV)*. Picasso, 1937
6. *Guernica*. Picasso, 1937

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# Chapter 21. Feeling alive! : Participatory visual arts programme and vitality in a nursing home – A Singapore case study

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## **Abstract**

The priorities many nursing homes give to physical care often supersede consideration for leisure arrangement and resources for residents. Such an approach often resulted in low level of activity. Inactive lifestyle in nursing homes can diminish the quality of life of residents and elicit negative emotions such as boredom, reinforced dependency, lowered self-esteem, and diminished morale. In the light of population ageing and an increased in demand for nursing homes in Singapore, this research addressed the current lack of research on lifestyle arrangement to promote the personal well-being of nursing home residents. In doing so, it investigates the effect of a participatory visual arts programme to foster the well-being of nursing home residents.

Through a novel approach that combined arts-health practice with social scientific qualitative case study, the link between participatory arts and vitality was explored. Participatory arts was found to vitalise the sensory, physical, cognitive, emotional, social dimension of residents and promote self-actualisation.

**Keywords:** arts, vitality, eldercare, ageing.

## **Theoretical background**

Singapore has one of the fastest ageing population in the Asia Pacific region (Mehta, Kalyani K & Vasoo, 2002). Although the Singapore government strongly favours a community-based long-term care delivery system that encourages the elderly to remain in the community (Mehta, Kalyani K. & Vasoo, 2000), it is inevitable that a portion of the elderly will need to engage

the services of nursing homes. While research in Singapore related to nursing homes is growing, there is a lack of knowledge of lifestyle arrangements and their impact on the personal well-being of residents.

## **Objective**

The study examines how a participatory visual arts programme might promote the personal well-being of nursing home residents.

## **Method / Description of the experience**

To facilitate evaluation and reflection, a case study was conducted as part of 12 week Participatory Visual Art programme with ten participants. The programme introduced and engaged the participants to create a variety of two-dimensional and three-dimensional art work such as paintings and small clay sculptures. The data collected are qualitative in nature. Research methods used include: Participant Observation, Semi-Structured Interviews, Focus Group and Video. The research took place over nine months starting from April 2014 to December 2014. Data collected were analysed and interpreted using grounded theory approach where the data were initially skimmed to obtain general themes followed by a more focused analysis to explore the relations between various themes.

## **Results**

### *Invigorating the Senses and Mind*

In contrast to the mundane and lacklustre atmosphere of the ward, the art venue is a sensory-rich environment charged by the myriad of colours,

textures and sounds of chatters and banter. Sensory enriched environment and activities are known to benefit older adults as the stimulation they received help promote physical and cognitive wellness (de Macedo et al., 2015). The opportunity to learn through the art programme is found to invigorate participants; making them feel more alert. Alice, a participant revealed the heightened sense of awareness.

*Alice: When you teach us things to do, we are alert. It is better that someone teaches us something. Otherwise, people will keep sleeping. It is better that you are here to teach us. Our mind will be more active as we need to decide and think how to get things done.*

Participants of the Participatory Visual Art (PVA) programme welcomed and looked forward to the change of scene afforded by the weekly session. Besides helping to inject a new activity, the PVA programme was found to stimulate the participant's senses. The comment from Clare, a participant, clues us to the invigorating quality of the art programme which she feels is not commonly offered to residents in their everyday life.

*Clare: It's not the same. Your activity engages the mind and eyes. But the nurses don't do that. You attend to our brain and our eyes. You take care of our mental wellness, our vision acuity, and the ability to make discerning judgments.*

Art activities can be a mentally demanding activity that also induces a certain degree of cognitive engagement. When making their work, participants also need to, from time to time, make decisions on colour choice, the position and placement of elements on their pieces. Such cognitive engagement can be found in James's comment on his art making process:

*James: I find myself using my brain, you make a decision about choice of colour.*



The varied themes of the creative projects that participants were introduced to weekly kept them on their feet and stirred their curiosity and anticipation. In a sense, it created a sense of futurity, giving participants a sense of going somewhere. At times, participants may also encounter circumstances where they may feel challenged by a new technique and need to problem solve. Although such encounters might be mentally demanding, their ability to overcome learning curve and solving creative challenges also fostered their sense of confidence and self-esteem.

### *Fostering Positive Emotions*

The PVA programme fostered growth and development that allowed the residents to connect with their latent potential from which they were able to gain a new perspective about their own ability and kindle new ambitions. Many were surprised and expressed amazement over their accomplishments. It elicited positive emotions such as confidence, relaxation, pride and kindled new ambition - motivating them to regain pursuit in life.

*Betty: I feel so free...like...no burden at all. Making art is very relaxing. I can forget everything.*

The arts sessions were found to be a useful resource to promote physical wellness of residents. Staff noted that residents showed more willingness and enthusiasm to participate in the arts programme than the scheduled physical exercise. The actions and movement required from participants in the art making process were seen as a good alternative approach to stimulate and help the residents to maintain or improve their physical wellness. Clare, a resident also took notice of the physical stimulation she gained from making art.

*Clare: It exercises our hands and our brains. Eyes, and the eyes. It very good. I like it.*

Although the art programme did initially raise a degree of uncertainty and self-doubt among participants who are physically impaired, it also led them to overcome their personal challenges. Clare's case provides an example of the invigorated sense of self-belief and identity.

*Int: Have you previously participated in any art program?*

*Clare: No. This is my first time. I think to myself how am I going to do it with one arm. I doubted because I only have an arm, I doubted myself...*

*Int: So you were previously concerned if you are able to participate with one arm?*

*Clare: I wondered, can I work with one arm.*

*Int: So how do you feel looking at your artwork?*

*Clare: Very Good. Didn't think that I can produce such things. I didn't...I didn't dare imagine. I thought, what can this one arm of mine do other than some weird looking things. I am very happy, very excited that I can produce thing of such standard, I consider that that is not bad an achievement. For a disabled person to be doing this.*

### ***Animating Sociability***

The participatory arts sessions are resources and opportunities for participants to connect themselves and interact with their counterparts. Unlike the clearly demarcated boundaries of bed in the ward, the art venue was set up in a manner where participants shared tables and are in closer proximity to each other. The play action involved in the art sessions and the light-hearted atmosphere had also secured a space that encouraged interpersonal communication.

*Alice: When you come and teach us thing to do, our spirit are better. When the session is on, the others will gather around to chit-chat, that is good.*

Occasionally, the curiosity of staff passing by the session would draw to visit the session and spark conversations between staff and the participants. The residents' creation offered staff a different aspect of the residents, showing their capability and imagination. Their artwork offered staff a conversation piece for staff to initiate conversation with them. And at times, the conversation can spark a group chatter that where it will attract contribution from other participants and staff.

## **Discussion**

### ***Participatory Arts Activities and Vitality***

Although the animating quality and capability of participatory arts activities have been indicated in many arts, health and well-being studies, the link between participatory arts and the notion of vitality appears to be rarely considered and explored. Based on the range of positive affective influences observed in participants of the PVA programme, it appears that vitality might be a useful concept to further understanding on the benefits of arts on and well-being.

As much as human existence is dependent on physiological functions and physical needs, it is also, in part, sustained and fuelled by what Bergson (1983) termed as *élan vital* or others have called a vital element (Stern, 2010). Vitality is a term commonly used to describe such experiences of aliveness. Vitality is understood as having and being aware of the availability of physical and mental energy to the self (Ryan & Deci, 2008). In order for

vitality to be experienced, our body and mind need to be subjected to a constant process of change when we are awake (Stern, 2010). ‘The experience of vitality is inherent in the act of movement. Movement, and its proprioception is the primary manifestation of being animate and provide the primary sense of aliveness’ (Stern, 2010, p.10), in other words, ‘vitality must have a basis in physical action and traceable mental operations’ (Stern, 2010, p.9). Vitality could be understood as an energised state and experience that is animated and thrive on the availability of movement, experience of positive affect and having ambition – a sense of pursuit in life. It is a felt-awareness of the availability and presence of vigour.

### ***Animating Physical and Emotional Vitality***

The opportunity to move one’s body is a quality of the PVA programme that many participants appreciate. The participants spoke about how the routine of spending too much time on their beds and the inactive lifestyle have made them feel tiresome and lethargic. The PVA programme puts the body in action by engaging participants to use their arms, hands and fingers as they paint, manipulate and shape the art material to create their artwork. The art-making sessions were found to be a useful resource to promote physical wellness of residents.

*Clare: Because every week, I get to go down there to move my body. It is not advisable to sit on the bed daily. Otherwise I sit here every day like a block of wood.*

### ***Animating Cognitive Vitality***

Art activities can be mentally demanding and can also induce a certain degree of cognitive action and movement. The process of creating often would require participants to envision ideas in response to the project brief. Besides feeling alert, participants also expressed appreciation for the

opportunity to be exposed to something new and the intellectual gain afforded through the PVA programme. Peter's comment provides an example of such intellectual developing capacity he found from his participation in the PVA programme.

*Peter: Making art makes my mind more active. Not so...not so...inactive. At least I have something to learn from it. In a way good for me to learn something new. At least I have tried something new for myself.*

The cognitive engagement and action induced by PVA programme also engendered a sense of curiosity and adventure for participants. The varied themes of the creative projects that participants were introduced to weekly kept them on their feet and stirred their curiosity and anticipation.

### ***Animating Sensory Vitality***

The art venue is a sensory-rich and stimulating environment. Besides affording the participants a momentary respite from the routine life of their ward, the participatory arts sessions were found to refresh residents' senses and stimulated them. The art material also offered different visual, tactile and olfactory sensation for the participants. In creating their work, they would make contact with the coolness of the water or clay, dripping off paints, feeling a drift of breeze, captivated by particular hue. These sensations were found to be therapeutic for residents. The emotional response emerged from admiring their creation or that of others could also be interpreted as an on-flow of sensory vitality. The art activity appeared to heighten the senses of the participants while at the same time it accentuated their sense of awareness, involvement and connectedness with their surroundings. This notion of connectedness and alertness are known to be indicators of vitality. In contrast to the mundane and lacklustre atmosphere

of the ward, the art venue is a sensory-rich environment charged by the myriad of colours, textures and sounds of chatters and banTERS.

## **Conclusion**

This discussion began by highlighting that although nursing homes provide care for persons, it seems that in its preoccupation with caring for residents' physical needs and health, to *keep* residents alive, nursing homes have overlooked residents' need to *feel* alive. As a result, the quality of life for residents is often compromised. The lack of attention to residents' quality of life has inevitably engendered a passive and inactive lifestyle and affected the prospect and security for individuals to age optimally in nursing home. Although multi-sensory stimulation is known to benefit residents' physical and cognitive wellness, many nursing homes continue to be impoverished environments with low physical and social activities.

In exploring how a participatory visual arts programme might ameliorate the inactive lifestyle and enhance residents' subjective well-being, the discussion has paid attention to considering the transformation process occurring in participatory arts activities through which well-being gain might arise. I have also ventured to explore the link between vitality and participatory arts activities. I interpreted and identified several vitalising attributes of participatory arts activities that contributed to augment the subjective well-being of participants. They include sensory vitality, physical and emotional vitality, cognitive vitality. I hope this consideration on of vitalising qualities in the arts on the health and well-being of residents in nursing home can support further engagement and implementation of the

arts in nursing home so that residents can become and feel alive instead of simply being kept alive.

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## Chapter 22. ProVACAT. Practising or viewing art cognitive ability trial. A collaboration between the Ben Uri Gallery and Museum and Hammerson House Care Home (2015/16)

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Figure 1. Participants enjoying a visit to 'Out of chaos: Ben Uri, 100 Years in London', 2015.



## Abstract

### Art Engagement to Slow Cognitive Impairment and Improve Wellbeing

As the UK National Health Service strives to support an ageing population with increased life expectancy we see a rise in social prescribing. Our ambition is to conduct a randomised, long-term intervention assessing the potential for arts engagement to slow expected cognitive decline and improve wellbeing.

We identified a residential care home with the appropriate facilities and support for a feasibility study. Our intervention sees Group A receive practical art sessions exploring new materials and techniques. Group B receive seminars responding to replica artworks with open discussion. Participant wellbeing was measured immediately following each session using the UCL Museum Wellbeing Measures Toolkit.

Over twelve weeks, two groups of four participants, each with an average age of 93 attended one hour creative sessions and seminars respectively. The results demonstrate a positive variability of outcomes with different wellbeing responses between the two groups at this early stage. They mark the potential for more ambitious projects, addressing a larger group of participants with greater measurement of cognitive function under a randomised controlled trial. The project seeks to achieve a generalisability applicable to varying demographics.

**Keywords:** art engagement, wellbeing, cognitive impairment, creative practice.

## Theoretical background

The UK has an ever-increasing ageing population as healthcare improves and life expectancy grows. Between 2002 and 2012 the number of centenarians living in the UK rose by 73% to 13,350 (Age UK, 2017). As the NHS strives to react to this vast social responsibility and to support it, we see an increase in social prescribing. This links primary care patients with sources of support within the community providing GPs with a non-medical referral option that can operate alongside existing treatments to improve health and wellbeing. It should not be seen as an alternative but an addition.

Cognitive impairment is an expected and natural element of ageing. It is noticeable and measurable primarily affecting memory, coordination,

judgment and comprehension of previously ordinary tasks. In correlation to this, the World Health Organization constitution states that ‘good health is a state of complete physical, social and mental well-being, and not merely the absence of disease or infirmity’ (WHO, 2014) It follows that cognitive ability is linked to an individual’s sense of wellbeing defined by Mind UK as central to confidence, relationships with others, expressing emotions, managing stress and connecting to the world around you (Mind, 2016).

Whilst there is significant interest in the capacity for arts engagement to both improve wellbeing and positively affect specific medical conditions, such as Dementia and Parkinson's disease, clinical research is lacking. This is particularly true for the visual arts over the broader ‘arts’ including music, singing, theatre and dance. This study seeks to overcome these barriers.

### **Method / Description of the experience**

Hammerson House Care Home was identified as an appropriate partner with the appropriate facilities to conduct a feasibility study. Ben Uri’s Learning and Wellbeing Officer designed a programme of twelve weekly practical sessions and twelve weekly seminars, which were delivered on site at Hammerson House in their activity space. Group A received practical art sessions exploring new materials and techniques. Group B received seminars responding to replica artworks with open discussion. Participant wellbeing was measured immediately following each session using the UCL Museum Wellbeing Measures Toolkit (Thomson & Chatterjee, 2013).

This report addresses Phase I, the feasibility study, simply designed to pilot the project and completed 2015/16. Phase II will consider changes outlined in this report and introduce a baseline measurement with which to collect

useful data, working closely with a university partner. Phase III will see the project rolled out on a bigger scale to reflect varying demographics and enable us to consider wider social implications.

***Planned intervention:***

*Group A* - Practical art making workshops:

Ben Uri worked with a trained, experienced arts facilitator to deliver sessions of around one hour and fifteen minutes beginning with refreshments and ending with an informal plenary to review everyone's work. A variety of materials and techniques were explored over the twelve week period including drawing materials, clay, printing, paint, mixed media, iPad art and textiles. The sessions are challenging yet adaptable for different abilities also considering common issues with dexterity, fine motor skills, vision and hearing. For this reason high quality, varied, individual outcomes and creative exploration are actively encouraged over a defined final product.

*Group B* - Art seminar with discussion:

The second session type, received by a separate group of participants is a seminar and discussion featuring replica Ben Uri artworks. Again this session lasted around an hour and fifteen minutes with a break for tea and cake. The chosen artworks span the collection from the Gallery's inception in 1915 to one of the most recent acquisitions, covering key aspects of history as well as different mediums and themes. We use facsimiles of collection works printed to replica size as high quality giclée prints, framed as closely to the current frame as possible and displayed on easels. Participation and accepted sharing of opinions is actively encouraged.

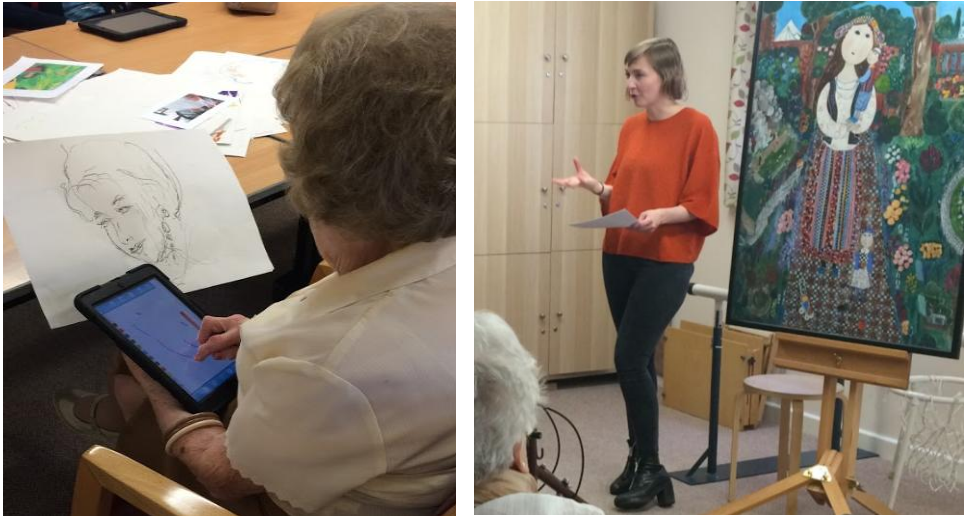


Figure 2: Left – Group A participant enjoying iPad art. Right – Group B engaged in a discussion of Dora Holzhandler’s *Mother and Child in Holland Park*, 1997, Ben Uri Collection.

***Criteria:***

The criteria of the Phase I feasibility study was to work with willing residents of Hammerson House over the age of 75. Participants were allocated randomly or by their care staff. Where the individual was unable to self elect, staff prioritised those they felt would benefit and perhaps flourish in a smaller group over those residents who readily attend existing activities.

As we progress to Phase II we will work specifically with those living with dementia in residential care settings in order to limit our variables. Once allocated participants will not interchange between Group A and Group B.

This is a complex intervention with many confounding variables. It cannot be ignored that the introduction of new people to the home and the socialness of the sessions might have a therapeutic impact so we have designed the trial to consider only one variable. We accept as a starting point that the experience of art is of value so the only change for the “control” group will be the replacement of the creative, practical workshop with a session of identical duration to view and discuss works of art from the Ben Uri collection. This assesses two key forms of traditional outreach arts engagement; practical art making in creative workshops and talks.

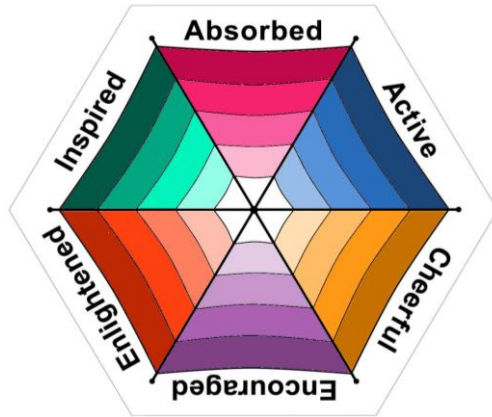


Figure 3: Positive Wellbeing Umbrella

***Intended Outcomes and Evaluation Methodology:***

Evaluations were conducted throughout the study immediately following each session. These were taken from the UCL Museum Wellbeing Measures Toolkit (Thomson & Chatterjee, 2013) specifically the ‘Positive Wellbeing Umbrella’ and ‘Generic Wellbeing Questionnaire’. The questionnaire acts as a baseline indicator given that it is straightforward and familiar in comparison to the umbrella format. Full details of the UCL Wellbeing toolkit can be found at the following address:

[www.ucl.ac.uk/museums/research/touch/museumwellbeingmeasures/wellbeing-measures](http://www.ucl.ac.uk/museums/research/touch/museumwellbeingmeasures/wellbeing-measures)

During the feasibility study at Hammerson House it became clear that the wellbeing umbrella would benefit from clearer colour differentiation rather than a colour wheel transitioning effect. Also, the presence of numbers, colours and a small to large selection area provided too many indicators and caused confusion. Ben Uri consequently made these alterations to achieve *figure 3*.

The primary outcome measure is the change in cognitive function over a period of 12 months. In addition to wellbeing tests conducted following each session, tests will be administered at the start, three months later (at the end of the intervention period), at 6 months and one year comparing Group A (art making) with Group B (seminar).

Secondary outcome measures will include quality of life and health economics. Our academic partners will control the provision and analysis of these outcomes independently.

Phase III studies rely on the continued feasibility of the study. If positive the study will roll out in suitable venues across a broad cross section of society in order to achieve a useful generalisability with which to progress.

## **Results**

Over a total of twenty four sessions, two groups averaging four participants with an average age of 93 attended weekly practical art making sessions and weekly art discussion seminars respectively.

As originally stated, intervention with Hammerson House represents the feasibility phase of the project and so it is too early to expect to extract useful quantitative data. Whilst we are able to make some early observations from the collated data, the sample size is too small to draw any numerical conclusions. Table 1 provides a summary of the total data collected across all twenty-four sessions in turn demonstrating a positive variability of outcomes and the potential to gather comparable data on a wider scale.

Table 1. Summary of the total data collected across the sessions

Group	Total * present	Avg age	Age Range	UmbrellaS core ** Mean	UmbrellaS core ** Range	Quest. Score** Mean	Quest. Score** Range
<b>A(Art making)</b>	24	93	87 - 98	16.75	8 - 29	18.92	13 - 28
<b>B (Seminar)</b>	29	93	87 - 98	17.1	14 - 29	22.86	12 - 30

\*Total over 12 weeks // \*\* Score out of 30 marks

From Table 1 we can tell that attendance was better amongst Group B and that they reported a higher mean umbrella score and questionnaire score. This reflects a greater interest in the seminars at Hammerson House, comprised of several external factors: an awareness of the Ben Uri Gallery, the existence of another regular art group and most interestingly, a real interest in learning and the ‘intellectual’ nature of the activity. This fundamentally challenges the misconception that older people and in particular those living with dementia don’t want to or are unable to learn new things. The highest umbrella scores for the seminars were feeling ‘absorbed’ and ‘encouraged’. By contrast for Group A it was feeling ‘cheerful’ and ‘encouraged’.

It is also interesting to note that on several occasions participants from Group B reported that they did *not* feel cheerful following their seminar, which could often be attributed to the subject matter of the painting discussed. This is evidence of the significant importance of qualitative assessments at this stage. Made following each session they consider the overall success of the session plus observations and quotes concerning individuals. In this sense it is possible to more accurately monitor a perceived improvement in wellbeing whilst also gaining useful feedback on content and structure. For Phase II a journaling system will be undertaken and we hope to have the support of an academic research assistant present at every session.

Up to this point we have been solely measuring wellbeing, using the adapted UCL toolkit (*Figure 3*) whilst any indications of a perceived positive effect on cognitive function are supported only by anecdotal evidence. As we look to Phase II and our academic partnerships, we are now in a position to assess cognitive ability.

***Three key changes following Phase I (the feasibility study):***

- The seminar artworks will not be addressed in chronological order following feedback that the theme of forced escape due to Nazi persecution of the Jews was troubling when addressed week by week. Instead key themes will be addressed.
- Given that the sessions happen on the same day at different times, it can be difficult to make that differentiation clear with participants. This resulted in some residents feeling they hadn't been invited to take part and others staying for both sessions. When collecting valid data it will be important for



both groups to remain distinct therefore we will address this vital secondary communication with the partner.

- The evaluation collection process can be lengthy even to a point of inadvertently evoking a negative response. It also does not account for participants leaving before the end despite taking part. For this reason we changed from the 12 question to 6 question generic wellbeing questionnaire (Thomson & Chatterjee, 2013) and will administer questionnaires one to one during the session, rather than on its conclusion. We would also follow up with anyone who leaves early for consistency.

## **Discussion**

The study originally proposed all sessions would take place at Ben Uri Gallery for those living with dementia to attend with their Carer. It then became clear the Gallery space is not suitable for this audience and the project would need to be delivered as outreach. It was also felt that by electing to work solely with those living with dementia at Hammerson House, we would not be reflecting the needs of our partner.

This decision is applicable solely to this stage of the project, enabling us to deliver to a wide range of needs. It is worth noting that an individual with dementia may well have other conditions or diseases whether lifelong or developed over time therefore it is helpful to have tested the programme in this context.

In the longer term ProVACAT seeks to achieve a generalisability applicable to varying demographics. Next, we hope to work with a new partner to collect data for formal evaluation with an academic partner enabling us to assess the comparative impact of art making and art viewing. We will then

use this evidence if positive to demonstrate that art has the potential to improve health and wellbeing and to open up avenues for further collaboration with a variety of likeminded organisations.

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# Chapter 23. Cyanotype: workshops for people with early dementia

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## **Abstract**

The workshop “*Cyanotype: Workshops for people with early dementia*”, carried out at the 5th International Conference on Health Humanities introduced the cyanotype. The cyanotype is a 19th century photographic technique that the research project used as a way for preventing the decline of faculties of people living with diseases that provoke memory loss.

The activities carried out in the cyanotype workshop at the Conference were based on the creation of photographic images that could be intervened or complemented with other traditional art techniques. It was specially targeted at educators who want to develop an occupational therapy experience. This engaged the participants in activating their vision and developing their fine motor skills so as to create their own personal artwork. These aspects are important when applying this technique to groups living with dementia.

The general aim of the workshops at the Conference was to develop the cyanotype as a resource for art educators or facilitators in experiences with people living with Alzheimer’s disease or other early dementias.

**Keywords:** Alzheimer, workshop, cyanotype, communication.

## **Theoretical background**

The experience is framed under the Arts & Health research line. This model allows associations, foundations and health services, social centres and research departments to work together. Under the auspices of this framework, the Grupo Interuniversitario de Investigación del Museo Pedagógico de Arte Infantil (GIMUPAI) develops this Project. The authors of this contribution include university professors and researchers of the Fine

Arts Faculty of the Complutense University of Madrid and the Department of Social Psychology and Anthropology of the Salamanca University.

## **Method / Description of the experience**

*CYANOTYPE. Theoretical description. Process and development of the photographic technique (Moreno 2003)*

This photographic technique consists in obtaining prints, always in blue, from an acetate negative of the same size as the final image. However, obtaining a printed image is not the only way the technique can be applied. It can also be used to produce photograms and other unusual pictures, allowing patients to play an active role in the whole process.

### *Materials needed*

- The appropriate emulsion
- Various everyday items for making photograms
- An acetate negative for obtaining prints
- A base (paper, craft paper, wood, stones, etc.)
- Brush for painting the emulsion onto the base
- Glass or perspex. A clip photograph frame can also be used.
- Trays for washing the pictures or a nearby supply of running water.

### *Scientific basis*

The scientific basis of the cyanotype process is based on the sensitivity to light (photosensitivity) of some chemical products when they are mixed together. These products are ferric ammonium citrate (green) and potassium

ferricyanide (red). When exposed to ultraviolet light, some of the ferric ammonium citrate is reduced down to ferric salts and part of the potassium ferricyanide becomes ferric ferrocyanide, producing a Prussian blue print that is water insoluble and permanent.

The most important features of this photographic technique are the following:

- It has a low toxicity rate, lower than many products for everyday use.
- It is a technique in which patients can play a direct role throughout the entire process, from mixing the two components to get the final emulsion, to handling the image while it is being exposed to ultraviolet light.
- The emulsion is not a thick substance, which makes it very easy to apply.
- The emulsion can be used on a range of different media.
- The light source for obtaining the prints is ultraviolet, readily available as sunlight.
- There is no need for a darkroom for applying the emulsion to the base.
- The developing process is simple and relatively short and does not need a developer or fixer.
- It is easily combined with traditional processes like drawing, painting and so on.
- It provides permanent prints.

### *Chemical formula*

#### Solution A

Ferric ammonium citrate 90 g

Distilled water to make up to 250 ml

#### Solution B

Potassium ferricyanide 50 g

Distilled water to make up to 250 ml

Store both solutions in black bottles until ready to use.

Mix equal parts of A and B in small quantities just before use.

### *Negatives*

The acetate negatives are only needed if prints are to be obtained. In this case, they should be the same size as the image, because the print is obtained by direct contact between the negative and the base. If the final image is to be sharp, a clip photograph frame should be used, to keep the emulsion and the base in close contact with each other.

### *Bases*

All kinds of materials are suitable, except metal. It is important to choose the correct base, depending on porosity, texture, and resistance to water.

The bases used for the workshops were craft paper and Canson paper. Given that the cyanotype is semi-transparent, when a coat of emulsion is applied to a coloured base, it interacts with the blue colour, resulting in a mixture. For example, if the emulsion is spread onto a yellow base, the result will be a green print; if the base is orange or red, the end result will be purple, and so on.

### *Tools for applying the emulsion*

Using, rollers, sponges or brushes, we spread the print evenly onto the base.

Different sized brushes make the most of each one's qualities and enable a range of textures.

### *Applying the emulsion*

This operation should be done in dim light. Printing can be done either completely or partially onto the base. The sensitised base, once dry, can be exposed to ultraviolet light. It can also be printed in advance and stored in a black folder to prevent the sun's rays acting on the emulsion.

### *Exposure (to sunlight)*

The base is exposed directly to sunlight or another ultraviolet light source (a lamp). Everyday items can be replaced on it. These can be moved during exposure to achieve different compositions and depth effects.

Prints can also be made from negatives. The chosen base should be paper or another base with similar features. In this case, exposure is done by placing the base with the emulsion in contact with the negative. So as to keep the negative in place, we cover the negative with glass or perspex to keep the negative in place.

The third option is the combination of the two previous techniques (photogram-positive). Exposure to light can be done either by placing the negative first and making a photogram at the same time that the negative is being exposed to light.

Another way of working would be to obtain an image of a photogram or a positive print. Once the images are dry, the emulsion is applied again. In this manner the result is by placing a negative on it.



***Exposure times***

The length of time that the base should be exposed to ultraviolet light varies, depending on the light source. In the case of sunlight, it on the time of day and the season.

Other things to take into account are if the light has to pass through an intermediate element (glass, acetate, etc.) as well as the density and contrast of the negative. Below is a table with guidance on the approximate times needed to obtain an image with cyanotype from a negative:

Table 1. Approximate times to obtain an image with cyanotype

	Spring	Summer	Autumn	Winter
Sunny	10 minutes	5 minutes	12 minutes	18 minutes
Cloudy	15 minutes	7-8 minutes	20 minutes	30 minutes

In the case of photograms, these times are reduced by up to 20%.

In exposures using natural light, the times can easily be controlled, as the colour acquired by the emulsion will show the state of exposure at any time. At the time of application it will be yellow. It then gradually changes colour until taking on a greyish tone that determines whether the ferrous salts have been completely reduced by contact with the light. This indicator is very reliable to calculate when exposure has been completed.

***Developing and fixing (washing)***

Once exposure is complete the base is washed in trays or, preferably, in running water. The yellowish film over the parts of the image that were not exposed to light must be removed totally. Once this has been done, the image appears with its characteristic blue colour.

### *Drying*

The next step after the washing process is drying, which can be done either in the open air or with a hair-dryer.

### *Manipulating the image*

Once the print is dry it can be manipulated with paint, wax crayons, water colours, felt tip markers, and so on, as contact with these media will not cause any kind of chemical reaction.

### *Process of working with cyanotype*

The process of working with this technique is described below:

1. If the aim is to produce a positive print, the first thing to do is to achieve a negative that is the same size as the final image, in acetate, as printing is done by contact.
2. The chosen base is coated either fully or partially with the photosensitive emulsion using a brush or any other suitable utensil. It is then left to dry, preferably in a dark place or in dim light.
3. Both the negative and the sensitised base are exposed by contact with ultraviolet light (natural or artificial). If photograms are being made, there is no need for a negative. Exposure depends on the intensity of the light source. Next, the base with the emulsion is washed under running water.
4. In the areas that were under the transparent parts of the negative, the emulsion will have undergone the corresponding chemical change and will have become insoluble. On the areas protected by the dense parts of the negative, the emulsion will have dissolved, resulting in the base being free of chemicals and showing the colour

of the base used. The result is the typical Prussian blue positive print.

5. The cyanotype, as mentioned earlier, is semi-transparent, so if different coloured bases are used, the final image obtained will be the mix of the blue of the cyanotype and the colour of the chosen base.
6. The final image can be manipulated using coloured crayons, felt tip marker pens, water colours, inks, charcoal, etc., as the cyanotype does not undergo any changes when it comes into contact with these materials.

Figures 1 and 2 show the development of the cyanotype workshop for the educators and facilitators' training:

*WORK PROCESS IN THE CYANOTYPY WORKSHOP*



Figure 1. The images are exposed to sunlight and washed



Figure 2. Some of the images obtained and chatting to participants

All images were taken by Ávila, N.

## Results

### *Participants' reactions*

Although the primary aim of the workshops was to teach and experiment with new methods and resources for working in general health contexts, and in particular with patients suffering from Alzheimer's disease and other early dementias, people who attended the workshops found the technique suitable for applying in a wide range of other situations because of the simplicity and speed of the process involved.

We would like to emphasise that everyone attending the workshops had nothing but positive reactions, showing curiosity, interest and the desire to learn a photographic process they knew nothing about. The benefits of implementing this technique with participants living with dementia are discussed in research projects carried out by the GIMUPAI research group (Ullán, 2011).

Once the workshop was over, most of the attendants wanted further explanations and a deeper knowledge of the technical side of the photographic production. Many participants expressed their desire to experiment with more complex exercises.

## Discussion

### *Sphere of application of the activity*

These activities designed for educators and facilitators working with people living with Alzheimer or other early onset dementias have already been put into practice with actual people in this situation. This previous experience supports its application with different groups that share these

characteristics. Four relevant aspects have to be taken into account for measuring success: creativity, learning, enjoyment and communication (Ullán, AM., et. al., 2013). The use of cyanotype translates into improvements in the self-esteem of the participants. For this reason, the implementation of cyanotype workshops is ideal for different contexts that want to carry out an occupational therapy activity.

Nevertheless, this technique is also apt for its application in other settings like schools, high-schools, universities, summer camps, etc.

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# Chapter 24. Creating doorways: finding existential meaning and growth through the creative arts in the face of life-threatening illness

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## **Abstract**

Life-threatening illness can be sufficiently traumatic to shatter one's beliefs about self, others, and the world. This disruption can trigger an instinctive search for meaning. Research highlights that how individuals respond post-adversity can make the difference between experiencing posttraumatic stress or posttraumatic growth (PTG) and existential growth (EG). This paper presents the findings of a pilot study situated in a tertiary care cancer centre and details the impact of creative arts therapy on the experiences of individuals living through breast cancer. Ten women were interviewed about their experiences making art, many for the first time. Emergent themes included: the significant benefits of art-making on their sense of self-efficacy; the emotionally enhancing nature of art-making; the power of their artwork to trigger insights (including subthemes of EG, PTG) or in communicating their experiences to loved ones; and how art-making changed their worldview and life philosophies, creating doorways of possibilities. Findings suggest that art-making provides a safe, dynamic context for individuals experiencing breast cancer to reflect on profound personal changes and to re-story losses following adversity through creative arts practices.

**Keywords:** posttraumatic growth, existential growth, cancer, art therapy, art making.



## **Theoretical background**

Breast cancer is the leading cancer for women in Canada. One in nine is expected to develop breast cancer in her lifetime (Canadian Cancer Society, 2015). The arts have been shown to be an effective tool in processing adversity, both in therapeutic and nontherapeutic contexts. With women experiencing breast cancer, the arts have been linked to:

- enhanced well-being (Burke, Sabiston, & Vallerand, 2011);
- a sense of control over the psychological and emotional impact of cancer on their daily lives, including warding off preoccupation with the illness (Link, Robbins, Mancuso, & Charlson, 2004);
- improving the quality of survival (Reynolds & Lim, 2007);
- significantly lower ratings of depression, anxiety, and somatic symptoms (Egberg Thyme, Sundin, Wiberg, Öster, Åström, & Lindh, 2009); and
- eliciting flow experiences that served to banish intrusive thoughts about cancer and provide experiences of mastery and control (Reynolds & Prior, 2006).

This particular pilot study, embedded and conducted in a tertiary care cancer centre, examined the impact of participation in an on-going creative arts therapy and support group on the experiences of women living through breast cancer. Using an interpretivist paradigm, which assumes that reality is socially constructed and accessed through language and shared meanings, we adopted a case study qualitative methodology (Creswell, 2012) and employed a cross-case comparative approach (Merriam, 1998), since creative

theoretical insights often arises from the juxtaposition of contradictory or paradoxical evidence.

*This paper details the findings of the following research question: What are the processes of meaning making used by women receiving treatment for breast cancer as expressed through group art therapy within a breast cancer centre?*

## **Method**

Ten women between the ages of 41 and 67 years, diagnosed with and treated for breast cancer, participated in a series of 2-hour art therapy group sessions. They were interviewed about the impact of art-making on their cancer experiences. A semi-structured interactive interview process was employed, using an open-ended, conversational format to facilitate the development of trust and rapport.

## **Findings**

When analysing the interview data using the constant comparison method, the overriding theme of existential growth emerged. Existential growth is the deep psychological and spiritual change that occurs when individuals face, rather than deny, their mortality (Sodergren, Hyland, Crawford, & Partridge, 2004). This existential growth emerged from the reflections and insights that occurred while making art or when reflecting about the pieces of art the participants made. This category existed across all 10 cases.

## *Existential Meaning and Growth*

### *Making sense of the cancer experience*

The women participants linked making art to being able to find meaning in the cancer experience and in life during or post-treatment.

*...being able to talk about it and explain why we did what we did to each other and to you. (Carolt)*

*It's funny the way, the things you came up with intuitively, very spontaneously then when you looked back at them you would find meanings that would relate to...I would find meanings to what I was feeling or thinking or going through. (Andrea)*

The process of art-making, or their art pieces, revealed to the women their thoughts, feelings, and desires which allowed them to make sense of their cancer experience in the context of their lives.

### *A desire for more self-direction*

This category illuminated the desire of these women who experienced breast cancer to have more choice, control, and autonomy in their lives.

*...at the same time it was the only thing I was believing at that time that could help me to get rid of my depression. (Gabriella)*

*...so for me the art was the only way that I could have some sort of control about what I have and what I'm going through. (Aurore)*

Art-making gave these women a sense of control and choice at a time when they felt most out of control with regards to their bodies and appearance, the course of the disease, and the outcomes of their life-threatening illness.

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†All names are pseudonyms.

### *The need for closer relationships*

The women in this study reported not only a deepening of relationships, but the need to be closer and the need to be part of a community.

*...it's still important after your treatment to be able to connect with people that have gone through the same thing. (Carol)*

*I wanted them [her daughters] to know how much they meant to me—that they had a huge, they still do have a huge place in my heart. (Aurore)*

The creative arts therapy group provided a space for these women to form relationships based on their shared art-making. The process of art-making also created a liminal space (an in-between transitional space) for the participants to recognize and express their needs for affiliation, connection, and closeness. This liminal space gave the women time to reflect, to collect their thoughts and reenergize, before taking action again.

### *A reconsideration of fundamental life values*

The group art therapy sessions created conditions that allowed the process of meaning making to progress. The participants reported that their cancer experience triggered a reordering of their values and priorities in life.

*There's a really nice poem by, I think it's, is it Erma Bombeck? It's like if I had to do things over again, and this is what I'd do, I'd spend more time playing with the kids and less time worrying about the handprints on the wall... (Élise)*

*[I] think that I need to appreciate more how precious each minute is because I think we get carried away with ambition, career, this and that and when I was threatened with...it doesn't matter anymore. Nothing matters anymore. What matters is that you're there to appreciate... (Sofia)*

Art-making created a space for the women to reflect on what was important for them at this critical juncture of their lives, and to reprioritize their values in the context of facing their own mortality.

### ***Posttraumatic Growth***

In addition, there were also strong indications of posttraumatic growth, the positive psychological change experienced when facing adversity and other challenges (Tedeschi & Calhoun, 2004). This posttraumatic growth emerged from the reflections and insights that occurred while making art, when reflecting about the pieces they made, and when reflecting on their lived experience. This category was present across all 10 cases.

### ***A deeper compassion for others***

As an additional outcome of the search for meaning, participants reported feeling more connection with others, specifically those who have experienced traumatic events.

*...when I had the cancer...I just didn't realize...I mean you go through hell. You don't realize that others close to you are going through hell too for different reasons...It's not physical but they are going through hell as well. (Sofia)*

*I probably shouldn't assume so, but actually anyone going through this or any kind of crises...This is kind of how you have to...I think it is really the only way you can deal with it. (Ray)*

Art-making created a reflective space for the women to develop compassion, empathy, and perspective-taking (i.e., temporarily suspending one's own point-of-view in an attempt to view a situation as someone else might).

### ***An emergence of new opportunities and possibilities***

The search for meaning also highlighted to the women participants how new opportunities and possibilities can become available to them, which

were unavailable prior to their cancer diagnosis and participation in the art therapy group.

*The disease seemed to have awoken a creative side in me that needed an outlet. (Élise)*

*Can you believe I didn't know how to knit? Now I want to learn how to knit. I want to learn how to crochet. I want to know all these things. I want to know and I started to do something so it was a new discovery, but something that I always wanted to do. (Gabiella)*

The majority of women in this study had no previous art-making experience (except as children); therefore, art-making opened up a new world for them to explore. This new endeavour generated passion and enthusiasm.

### ***Feeling able to meet future challenges***

The participants described a fortified sense of self- a resiliency, as in “what doesn't kill me makes me stronger”.

*...my famous golden tears. They were mine then and they are still mine today. Some days there are days when tears are still shed. I consider those golden tears because I understand them. I accept them. I wish they weren't there but they're a part of me, of course. (Eva)*

*As [another member of the art therapy group] mentioned something occurred to me this morning, and I believe this is so true. There is only one person I count on and this is myself and this is true. (Jeanne-Marie)*

Art-making created a reflective space for these women to identify and tap into inner resources to support their navigation of the cancer experience.

### ***Reordered priorities***

This code category displayed the participants' reordered priorities and a greater and fuller appreciation of life in general, and in their relationships in particular.

*...then the need to have nature around for me that was a need to have balance around me. (Eva)*

*And now money is more important because I want him [her son] to have the opportunities to go to school. I want him to be supported in ways that I never was. So he has those safety nets and if I don't live for long, I want to make sure there is something here for him. (Ray)*

Art-making created a liminal space for the participants to sift through their life priorities and re-align them to what was now most important to them.

All of the participants noted that it was the process of art-making that allowed these changes, insights, and transformations to occur. They attributed these dynamics to art as a process of connecting or reconnecting one with the self, the past self, or past or current relationships. This connection-reconnection acted as fertile ground for the processes of existential and posttraumatic growth to take root.

### *Art-making as Connector-Reconnector*

#### *Discovery of Self*

Making art allowed the participants to discover something essential or new by reflecting on all previous experiences.

*Every time I explore my "innerscape", I learn a little bit more about my true self, inner peace, the beauty and the joy of being myself, and feeling connected as a whole being. (Gabriella)*

*I'm being more assertive of who I am because remember when we were going through the art I always thought there was something special with the horse... I felt that I had to follow the rules or the expectations, whatever and what I really wanted was to be free to be me... (Sofia)*

### *Shifts in identity/sense of Self*

Making art fashioned a space for the participants to reconfigure their perceptions of self as a consequence of having experienced or engaged in art therapy.

*...those artworks that I mentioned, it gave me a sense of accomplishment, so I think that, yeah, so that was a nice feeling for me.  
(Rose)*

*I just wanted to feel good about myself and through art...art has helped me feel good about myself. (Aurore)*

Art-making created a *doorway* for self-discovery in the face of living with a life-threatening illness, which in turn allowed these women to refine and reshape their identities or discard ill-fitting aspects to their identities. This impacted their sense of self and provided rich soil for existential and posttraumatic growth.

## **Discussion**

Art-making and art therapy can be useful and important supplements to conventional treatment for breast cancer patients, fostering a space of meaningful reflection, growth, and transformation. The emotional and psychological rollercoaster that women experience post-breast cancer diagnosis must be addressed as a priority in conjunction with their medical treatment.

Art-making can be a mode of action and a means of intervening in the world. It allowed the participants to physically act in order to express to themselves (and others) their thoughts, feelings, struggles or triumphs, intentionally or unconsciously, at symbolic, metaphoric, or literal levels. Art-making creates interstitial spaces that foster the positive individual changes



that characterize existential and posttraumatic growth, which have implications for patient quality of life. We found that art-making was more than a *distraction* (a trivializing term), but shaped an active, dynamic, liminal space that allowed for patient agency to be enacted. These women participants had the time and space to reflect and actively construct meaning about their cancer experiences and about themselves in the context of cancer.

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Over the last five years the International Health Humanities Network has explored several themes related to Health Humanities, highlighting how the arts and humanities can enhance human health and wellbeing. To date, the network has generated an exciting interdisciplinary dialogue across diverse communities of arts and humanities academics and practitioners, clinicians, informal carers, service users, and the self-caring public.

The interest in the impact of creative practices and humanities on health, psychological well-being and the enhancement of social inclusion is growing worldwide. Drawing upon contributions to the 5th International Health Humanities Conference in Seville, this book accounts for this impact exploring practices such as innovative care (professional, non-professional, and self-care), achieving health, and wellbeing through social connectedness.

