FQS FORUM: QUALITATIVE SOCIAL RESEARCH SOZIALFORSCHUNG

Volume 15, No. 3, Art. 18
September 2014

"I Will Tell You Something of My Own"—Promoting Personhood in Dementia Through Performative Social Science

Helen Gregory

Key words: performative social science; dementia; personhood; creativity; art; poetry; photography; stigma

Abstract: "I Will Tell You Something of My Own" was a performative social science project, which drew on the combined efforts of four artists and one artist/social scientist. Its aims were to illuminate the experience of dementia and to help combat stigma around this condition. There were two aspects to this project: a piece of (ongoing) qualitative research and a multi-arts exhibition. This article focuses on the latter, with particular emphasis on the construction/narration of three dimensional collages and displays, in collaboration with people with dementia. Visitors' and participants' comments on the exhibition suggest that it was successful in its aims. The exhibition was also able to create a dialogue with its audience, albeit in unanticipated ways, with visitors being more keen to share stories through conversation and guestbook comments than to contribute items to the display. It is argued that "I Will Tell You Something of My Own" demonstrates the ability of performative social science to bring social scientific research to larger/broader audiences, to touch audiences on both emotional and cognitive levels, and to make a meaningful difference to the lives of participants and others in their community.

Table of Contents

I will tell you something of my own.
I will still be what I am,
I will still be on the slide.
I want the same as life.
I want the same.
From "The Same as Life"
by Olwen JONES and Karen HAYES

1. Introduction

The opening quotation is taken from a poem written by Olwen JONES and facilitated by Karen HAYES. This poem was part of a wider project, "Try to Remember," in which Karen worked with people with dementia (PWD) to create poems that gave voice to their thoughts, emotions and experiences. My involvement in the project was to evaluate its impact, interviewing care staff in the day care centers and residential homes that Karen visited (see GREGORY, 2011; GREGORY, HAYES, JONES & OPHER, 2012a, 2012b). "Try to Remember" was my first real introduction to dementia, as well as to arts interventions for health and well-being. It inspired me in both fields and ultimately flung me headlong into the world of performative social science. [1]

These interests converged in "I Will Tell You Something of My Own," a project which used social scientific research and innovative artworks to explore the everyday lives and selves of PWD. The project was funded by Arts Council England and NHS Gloucestershire, and supported by Age UK Gloucestershire. Its aims were twofold: Firstly, to understand better what it is like to live with dementia; and secondly, to help combat the stigma which PWD face daily, by illuminating the continuing humanity and competencies of those who live with this condition. This article explores the background, rationale, method and outcomes of "I Will Tell You Something of My Own," considering how it drew on performative social science to help improve the lives of people touched by dementia. [2]

Throughout the article, reference is made to the stories and words of PWD. It is standard practice for social scientists to disguise participants' identities in such cases. The value of this confidentiality is more ambiguous in artistic contexts however. Indeed, it is my experience that artists working with vulnerable and marginalized groups often seek to champion, rather than disguise, the identities of the individuals whose work they facilitate. This issue is hotly debated within the context of art therapy, with some contributors challenging the confidentiality principle by arguing that clients can benefit from seeing their work displayed and for being credited as the creators of these pieces (see for example, SPANIOL, 1994). For the current project it was decided that each artistic participant should be given the opportunity to make his/her own decision about anonymity. This process of individual negotiation with participants reflects SPANIOL's (ibid.) guidelines on the use of clients' artworks in an art therapy context. Following conversations with them and their carers, all of the participants referred to in this article expressed a desire to be associated with their work; therefore no attempt has been made to hide their identities. Social scientific conventions were followed, however, when reporting on visitors' and curators' feedback on the exhibition, with no names being used to identify these individuals. [3]

The article which follows considers the "I Will Tell You Something of My Own" project in detail. I begin by defining the challenge which dementia presents for all of us, and especially for those who live with this condition. Particular attention is paid here to the impact of dementia stigma, and the neglect of the social and interpersonal needs of PWD. I then set out how the arts and arts-based research can be used to address these issues and improve the lives of those who live with dementia. This is followed by a consideration of the aims and methodology adopted by "I Will Tell You Something of My Own." Finally, the project is evaluated in terms both of its aims to challenge dementia stigma and understand more about life with dementia, and its success as a piece of PSS. [4]

2. Dementia, Personhood and Disability

The term dementia covers a group of related, but heterogeneous conditions. These have in common a pattern of progressive neurological decline, which ultimately results in severe cognitive and behavioral problems (DURAND & BARLOW, 2013; FEINSTEIN, DUFF & TRANEL, 2010). The former U.K. Government's National Dementia Strategy declares that "dementia is now one of the most significant challenges facing our society" (DEPARTMENT OF HEALTH, 2009, p.70). The same report estimates that dementia costs the U.K. economy around £17 billion per year. Dementia affects a large and increasing number of people, with diagnoses in excess of 24.3 million cases worldwide (FERRI et al., 2005). Despite the many advances that have been made in understanding dementia, however, scientists are still remarkably far from comprehending fully the etiology, course and treatment of this condition (LUENGO-FERNANDEZ, LEAL & GRAY, 2010; RITCHIE & LOVESTONE, 2002). [5]

At present there is no cure for dementia and no medical treatment to reliably and significantly alter the progression of conditions like Alzheimer's disease (DURAND & BARLOW, 2013). Nonetheless, there is an over-reliance on anti-psychotic and other medication in dementia care, with drugs being prescribed widely to manage symptoms, behaviors and emotional states. Depression and anxiety, in particular, are often viewed as symptoms of dementia which can be treated in this way (SUE, SUE, SUE & SUE, 2010). There is growing evidence, however, that the distress, depression and anxiety associated with dementia are at least partly due to the social situations in which PWD find themselves (see for example BALDWIN et al., 2007). [6]

Despite this, the social context and interpersonal needs of PWD are often overlooked (see for example ALZHEIMER'S SOCIETY, 2007). Undoubtedly, this neglect is due partly to the limited resources available to those who care for PWD; however it is important not to ignore the impact which dementia stigma has on the care and daily interactions of people who live with this condition. Tom KITWOOD (1990, 1997) has written extensively on this topic. For him, dementia is more than neurological impairment alone. Instead, it can be defined according to a formula of D = P + B + H + NI + SP, where dementia is viewed as a combination of an individual's *p*ersonality, *b*iography, *h*ealth, *n*euro-*i*mpairment and *s*ocial *p*sychology. [7]

KITWOOD argues for a "new culture" view of dementia, where dementia is redefined as a disability, the nature and extent of which can be largely determined by the quality of care received. This "new culture" perspective rejects pessimistic, deterministic models which position PWD as little more than disintegrating shells, emphasizing instead their capacity to lead full and enjoyable lives in which their "personhood" is upheld and respected. KITWOOD (1997) defines "personhood" as "a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust" (p.8). The relationship between carer and client is thus of central importance here, and care staff are seen as having a responsibility to help clients maintain rich social and psychological lives. [8]

KITWOOD's (1990, 1997) landmark work has been highly influential in the literature and his concept of personhood has been developed further by several theorists (see for example BALDWIN et al., 2007; BARTLETT & O'CONNOR, 2007). "Person-centered care" is now a virtually ubiquitous phrase in the care sector, with numerous care homes, organizations and practitioners proclaiming their work to be based around this model. There is some doubt, however, over the extent to which the concept of personhood has permeated the daily lives of PWD. Sadly, fatalistic descriptions of dementia as "a slow unravelling of the self" or the "living death" (BEARD, KNAUSS & MOYER, 2009, p.227) remain common. Indeed, as STERIN's (2002) revealing autobiographical account observes, the dementia label is still "the kiss of death" (p.8) for many social interactions. [9]

PWD often find that others speak for them, talk about them as though they are not there, or otherwise avoid engaging them in conversation (KILLICK & CRAIG, 2012). This leads to a loss of agency, identity and social connectedness which could at the least be seen to exacerbate the symptoms of dementia and at most be viewed as an alternative explanation for these "symptoms" (KITWOOD, 1997). Related to this is the commonly held view that PWD lack insight into their condition, being unable to recognize or articulate their own needs or desires. Accounts such as STERIN's, however, bring such claims into question, and there is increasing recognition that PWD have greater awareness than they are typically credited with. This moves the onus onto others to provide the conditions which enable PWD to express these thoughts, needs and desires (KILLICK & CRAIG, 2012). [10]

This shift of responsibility away from the individual living with dementia, towards society as a whole, is reminiscent of the social model of disability. Indeed, authors like GILLIARD, MEANS, BEATTIE and DAKER-WHITE (2005) and MARSHALL (1994, 2000) have argued that this model has much to teach us about dementia. They contend that a social model of dementia has the potential to result in more attentive, personalized care, where clients' abilities are emphasized over that which they have lost, and their personal experiences are treated as paramount. As MARSHALL remarks, this model also allows us to take seriously the discrimination and marginalization which are a key feature of life for many PWD. [11]

3. Enter: The Arts

Arts-based interventions using music, dance, visual arts, poetry and life story work are becoming increasingly common in dementia care, as a means of supporting clients' personhood. There are numerous articles attesting to the benefits of such interventions for the sense of self, mood, confidence, cognitive functioning, behavior and quality of life of PWD, as well as for the environments within which these individuals are cared for (see ALLAN & KILLICK, 2000 and BEARD, 2013 for overviews). The arts could also offer a style of communication and self-expression which is better suited to the social and emotional competencies of PWD, than the calm, detached, structured talk which tends to predominate in care institutions (ALLAN & KILLICK, 2000; KITWOOD, 1997). KITWOOD, for instance, argues that we can gain both by listening to the stories and metaphors which PWD use, and by invoking our own poetic imaginations to better understand the dementia experience (and see KILLICK, 1994). [12]

According to ALLAN and KILLICK (2000), arts interventions offer a means to restore dignity to PWD, as well as providing them with a form of meaningful action and a means through which they can exert some control in their lives. DAYKIN, BYRNE, SOTERIOU and O'CONNOR (2010) reinforce this latter notion, arguing that participating in arts projects can open up alternative identities for clients to that of "patient," giving individuals a sense of power/control which they may otherwise lack. This is particularly poignant for PWD, where self-efficacy and autonomy are severely threatened. [13]

Despite the promising developments in this field, however, projects in which PWD are viewed as active, creative participants with the autonomy to make their own choices still form a relatively small proportion of arts interventions in dementia care. Instead, many dementia arts interventions seem to treat the arts as a kind of non-medical tranquilizer, which can be used to subdue and control patients. Thus, interventions have been developed which seek to reduce "wandering behavior," control care home residents during meal times or decrease levels of aggressive behavior (see SHERRAT, THORNTON & HATTON, 2004 for a relevant meta-analysis). Performative social science (PSS), with its emphasis on active participation, relational esthetics and meaningful, creative activities offers an alternative way of integrating the arts into dementia care. This latter approach has the potential not only to actively engage PWD in a way which retains KITWOOD's emphasis on personhood, but also to challenge the stigma which is such a strong feature in the lives of many PWD. [14]

3.1 The many possibilities of performative social science

PSS was described and illustrated in some depth in a special issue of *FQS* in 2008, reflecting a notable rise in such work over recent years (GERGEN & JONES, 2008). Although it is often treated as a single approach, PSS is perhaps better thought of as an umbrella term, which incorporates a wide range of different approaches to social scientific research. These approaches all seek to use the arts in some way as tools for data collection, analysis and/or dissemination. Thus, PSS offers a kind of toolkit, which practitioners can draw on to suit, weaving between different modalities and disciplinary boundaries in the process (ROBERTS, 2008). This inter-disciplinary process disrupts established frameworks, epistemologies and methodologies, opening up new forms of knowledge and new ways of conducting/disseminating research (JONES, 2006). The result is, at its best, neither art nor social science, but a seamless fusion of the two (JONES, 2012). [15]

PSS offers an exciting alternative to the traditional, linear research and dry, academic treatises which dominate the social sciences (ibid.). It allows researchers to draw on the creative and emotional aspects of their work, which are typically suppressed in academic outputs, and acknowledges the role of the researcher as co-creator of the world they represent (see for example BATTISTI & EISELEN, 2008; LAW & URRY, 2004). Accordingly, the "products" of PSS typically move beyond academic articles, to incorporate images, music, theatrical performances, and other media (see DOORNBOS, VAN ROOIJ, SMIT & VERDONSCHOT, 2008 and GLASS, 2008 for some examples). [16]

This opens up social scientific research to larger and broader audiences, exposing them to something which is more accessible, playful, meaningful and above all *human* than the typical journal article, conference paper or textbook (JONES, 2006). Incorporating the arts into research in this way need not mean abandoning the traditional tools of academia, but it does facilitate (and arguably necessitate) a reappraisal of them. JONES, for example, notes that experimenting with artistic means of research dissemination allows researchers to return to more traditional forms of output with a more creative lens. [17]

The term "performative social science" was not coined by DENZIN until 2001; however dialogue between the arts and social sciences has a long and complex history. ROBERTS (2008) traces multiple strands of PSS, each with its own developmental trajectory, concerns and methods. These strands originate in both the arts and the social sciences, and include such diverse traditions as ethnodrama/ethnotheater, performance art, experimental and ethnographic film, a/r/tography, ethno-mimesis, visual anthropology, movement studies and virtual ethnographies. [18]

ROBERTS locates PSS within a broader "turn" to performance, which arose from the 1940s-1950s focus on social interaction as a kind of dramaturgical performance (see for example GOFFMAN, 1971) and from later work on culture as a performance (see for example BUTLER, 1990). This "turn" to performance highlights the communicative nature of research and the inclusion of the audience as a key part of the research process, both concerns which are central to PSS. JONES' work (2006, 2012) illustrates this "relationality" well, drawing on BOURRIAUD's (2002) concept of "relational esthetics" to emphasize collaborative meaning, inter-subjectivity, and "conviviality." BOCHNER and ELLIS (2003), meanwhile, contend that PSS can challenge the traditional separation between researchers, artists, participants and audiences by providing new forms of meaning, investigation and expression. Thus, PSS offers an innovative means for social scientists to empower participants, engage new audiences and achieve meaningful change for the communities at the heart of their research. [19]

"I Will Tell You Something of My Own" fits firmly within this collaborative remit. Central to this project was the desire to give PWD the opportunity to express themselves in creative, meaningful ways and to help combat the stigma which these individuals face because of their condition. PWD were involved in designing and promoting the project; they inspired, created and narrated the project's artworks; and they formed a key part of its audience. The project also speaks to BOURRIAUD's (2002) aim of bringing together disconnected levels of reality, in that it sought to ignite conversations between PWD, members of their local communities and others, as well as between artists and social scientists (see JONES, 2012). [20]

Whilst there are clearly many benefits to be gained by forging connections between the arts and social sciences, this ambitious endeavor also presents many challenges however. SALDAÑA (2003), JONES (2012) and others, for instance, have criticized the tendency of some researchers to look to the arts, without giving sufficiently close thought to the modalities, principles and processes on which they draw. JONES is particularly critical of what he sees as the over-use of theater in PSS, and of the failure of some researchers to fully grasp the extent of the skills and knowledge they require to work successfully in the artistic domain (see for example GERGEN & JONES, 2008). One solution which JONES proffers is for social scientists and artists to form partnerships, pooling their respective skills and knowledge. In line with this, the current project utilized the combined talents of visual artist Elisabeth TURFREY, musician Benita JOHNSON, poet Karen HAYES, photographer Viv JONES and myself (a poet and social scientist). [21]

4. Creating/Performing "I Will Tell You Something of My Own"

"I Will Tell You Something of My Own" took as its starting point (and for its title) a collection of poems co-written by Karen HAYES for the "Try to Remember" project (see GREGORY et al., 2012a, 2012b). In "Try to Remember," Karen worked with PWD to create poems about themselves and their lives. The poems were then read back to co-authors, their carers and their family. Many of the professional carers who were interviewed about the project said that these poems changed their view of those in their care, emphasizing clients' humanity and personhood (GREGORY, 2011). [22]

"I Will Tell You Something of My Own" sought to make these poems available to a broader audience and to develop a wider collection of artworks with PWD. The project brought together Karen's poems with photographs by Viv JONES, songs by Benita JOHNSON, poetry-song fusions by Yaffle[1], and a collection of three dimensional collages, created/narrated by PWD and Helen GREGORY. These artworks were initially displayed in a six week long exhibition in Stroud, England between December 2013 and January 2014, and shortly afterwards in a three day long exhibition for "Strike a Light Festival" in nearby Gloucester. [23]

The exhibition was staffed by a team of 24 volunteers, who were trained by the project team over one of three sessions. Training sessions covered the project aims, methodology and background, the structure of the exhibition, the curatorial role and issues around dementia awareness. Volunteers were asked to guide visitors around the exhibition, look after the artworks and manage any contributions to the collaborative elements of the collection. These contributions were invited from visitors with experience of dementia, and could take the form of photographs, journal entries or everyday objects added to Elizabeth TURFEY's collaborative display. [24]

4.1 Poems, photographs and songs

Eight of the "Try to Remember" poems were presented in the exhibition. Six of these were displayed on semi-transparent viscose curtains. The remaining two were printed on a canvas and an old suitcase respectively. For the main run of the exhibition, these objects were arranged as part of a living room scene which made use of a fireplace on one of the gallery's walls (see Figure 1).

Figure 1: Living room scene (Gary LEARMONTH, Red Piranha Photography)[2] [25]

---

[1] A poetry/music duo formed by Benita JOHNSON and Helen GREGORY, see f.e. https://www.youtube.com/watch?v=Ihf6cHqc-2k [Accessed: August 28, 2014].

[2] All photographs presented in this article are published with permission from the photographer.

The poetry composition process is described in full in GREGORY (2011). Briefly, Karen met with PWD in care homes, residential centers and their own homes. She asked participants to tell her about themselves and wrote down their responses as fully as possible. These notes formed the basis of the poems. Importantly, Karen deleted words from her notes, but did not add any, so that the poems are composed entirely in participants' own words. [26]

The poems displayed in the exhibition speak to a range of topics, reflecting participants' diverse interests, emotions, experiences and recollections. Some, such as the poem which opens this article ("The Same as Life"), are poignant musings on life with dementia, covering issues like memory, identity and the slippery, transience of everyday life. Others appear to leave aside dementia, focusing instead on fragments of memories—the scent of roses, childhood lessons, adventures made unreal by time, "fairies in [the] bedroom." Most combine these concerns, revealing dementia as just another aspect of participants' lives—important yes, but framed by a lifetime of experiences and intermingled with the familiar hopes, challenges, highs and lows of lives being lived. [27]

Each poem was accompanied by a photograph, which was either mounted on the wall behind the relevant curtain or set amongst the fireside scene. The photographs were taken in direct response to the poems. They feature everyday objects and scenes from contemporary and remembered landscapes—a makeshift scarecrow framed by garden rubble, a moldering caravan, an old radio, a distant fishing boat sailing towards the shore. The photographer, Viv JONES, worked with Karen as project manager on "Try to Remember," and was thus able to meet many of the co-authors who inspired her photographs. [28]

Benita JOHNSON's songs and Yaffle's poetry-song fusions were available for exhibition visitors to listen to using a computer, which also linked visitors to websites offering information and support around dementia. (For the Gloucester run the pieces were presented instead using a wireless MP3 player.) Benita's songs were inspired by conversations with PWD. "Train of Thought" draws on Gordon PAVEY's metaphor of his difficulties with thought and communication as being like waiting for the last carriage of a train to catch up with the others. "Feel Your Way," meanwhile, was inspired by ex-minister Lewis REYNOLDS' parable-like stories of meeting someone in need[3]—another metaphor for life with dementia, but one containing a lesson about how he would like to be treated. [29]

Benita's songs were specially commissioned for "I Will Tell You Something of My Own." The Yaffle pieces, in contrast, date back to the "Try to Remember" project. These poetry-song fusions (affectionately termed "pongs") speak to themes of love, loss and memory, which were prominent in this earlier intervention. These "pongs" and Benita's songs can also be listened to on the "I Will Tell You Something of My Own" Soundcloud site. [30]

---

[3] Both sources from personal communications with Benita JOHNSON.

4.2 The collaborative display

The collaborative display was included in the main (Stroud) run of the exhibition only, due to space restrictions at Gloucester. This display offered an opportunity for visitors with experience of dementia (either directly or through family members, friends, clients and others) to contribute to the exhibition themselves. Visitors were asked to leave an object which evoked something about their dementia experiences, and to complete a small index card explaining the object's significance to them. These objects were placed on a display designed by Elisabeth TURFREY. The display was formed from a jumble of second hand coffee tables which Elisabeth describes as "a small monument to those living with dementia" (TURFREY, 2013, p.33). The tables, with their pocked surfaces, coffee cup scars and wobbly legs, evoked the everyday "human-ness" of times gone by. As Elisabeth puts it in the exhibition brochure: "These ordinary objects, which we can all relate to are representative of past lives and of the domestic, a poignant reminder of lives lived" (p.32). Figure 2 shows the display as it was towards the start of the exhibition run.

Figure 2: Collaborative display (Gary LEARMONTH, Red Piranha Photography) [31]

Visitors were also able to contribute to the exhibition by inserting photos of, by or about PWD in a shared photograph album, by writing stories, poems and other recollections in a journal, and by leaving comments in the guest book. These books were placed on an old writing bureau, which underscored the installation's intermediate status somewhere between artistic and domestic spheres. [32]

4.3 Creating collages

The confluence of art and social science in this project is most readily observable in the construction of the three dimensional collages and their accompanying narratives. Five of these pieces were created, in collaboration with five PWD and one participant whose father had been diagnosed with dementia prior to his death. The pieces contain objects which were selected in a series of creative sessions facilitated by GREGORY. Four of the pieces took the form of box frames, while the fifth used unframed objects arranged on a white plinth. [33]

The creative sessions were based around semi-structured interviews, in which participants were asked about their everyday lives, selves and experiences (see Appendix 1 for the interview schedule and GUBRUIM & HOLSTEIN, 2002; SMITH, 1995 for more on semi-structured interviews.) Most participants were interviewed over two sessions. The one exception to this was the participant who created a frame for his father, where the work was carried out over a single session. In the first interview, the questions were designed to glean a general understanding of participants' interests, activities and identities, as well as exploring what they felt about dementia and how the condition had impacted their life. The latter portion of these interviews focused on salient objects, which participants felt told a story about their life or represented something that was important to them. In the second interview, participants were asked to expand on the significance of the objects they had chosen to include in their piece. [34]

The process through which the final set of objects was selected varied. In the majority of cases participants worked with family members between sessions to make their final selection. In one case, however, the participant had no one to work with in this way. Further, living in a care home meant that she had few personal possessions from which to draw. This difficulty was overcome by providing the participant with a collection of objects, selected to represent core themes from her initial interview. The participant chose her frame items from this larger collection. These selected objects were then clustered around a copy of a photograph of her and her family taken when her children were young (see Figure 3).

Figure 3: "And off we'd go to the dances" (Gary LEARMONTH, Red Piranha Photography) [35]

The interviews were audio recorded and transcribed, and the transcripts analyzed using thematic analysis. Thematic analysis is an iterative process, where the text is read repeatedly, with the researcher seeking to identify recurrent patterns of meaning within the data (see BRAUN & CLARKE, 2006). It is a flexible method, which is used widely (though less often unacknowledged), and which can be applied to a range of different research questions and epistemological stances. This flexibility makes it an ideal tool for PSS practitioners. In this study, thematic analysis was used to construct a narrative to accompany each frame/display. These narratives use the objects in the piece to illuminate their lives, selves and experiences, with the emphasis on participants' own words as far as possible. Thus, the objects were taken as the starting point for the thematic analysis process and themes were "pinned" to these. This created a series of multi-layered texts, each titled with a quotation from the piece's co-creator/s. [36]

As with the poems, these pieces reflect on general memories, experiences and emotions, as well as issues that are more specific to life with dementia. For example, Lewis (an ex-minister and postman with a diagnosis of Alzheimer's disease) contends that dementia is "the background," rather than the essence of his identity. He stresses: "It's not me ... it isn't who I am. It's part of my situation." These dialogues demonstrate participants' awareness both of their cognitive difficulties and of how others respond to them, challenging the notion that PWD have no insight into their condition. Thus, Joyce (a former nanny living with Alzheimer's disease) complains that people "treat me like I'm old sometimes. You know 'Oh she won't remember' or whatever" (see Appendix 2 for the full narrative that accompanies Joyce's frame, as depicted in Figure 3). [37]

5. Impacts and Outcomes

JONES (2012, p.6) argues that "part of 'doing' PSS is the breaking down of old boundaries and previous expectations such as what research is supposed to resemble after it is 'finished.'" PSS also disrupts the traditional, linear research trajectory which begins with the formulation of a project, and moves through data collection and analysis, before settling on dissemination of the finished product (ROBERTS, 2008). This presents something of a challenge for performative social scientists seeking to write up their research. It raises questions around what counts as "results" in PSS research and how these can best be conveyed. One possibility is that the artworks themselves constitute the "findings" of a piece of PSS. This reflects the blurring of boundaries between methodology and results to which ROBERTS alludes. [38]

In this sense, the output of "I Will Tell You Something of My Own" is illustrated in Section 4 of this article. It is told through the photographs of the artworks and the extracts of the narratives created for this project, as well as the exhibition brochure, websites and, of course, the exhibition itself. For projects like this, with parallel (as well as blended) arts/social science outputs, the findings are also conveyed through more traditional journal article formats. In this case, an interpretative phenomenological analysis of the interview data will be written during the project's second stage (see SMITH & OSBORN, 2008 for more on interpretative phenomenological analysis). This analysis will focus on participants' discussions of what it is like to live with dementia, aiming to illuminate these subjective experiences further. [39]

In order to evaluate the project's impact fully, however, it is important to critically consider the effectiveness of the exhibition and the wider project within which this is embedded. There is no agreed standard as yet by which to judge the quality of PSS work (GERGEN & JONES, 2008). JONES (2007) does, however, provide us with a starting point for this endeavor. He argues that PSS projects should be evaluated on six core criteria: the impact they have on the audience; the extent to which the audience is involved in a dialogue with the work; the inclusion of the public as co-creators; their ability to bring people together to build their understanding of an issue; their capacity to bridge distances between people through intuition and association; and their ability to connect previously disconnected levels of reality. The extent to which "I Will Tell You Something of My Own" met each of these criteria is considered below: Subsection 5.1 focuses particularly on audience impact and understanding; subsection 5.2 explores dialogue and co-creation; and subsection 5.3 emphasizes connections and bridge building. [40]

These discussions are illustrated with reference to qualitative and quantitative data, including visitors' comments, participants' comments and audience figures. These data were taken from 33 questionnaires completed by exhibition visitors (see Appendix 3), ten e-mails sent by visitors and participants, 47 guestbook comments and records kept by the project team. [41]

5.1 Audience impact

For JONES (2006, 2012), it is vital that PSS is embedded in communities and aims to achieve meaningful change for members of those communities. The current project aimed to enact meaningful change for PWD by altering the ways in which others think about and interact with individuals diagnosed with this condition, and by challenging pervasive dementia stigma. In order for this to happen, the work must first reach its intended audience. In this respect, the project was certainly successful, with a total of 894 visits to the Stroud run of the exhibition, and an estimated total reach of approximately 9,510 people (including exhibition visitors, audience at outreach talks, listeners to radio broadcasts, visitors to internet platforms and other project offshoots). This audience is expected to grow as the project continues to be promoted online, through conference presentations and through articles such as this. [42]

From comments in the guestbook and feedback questionnaires, however, it is clear that many of the visitors already endorsed the project's aims prior to attending the exhibition. One questionnaire respondent, for example, wrote that: "I already felt compassion and respect for [people with] dementia and still do." For many visitors, then, the exhibition reinforced their positive perceptions of PWD, rather than challenging more negative views. Interestingly, several such individuals returned to the gallery with others or recommended the display to their friends and colleagues, suggesting that they were using the exhibition as a vehicle through which to communicate these pre-existing views and perhaps challenge the more negative views of others. This desire to share the exhibition materials/messages more widely is supported by a number of comments. Thus, one respondent said that: "[The exhibition has] endorsed my own attitudes and knowledge. We still have a long way to go in helping others with no experience understand" (questionnaire comment). Other questionnaire comments, meanwhile, urged the team to carry on "spreading the word, so that the public are aware of the continuing contribution sufferers can make" or argued that the project "deserves greater public exposure till we understand." [43]

Nonetheless, many visitors did report that their views had been challenged. Overall, 38% of questionnaire respondents said that the exhibition had changed the way in which they viewed PWD, compared to 50% who said that it had not and 12% who did not answer this question. When asked how their views had changed, participants gave a range of answers, including that it had shown them PWD "have a lot more to offer," can be "creative" and have "stories to tell and share," and that they felt less "fearful" and more respectful of PWD (all questionnaire comments). A common thread here was that visitors felt more positive about dementia than they had done previously. This is summed up well by one questionnaire respondent, who commented that: "It has given me a much more positive view of people with dementia—it has always seemed so negative." [44]

For most commentators this positivity was welcome, with one visitor referring to the exhibition as "more of a tribute really" and another musing: "Let's hope we learn to treat dementia more as a friend than an enemy" (both guestbook comments). Other visitors specifically valued the exhibition's focus on the individual lives and selves of PWD. Thus, one guestbook comment read:

> "This exhibition makes Dementia more understandable as a reality, not just a label for a condition. ... It is very interesting and poignant (as before in comments) to see how people's lives and experiences influence what they make of their condition positively and creatively!" [45]

It is clear from these comments that the personhood of participants was prominent for many visitors, and that they left the exhibition with a sense that participants could be defined by numerous experiences and attributes, rather than by dementia alone. (In KITWOOD's,1990 terms they acknowledged the project's participants as *people* with dementia, rather than people with *dementia*.) Not everyone valued this positive portrayal of PWD however, and one visitor complained that: "You've missed the dark side. I would have liked to see all sides of dementia represented" (guestbook comment). [46]

Taken together, these comments suggest that the exhibition was successful in its aim of illuminating the continuing competencies, humanity and worth of PWD. For some visitors this challenged their existing views of dementia and of those who live with this condition. In this sense, the exhibition also met its aim of combating dementia stigma. Others, however, arrived already valuing a person-centered approach to dementia. For this latter group, the display served a different function, reinforcing their convictions and, in some cases, providing them with a medium through which they could communicate these to others. [47]

5.2 Participation and dialogue

For JONES (2006, 2012), "relationality" is a key aspect of PSS. It is important that members of a community play a role in creating work and that the audience is able to enter into a dialogue with work once it is created. "I Will Tell You Something of My Own" was conceived of as a participatory project throughout. PWD were involved in designing the exhibition through informal consultations and participation in a steering group. Furthermore, all of the artworks displayed in the exhibition were either created in collaboration with individuals from this community or inspired by conversations with them. The project was also collaborative in other ways: The exhibition audience was invited to augment the collection with contributions to the photo album, journal and collaborative display; and a team of 24 volunteer curators joined the project team to help staff the exhibition throughout each of its runs. [48]

Participants with dementia who helped to create artworks for the exhibition were typically very positive about their role, welcoming the opportunity to express themselves creatively. As RATNAIKE (2013) reported after interviewing one participant for an Alzheimer's Society magazine article: "Lewis says he feels proud to be part of the project. 'Helen [GREGORY] helped me to pick objects from my life and build up a picture using little things that are symbols of what I've done and achieved'" (pp.18-19). The exhibition launch, which featured performances from Benita JOHNSON, Karen HAYES and Yaffle, as well as short talks from other members of the project team and the project's celebrity patron Jamie ANDERSON, was an especially enjoyable experience for those who attended. The daughter of one participant, for instance, e-mailed after the event to say "We had a great evening and Mum [was] much brighter even next morning!" The launch was particularly welcomed for the opportunity which it gave participants to be heard. As one participant said: "People were listening—that was the thing—they wanted to hear what we were saying ... Special is what it was. They took the time to talk to us" (comment in e-mail from participant's step-daughter). Several participants made similar comments in the interview sessions, with one saying simply, "Thank you very much for talking to me." [49]

The exhibition curators, meanwhile, participated in the project by staffing the exhibition and interacting with visitors. It was also part of their role to manage visitor contributions to the collaborative display and photograph album. The 24 volunteers were recruited from a range of sources, including Age UK Gloucestershire, the University of Gloucestershire and Barnwood Trust. As mentioned previously, all volunteers were trained about the project and its aims. Their prior experience and knowledge around dementia varied greatly however. Some had worked in care homes with PWD or trained in the field, others had family members with diagnoses of dementia, some had a basic theoretical knowledge of dementia as a medical condition, while others came to the project knowing little about dementia or what it is like to live with this. [50]

The nature and extent of volunteers' participation in the exhibition also varied. Some keenly engaged visitors, encouraging them to chat and to contribute to the collaborative collections. Others sat quietly when people entered, allowing visitors to look around in silence. Unfortunately, relatively few of the volunteers provided written feedback on their role. Those who did send comments, however, were enthusiastic about their participation. One curator, for instance, e-mailed to say:

> "I just wanted to say a massive thank you for letting me be part of the ‘I Will Tell You Something of My Own Project', it really opened my eyes to the many positives around dementia rather than the negatives that are frequently illustrated ... it was fascinating to meet people and talk about their own experiences and knowledge about dementia as well as the enthusiasm they had for potential future projects." [51]

As this comment makes clear, many visitors were keen to share their own stories about dementia with the curators, and one curator commented on "the many interesting, touching, difficult and challenging conversations that visitors drew me into" (e-mail). Conversations like these were the principal means through which most visitors contributed to the project, and they represent an important point of dialogue between audience and artworks. Thus, as another curator wrote: "The exhibition stimulated several different types of conversations, about people's own experiences of people with dementia, the prospect of getting it themselves and how they felt about that and just the quality and characteristics of the art" (e-mail). [52]

Audience members also engaged actively in the project by completing feedback questionnaires and adding their reflections to the guestbook. (Overall, there were 47 guestbook comments, some of which ran to several pages.) Visitors were less keen, however, to contribute to the shared photo album or collaborative display. Indeed, the majority of such contributions were supplied by participants who had already helped to create artworks for the core collection. These contributions were joined by photographs e-mailed to the project lead and posted on the "I Will Tell You Something of My Own" Facebook page, and by an assortment of old clothes collected by the activities coordinator of a local day care center. [53]

Overall, the project succeeded in engaging members of the target community and in creating a dialogue with the audience. PWD participated in creating and inspiring art works, welcoming this opportunity for a creative outlet through which they could express themselves. Curators participated too, though their curatorial role was limited by the scant number of visitor contributions to the collection. Instead of managing an evolving collection of objects and photographs, curators participated by engaging with visitors and providing a space within which these individuals' stories could be heard. Indeed, it was common for curators to report having (often long and emotive) conversations with visitors. Whilst it did not take the expected form, then, dialogue with the audience remained an integral part of this project. [54]

5.3 Connections and synthesis

JONES (2007) highlights several points of connectedness, which he feels are important for PSS. These describe a project's ability to bring together both people and different levels of reality, building new associations and forging new understandings in the process. This kind of bridge building should be central to any project that seeks to challenge social stigma, as does "I Will Tell You Something of My Own." Accordingly, the key point of connection which this project sought was between PWD and others, including both individuals who had previous experience of dementia (82% of questionnaire respondents) and those who did not (18% of respondents). [55]

As the comments above indicate, many visitors and PWD alike felt that the project was successful in forging such connections. Participants with dementia spoke of being listened to and feeling more understood as a result of their involvement in the project. Many visitors and curators, for their part, reported an increased level of understanding and empathy with PWD. One visitor, for example, commented on "the whole feeling of there being no 'them and us'" (questionnaire comment). Another visitor, meanwhile, wrote that that the exhibition "really communicates the experience of dementia, but from the inside and the impact of those trying to understand and relate to it from the 'outside'" (guestbook comment). Others argued that the exhibition helped them to articulate their existing opinions about dementia, rather than challenging these ideas: "It's just put into very moving words some of my existing thoughts ..." (questionnaire comment). [56]

JONES (ibid.) emphasizes the importance of intuition and association as a means through which PSS can bridge the gaps between people. This alludes to the ability of artworks to touch their audience on an emotive and unconscious level (see for example BATTISTI & EISELEN, 2008). The guestbook comments give a good feel for the exhibition's ability to do just this, with visitors describing the display as "moving," "poignant," "peaceful" and "evocative." These are words which conjure up emotions and felt associations, rather than the rational, intellectual responses typically associated with academic outputs. That is not to say, however, that visitors did not also reflect on the artworks in this latter sense. Indeed, the very fact that they wrote these comments suggests some conscious reflection on the work. Accordingly, for many visitors the exhibition was both "thought provoking and moving" (guestbook comment). [57]

In terms of different levels of reality, the most obvious connections forged by PSS are interdisciplinary—between the arts and social sciences, academics and artists. "I Will Tell You Something of My Own" brought together four artists and one academic and created pieces which contain elements of both these domains. The clearest example of this confluence is the three dimensional collages, which could be described as visual artworks, narrated through qualitative methodology. Individuals' subjective experiences could also be viewed as constituting different levels of reality. Thus, it could be argued that the exhibition brought together previously unconnected levels of reality by enabling the outward expression of participants' lives and selves. As one visitor wrote: "I felt the poems and art works were real voices of those taking part, that I could very nearly hear them speaking about their objects, artworks and lives" (questionnaire comment). For many visitors this sparked off their own memories of people they know or had known with dementia. One guestbook comment, for example, read: "So much resonated with me in remembering my own mother and her life." Others felt spurred to seek out these stories and build new connections: "This reminded me of the stories people have to tell and the wish I have to get those stories from [my] Nan" (questionnaire comment). [58]

6. Conclusions

"I Will Tell You Something of My Own" was an innovative project using performative social science to explore the lives, selves and art of people with dementia. The aims of this project were twofold: to understand better what it is like to live with dementia; and to help combat the stigma which PWD face daily, by illuminating the continuing humanity and competencies of those who live with this condition. The project sought to fulfill these aims through the creation and display of collaborative poems, photographs, songs and visual artworks and through qualitative analysis of interviews with PWD. [59]

To a large extent, the project can be considered to have met its aims. Many visitors and curators reported an increased understanding of what it is like to live with dementia, and greater respect and empathy for those who have this condition. Others, who arrived at the exhibition with a pre-existing belief in the value of person-centered care in dementia, used the artworks to reinforce these convictions and sometimes to share them with others. The project was also successful in terms of JONES' (2007) criteria for evaluating PSS, providing opportunities for dialogue and participation, building bridges between different disciplinary and subjective worlds, and impacting the audience both emotionally and cognitively. [60]

The project did not always unfold as expected however, and there is certainly room to develop this work further. In particular, more work needs to be done to reach audiences who hold strongly negative views of dementia, where the dominant perception is of PWD as "sufferers," rather than people who live with a condition or disability, and dementia itself is seen as a kind of "living death" (BEARD et al., 2009, p.227). Reaching this audience may mean working within different art forms and platforms, making greater use of online sites like YouTube and Soundcloud, and creating artworks that appeal to the kinds of audience who are unlikely to visit an art gallery. The time is ripe for such developments, as the worlds of art and academia continue to create sparks with the controlled collision that is PSS. [61]

Acknowledgments

I would like to thank the artists, supporters, participants and their families without whom this project would not have been possible, in particular: Arts Council England/The National Lottery and NHS Gloucestershire who funded the project; Elisabeth TURFREY, Benita JOHNSON, Karen HAYES and Viv JONES who created artworks for the exhibition; and Christina SNELL and Chris WALKER of Age UK Gloucestershire, who were supportive in many ways.

Appendix 1: Sample Interview Schedule

Interview sessions were led by participants' interests, enthusiasm and cognitive abilities, as well as by the objects they selected. Accordingly, this represents a prototypical schedule only. Following the semi-structured interview method, both the order of the questions/stages and the questions themselves differed notably between participants.

Interview One

Warm up:

- Description of project aims, interview structure and process of collage construction
- Discussing of ethical issues including consent, right to withdraw and confidentiality

Stage one:

- Can you tell me a little about yourself?
- What is important to you?
- What kinds of thing do you do? (What do you like to do?)

Stage two:

- What is it like to live with dementia?
- What is challenging/difficult about living with dementia?
- Do you think that people treat you differently now that you have dementia?

Stage three:

- Reminder of collage construction
- What objects are important to you?
- Is there anything in this room that really says something about you and your life?
- Can you tell me more about this particular object? Why is it important to you?

Stage four:

- Is there anything else you'd like to tell me?
- Let's end on a positive note. Can you tell me what kind of things make you happy?

Interview Two

Warm up:

- Reminder of project aims and previous interview conversation (In some cases it was possible to give the participant the transcript of the first interview at this point.)

Stage one: Taking each object in turn …

- Can you tell me why you chose this object?
- Why is it important to you?
- Is there anything in particular you'd like to say about it?

Stage two:

- Would you like these objects displayed in any particular way?
- Discussion of fixings (permanent or temporary)
- What do you think we should call this collage?

Stage three:

- Is there anything else you'd like to tell me?
- Thank you and reminder of project aims/details and right to withdraw

Appendix 2: Joyce's Frame—"And Off We'd Go to the Dances"[4]

As the title indicates, dancing has always been very important to Joyce: "During the war I used to spend my every evening on a dance floor, because where I lived in South London all the dance halls were around there ... it was 'which one we going to tonight?' and off we'd go to the dances." This passion and energy are juxtaposed against her current life, which she describes as "nothing very exciting," adding: "I'm just old now, all the fun's gone out of me." Joyce struggles with her memory and with ordering her thoughts, saying "my brain isn't as good as it used [to be]." She prefers to "try and avoid" thinking about dementia and to focus on "the happy times." Creating this frame gave Joyce the opportunity to reflect on these times, interacting "on a different angle to what I'm with every day." This contrasts with occasions when others "treat me like I'm old sometimes. You know, 'Oh she won't remember' or whatever."

Figure 3: "And off we'd go to the dances" (Gary LEARMONTH, Red Piranha Photography)

The photograph is taken from Joyce's collection. She treasures these pictures, as they "really trigger things that I love." Joyce describes this photograph as "a very

---

[4] As with the other collage narratives, this text was written by Helen GREGORY, drawing heavily on interviews with Joyce. The piece was titled by Joyce and Helen collaboratively and the overall piece was approved by Joyce prior to it being exhibited.

casual picture ... not too regimented." It shows Joyce with her husband and her sons, all of whom she values greatly. She describes her husband as "clever," "handsome," and "the love of my life." Joyce misses him enormously now that he is dead, saying: "I know I shall never see him again now, and that's the horrible part." The picture was taken in their garden in Florida, America, which Joyce describes as a "lovely country, lovely people." It is mounted on some *book pages*, which show how Joyce spends some of her time now, reading what she labels "all sorts of junk." The pages are jumbled up, because Joyce feels that her current life lacks clarity and order: "My life now is very mixed up and nothing's solid really."

The piece of net indicates Joyce's love of dancing. She associates dancing very much with her husband, who she met on a dance floor and who taught her to dance everything from ballroom to "waltz, quickstep and jitterbug, jive." As she says "[I] loved every minute of it," "dancing was my life." *The foot plasters* allude to how tough all this was on Joyce's feet. Thus she describes the stilettos she once wore: "Did you see these ridiculous shoes I used to wear? ... they were like satin, royal blue satin." Joyce loves dancing still, but she no longer dances herself: "I couldn't dance like I used to. I haven't even got any shoes to dance in anyway, except these damn things."

The spy hole represents Joyce's need for "peace and quiet," something which can be difficult to find in a care home. This is particularly pressing for Joyce because of the conservatory being built outside her room. She worries about the builders working nearby and about the residents who will sit in the conservatory, saying "I'm entitled to my privacy."

The mittens show how much Joyce loves children, both her own and others she has cared for: "I've always been very associated with children, being a nanny ... I do love children, and I've looked after an awful lot." Childcare is not a role Joyce is about to reprise however: "I don't think I'd want to do it now though. I've got over the charm, because they take a lot of your time, children, and you've gotta make them behave too ... some of them are little devils."

Dogs have also been prominent in Joyce's life, as shown by *the dog lead*. She worked at a kennel club when she was younger and says: "We used to go to all the dog shows, Crufts[5] especially, and a great doggie life it was." Joyce always had the kind of dog she describes as "daft," rather than larger Alsatian types. Like many of the other objects in this frame though, dogs are no longer an active part of Joyce's life. As she remarks: "I don't have a dog now. I mean I couldn't look after a dog here. It's too difficult."

---

[5] Crufts is an annual U.K.-based event, that bills itself as "the world's largest dog show."

Appendix 3: Feedback Questionnaire for Exhibition Visitors

If you have a few minutes spare, we would appreciate your feedback. This will be fed back to our funders and used to inform future work around dementia. Comments may also be used to enrich Helen Gregory's research in this area. If you do not wish your comments to be included in this research, please write ‘not for analysis' in the top right hand corner of this sheet.

Q1) How did you hear about the exhibition? (Please delete as appropriate.)

flyer / poster / outreach talk / from a friend or colleague / radio / newspaper / other (please state):

Q2) What made you decide to visit this exhibition?

Q3) Did you loan any items or photos to the exhibition?

Yes/No (delete as appropriate)

Q4) Do you have experience of dementia yourself (either directly or through work, family or friends?)

Yes/No (delete as appropriate)

Q5) Has this exhibition changed the way you view people with dementia?

Yes/No (delete as appropriate)

If so, in what ways?

Q6) What did you like most about the exhibition?

Q7) How do you feel the exhibition could be improved?

Q8) Would you recommend this exhibition to others?

Yes/No (delete as appropriate)

Q8) Is there anything else you wish to add?

Thank you for visiting our exhibition and taking the time to tell us what you think about it.

Helen Gregory

Project Lead

References

Allan, Kate & Killick, John (2000). Undiminished possibility: The arts in dementia care. *Journal of Dementia Care*, *May/June*, 16-18.

Alzheimer's Society (2007). *Dementia UK. The Full Report*, http://alzheimers.org.uk/site/scripts/download_info.php?fileID=2 [Accessed: March 11, 2014].

Baldwin, Clive; Capstick, Andrea; Phinney, Alison; Purves, Barbara; O'Connor, Deborah; Chaudhury, Habib & Bartlett, Ruth (2007). Conceptualizing personhood in dementia. In Clive Baldwin & Andrea Capstick (Eds.), *Tom Kitwood on dementia: A reader and critical commentary* (pp.171-188). Berkshire: Open University Press.

Bartlett, Ruth L. & O'Connor, Deborah (2007). From personhood to citizenship: Broadening the conceptual base for dementia practice and research. *Journal of Aging Studies*, *21*(2), 107-118.

Battisti, Martina & Eiselen, Tanja (2008). Insights through performative approaches. *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research*, *9*(2), Art. 44, http://nbn-resolving.de/urn:nbn:de:0114-fqs0802444 [Accessed: March 7, 2014].

Beard, Renne (2013). *Dancing away memory blues. Enriching lives of persons with memory challenges*, http://dancing-away-memory-blues.blogspot.com/feeds/posts/default?orderby=updated [Accessed: March 13, 2014].

Beard, Renee L.; Knauss, Jenny & Moyer, Don (2009). Managing disability and enjoying life: How we re-frame dementia through personal narratives. *Journal of Aging Studies*, *23*, 227-235.

Bochner, Arthur P. & Ellis, Carolyn (2003). An introduction to the arts and narrative research: Art as inquiry. *Qualitative Inquiry*, *9* (4), 506-514.

Bourriaud, Nicolas (2002). *Relational aesthetics.* Dijon: Les Presses du Réel.

Braun, Virginia & Clarke, Victoria (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77-101.

Butler, Judith (1990). *Gender trouble.* London: Routledge.

Daykin, Norma; Byrne, Ellie; Soteriou, Tony & O'Connor, Susan (2010). Using arts to enhance mental healthcare environments: Findings from qualitative research. *Arts & Health*, *2*(1), 33-46.

Denzin, Norman K. (2001). *Interpretative interactionism* (2nd ed.). London: Sage.

Department of Health (2009). *Living well with dementia: A national dementia strategy*, http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_094058 [Accessed: March 11, 2014].

Doornbos, Anja; van Rooij, Marloes; Smit, Maaike & Verdonschot, Suzanne (2008). From fairytales to spherecards: Towards a new research methodology for improving knowledge productivity. *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research*, *9*(2), Art. 48, http://nbn-resolving.de/urn:nbn:de:0114-fqs0802484 [Accessed: March 13, 2014].

Durand, V. Mark & Barlow, David H. (2013). *Essentials of abnormal psychology* (6th ed.) Belmont, CA: Wadsworth.

Feinstein, Justin S.; Duff, Melissa C. & Tranel, Daniel (2010). Evidence for the sustained experience of emotion beyond declarative memory. *Proceedings of the National Academy of Science*, *107*(17), 7674-7679.

Ferri, Cleusa P.; Prince, Martin; Brayne, Carol; Brodaty, Henry; Fratiglioni, Laura; Ganguli, Mary; Hall, Kathleen; Hasegawa, Kazuo; Hendrie, Hugh; Huang, Yuegin; Jorm, Anthony; Mathers, Colin; Menezes, Paulo R.; Rimmer, Elizabeth & Scazufca, Marcia (2005). Global prevalence of dementia: A Delphi consensus study. *Lancet*, *366*, 2112-2117.

Gergen, Mary & Jones, Kip (2008). Editorial: A conversation about performative social science. *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research*, *9*(2), Art. 43, http://nbn-resolving.de/urn:nbn:de:0114-fqs0802437 [Accessed: March 7, 2014].

Gilliard, Jane; Means, Robin; Beattie, Angela & Daker-White, Gavin (2005). Dementia care in England and the social model of disability: Lessons and issues. *Dementia*, *4*, 571-586.

Glass, Nel (2008). Interrogating the conventional boundaries of research methods in the social sciences: The role of visual representation in ethnography. *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research*, *9*(2), Art. 50, http://nbn-resolving.de/urn:nbn:de:0114-fqs0802509 [Accessed: March 7, 2014].

Goffman, Erving (1971). *The presentation of self in everyday life*. Harmondsworth: Penguin.

Gregory, Helen (2011). Using poetry to improve the quality of life and care for people with dementia: A qualitative analysis of the Try to Remember programme. *Arts & Health*, *3*(2), 160-172.

Gregory, Helen; Hayes, Karen; Jones, Viv & Opher, Simon (2012a). Using poetry in dementia care: Four voices, one journey. *Journal of Dementia Care*, *Jan/Feb*, 27-30.

Gregory, Helen; Hayes, Karen; Jones, Viv & Opher, Simon (2012b). Issues and impacts of poetic interventions in dementia. *Journal of Dementia Care*, *March/April*, 20-23.

Gubrium, Jaber F. & Holstein, James A. (Eds.) (2002). *Handbook of interview research: Context and methods.* Thousand Oaks, CA: Sage.

Jones, Kip (2006). A biographic researcher in pursuit of an aesthetic: The use of arts-based (re)presentations in a "performative" dissemination of life stories. *Qualitative Sociology Review*, *II*(1), 66-85.

Jones, Kip (2007). How did I get to Princess Margaret? (And how did I get her to the World Wide Web?). *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research*, *8*(3), Art. 3, http://nbn-resolving.de/urn:nbn:de:0114-fqs070338 [Accessed: March 6, 2014].

Jones, Kip (2012). Connecting research with communities through performative social science. *The Qualitative Report*, *17*(18), 1-8.

Killick, John (1994). There's so much to hear, when you listen to individual voices. *Journal of Dementia Care*, *2*(5), 12-14.

Killick, John & Craig, Claire (2012). *Creativity and communication in persons with dementia*. London: Jessica Kingsley.

Kitwood, Tom (1990). The dialectic of dementia. *Ageing and Society*, *10*, 177-196.

Kitwood, Tom (1997). *Dementia reconsidered.* Maidenhead: Open University Press.

Law, John & Urry, John (2004). Enacting the social. *Economy and Society*, *33*(3), 390-410.

Luengo-Fernandez, Ramón; Leal, Jose & Gray, Alastair (2010). *Dementia 2010: The economic burden of dementia and associated research funding in the United Kingdom*, produced by the Health Economics Research Centre, University of Oxford for the Alzheimer's Research Trust, http://www.herc.ox.ac.uk/pubs/downloads/dementiafullreport [Accessed: August 4, 2014].

Marshall, Mary (1994). How it helps to see dementia as a disability. *Journal of Dementia Care*, *Nov/Dec*, 15-17.

Marshall, Mary (2000). *A social and technological response to meeting the needs of individuals with dementia and their carers*. London: Hawker Publications.

Ratnaike, Danny (2013). An exhibition involving people with dementia in challenging stigma. *Living with Dementia*, 18-19, http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=2373&pageNumber=3 [Accessed: March 12, 2014].

Ritchie, Karen & Lovestone, Simon (2002). The dementias. *The Lancet*, *360*(9347), 1759-1766.

Roberts, Brian (2008). Performative social science: A consideration of skills, purpose and context. *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research*, *9*(2), Art. 58, http://nbn-resolving.de/urn:nbn:de:0114-fqs0802588 [Accessed: March 6, 2014].

Saldaña, Johnny (2003). Dramatizing data: A primer. *Qualitative Inquiry*, *12*(6), 1091-1098.

Sheratt, Kirsty; Thornton, Amanda & Hatton, Chris (2004). Music interventions for people with dementia: A review of the literature. *Aging & Mental Health*, *8*(1), 3-12.

Smith, Jonathan A. (1995). Semi-structured interviewing and qualitative Analysis. In Jonathan A. Smith, Rom Harré & Luk Van Langenhove (Eds.), *Rethinking methods in psychology* (pp.9-26). London: Sage.

Smith, Jonathan A. & Osborn, Mike (2008). Interpretative phenomenological analysis. In Jonathan A. Smith (Ed.), *Qualitative psychology: A practical guide to research methods* (pp.53-80). London: Sage.

Spaniol, Susan E. (1994). Confidentiality re-examined: Negotiating use of art by clients. *American Journal of Art Therapy*, *32*(3), 69-74.

Sterin, Gloria (2002). Essay on a word: A lived experience of Alzheimer's Disease. *Dementia*, *1*(1), 7-10.

Sue, David; Sue, Derald Wing; Sue, Diane & Sue, Stanley (2010). *Foundations of abnormal behavior* (10th ed.) Hampshire: Wadsworth.

Turfrey, Elisabeth (2013). Collaborative display. In Elisabeth Turfrey & Benita Johnson (Eds.), *"I Will Tell You Something of My Own"* (pp.32-33). [Exhibition brochure], http://www.tinyurl.com/somethingofmyown [Accessed: August 4, 2014].

Author

Helen GREGORY is a social scientist, psychology lecturer and performance poet. She is interested in the study of arts and creativity, and in performative social science (or arts-based research). She has studied spoken word and poetry slam communities, educational applications of youth poetry slam, and arts-interventions in dementia care. In recent years, she has begun to combine her research with poetry and visual arts, using art as a means of data collection, analysis and dissemination. She also runs poetry events, and programs the poetry stages for Glastonbury and Larmer Tree Festivals. Helen is a Psychology Lecturer at the University of Brighton.

Contact:

Dr Helen Gregory

School of Applied Social Science
University of Brighton
Falmer Campus
Lewes Road
Brighton, England

E-mail: helen@hgregory.co.uk
URL: http://www.hgregory.co.uk
Project URL:
http://www.tinyurl.com/somethingofmyown

Citation

Gregory, Helen (2014). "I Will Tell You Something of My Own"—Promoting Personhood in Dementia Through Performative Social Science [61 paragraphs]. *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research*, *15*(3), Art. 18, http://nbn-resolving.de/urn:nbn:de:0114-fqs1403183.