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# Re-thinking and re-positioning ‘being in the moment’ within a continuum of moments : introducing a new conceptual framework for dementia studies

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# AGEING & SOCIETY



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## Abstract

This article draws upon six social research studies completed by members of the Dementia and Ageing Research Team at The University of Manchester and their associated networks over an eight-year period [2011-2019] with the aim of constructing a definition of ‘being in the moment’ and situating it within a continuum of moments that could be used to contextualise and frame the lived experience of dementia. Using the approach formulated by Pound *et al.* (2005) to synthesising qualitative studies, we identified this continuum of moments as comprising four sequential and inter-linked steps: i) ‘Creating the moment’, defined as the processes and procedures necessary to enable being in the moment to take place. The time necessary for this to occur can range from fleeting to prolonged; ii) ‘Being in the moment’, which refers to the multi-sensory processes involved in a personal or relational interaction and embodied engagement. Being in the moment can be sustained through creativity and flow; iii) ‘Ending the moment’, defined as when a specific moment is disengaged. This can be triggered by the person(s) involved consciously or subconsciously, or caused by a distraction in the environment or suchlike; and iv) ‘Reliving the moment’, which refers to the opportunity for the experience(s) involved in ‘being in the moment’ to be later remembered and shared, however fragmentary, supported or full the recall.

## Background

This article is drawn from two sources. First, the completion of four PhD studies at the interdisciplinary Dementia and Ageing Research Team at The University of Manchester in the United Kingdom (UK) between 2011 and 2019. These PhD studies were individually conducted by the authors SC, RD, LJ and JK at different times over these eight years and used creative social research methods to place the lived experience of people with dementia

centre stage in their design and conduct. The first author of this article (JDK) acted as primary supervisor to each PhD study and as lead of the Dementia and Ageing Research Team. Across the four PhD studies, people living with dementia experienced a number of diagnostic variants with a wide-variety of cognitive abilities, ranging from full capacity to consent to participate to those living in care homes and towards the end of life.

The second source is drawn from the 'Neighbourhoods and dementia study', a five-year programme of research in the UK [2014-2019] led by The University of Manchester with JDK acting as chief investigator. This work was funded by the Economic and Social Research Council (ESRC) and the National Institute for Health Research (NIHR) under key commitment 12 of the first Prime Minister's Challenge on Dementia (Department of Health 2012), a stream of research that was mainly social sciences orientated. The ESRC/NIHR Neighbourhoods and dementia study [the 'Neighbourhoods study' hereafter] was one of the six major investments funded under this initiative. Work programme 1 (of the 8 work programmes) on the Neighbourhoods study enabled those with the lived experience of dementia to come together and perform their own neighbourhood-level research and report on its outcomes in personally meaningful, relevant and creative ways, such as through the use of visual narratives, film-making and animation. Work programme 1 was facilitated by CS in the authorship with participants (people living with dementia [with and without capacity], care partners and staff) able to receive well-being support from a trained clinical psychologist attached to the programme of study if the need arose (RE lead and co-author). Work programme 4 on the Neighbourhoods study was co-led by AC as part of the authorship with SC acting as the lead researcher in the north west of England field site. Work programme 4 involved the use of a range of creative social research methods, such as go-along and home tour interviews, where people living with dementia were encouraged to shape and tell stories about their neighbourhood and places where they lived.

Against this backdrop, and during regular team meetings of the Dementia and Ageing Research Team and the Neighbourhoods study work programmes, the existence of ‘being in the moment’ was repeatedly seen within and across all our studies. However, recognising and understanding what is meant by ‘being in the moment’ is not unproblematic and in this article we suggest that rather than a standalone event ‘being in the moment’ is just one step in a continuum of moments that connects the person living with dementia to a sense of self and to the people, spaces and places in their surroundings. Moreover, we contend that the literature relating to ‘being in the moment’, and moments in general in dementia studies, is surprisingly sparse and under-theorised. This article, therefore, is an early attempt at addressing this knowledge deficit by drawing upon our collective studies, data sets, analyses and regular conversations, including with those living with dementia, to reveal a new definition of ‘being in the moment’ and to identify its location within a continuum of moments. However, before this is approached, we will start the article by reviewing the broad positioning of ‘moments’ firstly within the wider literature and then as applied to dementia studies and care practices.

### **Moments and living with dementia**

In everyday language, a moment can have a range of meanings and colloquial understandings, such as to have a ‘moment to oneself’, a ‘lightbulb moment’, a ‘senior moment’, a ‘precious moment’ or to live ‘moment by moment’. Indeed, on this latter point, the recent proliferation of the practice of mindfulness has made much of the personal benefits of engaging with the present moment in order to ameliorate anxiety-provoking events experienced in the past (Wong *et al.* 2011; Hoge *et al.* 2013). However, what binds each of these understandings together is the recognition that a moment is transitory and, as Georgakopoulou (2019) has recently argued, is seen to exist as a metaphor for the present.

Interestingly, within sociological studies, an exploration from a more theoretical standpoint about the nature of moments, and how they can be defined, has a relatively long history. For example, at the turn of the 1990s, the work of Giddens (1991) explored ‘fateful moments’ which implied experiencing a moment of extraordinariness, or a turning point, after which life for a person (or for a collective) can take an entirely different course. In some of the literature on the sociology of the family, the extraordinariness of the moment continued to be a dominant thread which was evident in studies about ‘quality time’, as illustrated in the work of Kremer-Sadlik and Paugh (2007) for example. Researching in this space, Tipper (2013), drawing upon Virginia Woolfe’s ‘moments of being’, later explored human engagement and interaction with family pets and made the telling observation that:

*‘...moments are centrally about a shift in perception. They have in common a sense of sudden connection or empathy and a dissolution of conventional boundaries between things...they seem to entail an awakening to the enormity of life and death, to the sadness and vastness of the world, and to the infinite, inexplicable interrelations between its parts’.* (p.15)

For Tipper, therefore, understanding the ordinariness of human-to-family pet interaction was enhanced by attentiveness to the extraordinary moments of an encounter.

In a related vein, Gabb and Fink (2015) have explored how ‘moments’ might provide the fine-grained texture in everyday human-to-human relationships and where they can be understood through a variety of meanings, such as being ‘intimately revealing’ (p.978), ‘ephemeral, fleeting and transitory’ (p.978) and, ultimately, ‘enduring’ (p.984). Accordingly, in such an understanding, everyday mundane moments live on in the narratives we tell about ourselves and remember to others. Building upon this point, the methodologist and sociologist Jennifer Mason has recently suggested that a moment is a specific temporal

experience that does not have a temporal limit (Mason 2018). In other words, a moment is as long or as short as the particular occurrence it seeks to represent and is not a precise amount of time. As Mason (2018) goes on to explain, moments are charismatic not because they are measurable fractions of clock time, but because they are ‘multi-sensory glimpses, windows, apertures or revelations’ (p.193) into a person’s everyday world and lived experience.

Turning to the literature in dementia studies, almost twenty years ago now Killick and Allan (2001) advised that healthcare professionals should aim to meet people living with dementia ‘in the moment’ in order to ensure that each encounter was entered into with full attention and an open mind. These authors suggested that this reflexive positioning enabled a deeper person-to-person connection to be made and facilitated a greater understanding about a different perception of time that might be being experienced by a person living with dementia. Such an acceptance and empathetic point of connection between those with and without dementia was seen to be foundational to person-centred care and in all interaction that subsequently followed (see: Kitwood 1990a,b; 1997; Kitwood and Bredin 1992; Kitwood and Brooker 2019).

The situational importance of this empathetic point of connection is supported by the testimonies and narratives of people who live with dementia. To take one example, Dr Ann Johnson, who had been a Nurse Tutor in Ophthalmic Nursing at an UK-based University prior to the onset of young onset Alzheimer’s disease at the age of 52, shared the following observation:

*‘The greatest encouragement can come from an understanding friend/carer/supporter who is aware of the problems with which the person [with dementia] is struggling. Sympathy is not required. Trying to ‘get inside the skin and brain’ of the person with*

*dementia and 'being there with them' is vital in handling what I call an accursed, unremitting disease'. (Johnson 2010 p.8)*

Arguably, in order to 'get inside the skin and brain' (to use Johnson's descriptive and emotive terminology) of the person diagnosed and thereby understand the way he or she experiences the everyday world, the use of creative and arts-based programmes, coupled with an 'in the moment' frame of reference, has so far proven to be the most successful way of 'being there with them' (see for example: Brotherhood *et al.* 2017; Zeilig, West and van der Byl Williams 2018; Zeilig *et al.* 2019). By way of illustration, Dowlen (2019) recently reported on the musical contributions of people living with dementia and how they engaged in prolonged periods of musical improvisation in which they invited others to meet them 'in the moment' and to share that performance space together.

Such experiences of 'in the moment' creativity have been linked to the concept of flow (Csikszentmihalyi 1996, 1997, 2014) which is seen to be a creative state of 'optimal experience' where those involved are completely immersed in the present and in what is going on in the here and now. Killick (2016) has suggested that for people living with dementia, this opportunity to be immersed within a flow state may result in feelings of total absorption and heightened senses of satisfaction and achievement. Indeed, Killick (2016) developed his argument further and suggested that supportive strategies need to be employed by care providers of people living with dementia in order to 'fill as many of these moments with as much meaningfulness as possible' (p.181). Accordingly, in such instances, a moment can become a basic unit for creative expression and provision, isolated from external influences and interferences and sustained through interactional processes of meaningful exchange (see also: Jonas-Simpson *et al.* 2012).



Such identification to the meaning of moments has also been described by Christine Bryden who was diagnosed with young onset Alzheimer's disease at the age of 46. Writing in her first book 'Who will I be when I die?' Bryden (1998) shared the following self-reflection 'I plan to enjoy each and every experience, even though I might not remember them from moment to moment – the experience of each moment will be enough for me' (p.144). This experience of being immersed in the moment was further developed in her second book, 'Dancing with dementia: My story of living positively with dementia' (Bryden 2005) when the author writes 'many of us seek earnestly for this sense of the present time, the sense of 'now' of how to live each moment and treasure it as if it were the only experience to look at and wonder at' (p.11). This description of the transitory and fleeting nature of moments is similar to the previously highlighted work of Gabb and Fink (2015) although interestingly, Bryden (2005) goes on to describe how she uses her voice and/or her written word(s) in order to ensure that the moment is not 'lost forever' (p.101). For people living with dementia therefore, and where it is possible, capturing and recording moments in real-time could be considered an important activity in preserving a sense of identity and selfhood (see also: Sabat 2001).

Recently, a growing body of literature has emerged relating to the everyday creativity of people living with dementia (Bellass *et al.* 2018), drawing particularly from the notions of 'little-c' creativity (Simonton 2013; Silvia *et al.* 2014). This focus on everyday creativity also incorporates ideas of 'being in the moment' with the person living with dementia positioned as an active, creative contributor to the artistic process, rather than as passive recipient of whatever task it is that he or she is being asked to perform (Zeilig, West and van der Byl Williams 2018). That said, whilst there has been a growth in work regarding 'being in the moment' in the context of dementia studies and care/interactive practices, the experience

itself is currently lacking a definition and conceptual framework on which to build a consensus of understanding. It is to this area that the article will now turn.

## **Study Design**

### *Establishing the research question and its context*

As previously shared, this work has its foundations in four qualitatively-driven PhD studies in various aspects of dementia care/studies that took place between 2011 and 2019 and in the Neighbourhoods study, drawing specifically on work programmes 1 (member involvement) and 4 (Neighbourhoods: Our People, Our Places; N:OPOP hereafter). In the context of work programme 1, ‘member involvement’ was the name chosen by people living with dementia to reflect their status as co-researchers and co-designers of various neighbourhood-level research projects that were subsequently conducted and disseminated (see for example: Swarbrick *et al.* 2019).

At the time of data collection in each study, most were undertaken through The University of Manchester with seven of the nine authors of this article part of the Dementia and Ageing Research Team whose operational values and vision are described in Table 1.

INSERT TABLE 1 ABOUT HERE

Through the regular methods and network discussions of the Dementia and Ageing Research Team three observations arose. Firstly, ‘being in the moment’ was regularly used in everyday conversation to explore/explain the way persons living with dementia experienced a

connection to the world around them. Second, 'being in the moment' did not appear to exist in isolation but in connection with other moments. Third, 'being in the moment' was a transitory and temporal state of being. This led the authors to pose the following question: 'Can we define 'being in the moment' and its positioning within a continuum of moments for people living with dementia?'

To address our set question, and to ensure that we did not become too inward-looking in our critical thinking and discussions around secondary data analysis, we commenced a dialogue with an academic from another university in the UK at the start of this process (SW in the authorship) who had subject expertise in social research methods in dementia studies as well as an awareness of the topic under discussion. This connection helped us to refine, test and shape the ideas that were emerging in the on-going analytical meetings.

#### *Study foundations and data analysis*

The data related to our set question are embedded within six social research studies that comprise the empirical foundation for this article, as summarised in Table 2.

INSERT TABLE 2 ABOUT HERE

In outlining each study in Table 2, we have included a one-word mnemonic to help the reader locate its source context when data are reported in the findings. A key reference, or references, to the source material are also included in each study outline as space does not permit a detailed exploration of the study design and approach to data analysis.

Since all of the six studies in Table 2 had already generated their own bounded findings, we initially sought to derive a shared meaning and understanding about the presence of ‘being in the moment’ whilst preserving within-case uniqueness and facilitating cross-case comparison (Noblit and Hare 1988). We achieved this by following the approach suggested by Pound *et al.* (2005) in synthesising qualitative studies and, in our case, by generating ‘being in the moment’ maps that held meaning for each researcher based upon their individual experience/exposure and data. The individual maps relating to studies one to six were then shared with the other authors of this article so that the multiple maps relating to the same phenomenon could be contrasted and compared. At this point of map-sharing (from individual to group) we looked for points of connection across all six generated maps to provide the main building blocks for what would become our definition of ‘being in the moment’. Whilst this was a consensus-driven exercise, JDK steered this process to ensure that agreement was eventually reached among all authors.

Once an agreed definition of ‘being in the moment’ had been reached, we repeated the exercise and held a series of follow-on meetings to produce a series of individual maps that explored and explained the position of ‘being in the moment’ within a continuum of moments. However, on these occasions, terms used on the individual maps were supported by extracts of data from each of the six studies so that a measure of reflexive thematic analysis could be applied to the process (Braun and Clarke 2019). This was, by its nature, a protracted and iterative process and we used email dialogue as well as face-to-face meetings in order to refine our thinking and reach agreement on the emergent positioning of ‘being in the moment’ within a continuum of moments. These discussions were subsequently tested out with SW acting as the external independent analyst and sounding board. This reflexive analytical process was again facilitated by JDK and, as part of the systematic synthesis supported by the data, ‘being in the moment’ was seen to be part of a continuum of moments

that we identified and named as: i) creating the moment; ii) being in the moment; iii) ending the moment; and iv) reliving the moment. Both the 'being in the moment' definition and the emergent continuum of moments, together with their defining properties, were then shared with people living with dementia attached to the Dementia and Ageing Research Team to ensure that they held authenticity and meaning in reporting what it means to be in the moment.

As ethical approval had already been granted for each of the six studies in Table 2, no formal ethical permission was necessary for the reporting of this work. However, we have followed the reporting protocol of each study in communicating findings attached to the study; for example, all participants' names in the PhD studies (1-4) are pseudonyms, as is any mention of ward names, care home names and so forth.

## **Findings**

### **'Being in the moment': a definition**

Following the individual to group mapping and analytical approach described above, we defined 'being in the moment' as it related to people living with dementia in the following way:

*'Being in the moment is a relational, embodied and multi-sensory human experience. It is both situational and autobiographical and can exist in a fleeting moment or for longer periods of time. All moments are considered to have personal significance, meaning and worth'.*

In order to fit and work within the context of an interactive process, 'being in the moment' was not an isolated event and was seen to exist as part of a continuum of moments with

transitional, temporal and, potentially, cyclical properties. We will now turn to describing this continuum of moments, sequentially represented as a series of four inter-linked steps, and to further fleshing out the situational context of 'being in the moment'.

## **Outlining a continuum of moments**

### **Step 1: Creating the moment**

As its name implies, this first step in beginning a continuum of moments is the pre-requisite for a moment to be created. Our data suggests that there are two ways to do this. Firstly, a person living with dementia can create a moment for themselves by recalling and responding to a particular sensory, emotional or autobiographical memory or one that had been stimulated through a personal connection to the natural/physical environment. Second, a moment can be created via a relational interaction with other people, such as close family member(s), friends, other people living with dementia, care providers or researchers (this list is not exhaustive). In this instance, a relational interaction can extend to a group setting and creating the moment can be initiated by the person living with dementia him- or herself or by others involved in the engagement process. All six studies in this article provided examples of creating the moment and the three examples below have been specifically chosen to illustrate the diversity in the data and how creating the moment arose for different people living with dementia at different points in time and in different circumstances.

Example 1 taken from study 1 (Atmospheres). One of the recruitment sites in SC's study was a mental health NHS dementia inpatient ward for people living with dementia experiencing an acute crisis due to the presentation of their dementia. In SC's mid-morning ethnographic observation of Larry, who was a resident on the ward and had lived with dementia for a

number of years, SC noted the morning sun had started to light-up the darkened spaces in the day room, an atmospheric shift that caught the attention of Larry, as SC recorded in her field notes at the time:

*'Larry says 'It's bright out there' [pointing to one of the windows in the day room].  
The Nursing Assistant and Student Nurse who are there say 'Yes' and they go on to  
have a chat about the weather and the springtime'. (11 am. 23<sup>rd</sup> January 2012)*

At this point, creating the moment was initiated by a multi-sensory connection to the present that comprised both the sunlight and atmospheric and the four individuals involved, namely: Larry, the two staff members and SC.

Example 2 taken from study 2 (Music). One example of a person living with dementia personally creating the moment was observed in RD's study. Here, Phillip, who was living with advanced young onset dementia, entered the room in which a *Music in Mind* session was going to take place and repeated over and over again a simple rhythmic phrase of 'Pa Pa; Pa Pa; Pa Pa; ...'. In so doing, by entering the performance space, Phillip began to improvise and create the moment for himself; a moment that was then picked up by his wife, Esther, who repeated the rhythmic phrase back to him.

Example 3 taken from study 4 (Conversation). In JK's data there were numerous instances of family members using their relational and biographical knowledge of the person living with semantic dementia to create the moment by drawing upon topics that they knew would spark a response. Joanna described this process as 'feeding the line' i.e. using certain topic openers with specific personally relevant key information contained within them to encourage her

husband, Peter, to talk. Another care partner, Reg, commented on the difficulties his wife Sarah had with starting-up a conversation and his role in 'feeding the line' to her:

*'I know the right buttons to press to make her say things, if you're with me, start talking to me...like you've just said about her mum telling her to go get this job. We could be sat here and if I just mention that, that will get the same response...because I know that that seems to be up there all the time. Everything else has gone'.*

Furthermore, in academic practice, the authors behind the six studies described in this article also took steps to create the moment where data reporting could take place. For each member of the authorship, the steps to creating the moment took many months to achieve owing to the need to produce a research design and the protocol(s) necessary for each study to be ethically approved before the person living with dementia and his/her family carer/support network (as appropriate) could be approached to take part. At times, gaining such agreement provided a challenge for ethics committees approving the respective study. For example, in study 5 (Filming), the adopted methodology of cooperative inquiry (Heron 1996) positioned people living with dementia as co-researchers who wanted to be known by their real names in the research act and reporting, rather than via an assigned pseudonym hidden under the blanket of anonymity. This challenge to the accepted convention of 'who is the research participant' and 'who is the researcher' took a long time to resolve. This delay in ascertaining approval to proceed with the study was similar to study 3 (Complexity) where people living with dementia, who were formally detained in a mental health NHS dementia inpatient ward for assessment under the provisions of the Mental Health Act (Department of Health 1983), were recruited into the study.

Arguably, such contextual considerations for creating the moment are important to document and require a heightened focus in research reporting. However, once creating the moment



was set in motion, how it was sustained, and for how long, underpinned the second continuum step of ‘being in the moment’.

## Step 2: Being in the moment

As seen across the six studies, being in the moment could be a fleeting or protracted process, and exist at all points in between. As our earlier definition revealed, being in the moment could be experienced solely by the person living with dementia or it could exist in the context of a relational and interactive process, as these three slices of data attest:

- In study 2 (Music), being in the moment was observed particularly in the later weeks of the 15-week *Music in Mind* programme, when people living with dementia had become more accustomed to the freedom the improvised music-making activity afforded them. One group member, Mary, who had lived with Alzheimer’s disease for some time, described her complete concentration on music-making during one interview with RD, as this extract from the data reveals:

*‘I was able to play all things. Makes meaning to me. I don’t know whether it’s making any meaning to anybody else but it’s giving me concentration. You know, I found it difficult to concentrate, I’d start another thing, and I’d stop it. But when I’m playing one thing, I tend to get the concentration. I want to hear what I’m playing whether it’s making any good sounds that make meaning or if I’m just making a noise. But I can see it bringing down my concentration and I would like to focus on it for the period I’m holding that particular [instrument]. I want to make good use of it...It’s like putting your best foot*

*forward. Play what you can play. It might not be pleasant to another person 'cos I'm not listening to that one, I'm listening to what I am'.*

This excerpt showcases the power of music in enabling Mary to 'be in the moment', forgetting the stresses in her everyday life and focussed on creating music that was personally significant to her.

- In study 5 (Filming) Lesley Calvert, a person living with dementia, became immersed in chaptering her life story, which she presented under the headings: 'About Me'; 'My Childhood'; 'School and Shopping'; 'Growing Up'; and 'My Life Now'. These chapter headings were then fleshed out during a period of several hours by Lesley using written text, photographs and film, at times visiting a local museum in the city of her birth to access historically accurate artefacts (such as photographs of significant and remembered local landmarks) to place in her life story book. The five chapter headings therefore acted as a storyboard from which Lesley narrated and illustrated the story of her life, making meaning about her dementia from within her own biographical life course. Lesley's production of her storyboard was underpinned by a period of intense concentration and creativity and revealed a connection between her sense of place and storied identity.
- In study 6 (N:OPOP) Suzanne, who was a person living with dementia, took AC and SC on a walk through a wooded valley a short distance from the home she shared with her husband and where they had raised their daughters. Accompanied by her dogs, Suzanne knew 'every inch' of the walk and purposefully strode forward with a mixture of certainty about knowing the route and pride in revealing to others a place

she considered *'very, very special to me...it's always gorgeous whatever the season or whatever the weather and it's just special really, it's fabulous and with the stream and the noise that makes and the birdsong and it's...oh, it's special'*. Suzanne's walk was routed in a sense of her being in the moment with the memories she held of the valley re-enacted during the walk. Moreover, the environment conjured up recollections and moments for Suzanne that remained important to her and which were, perhaps, life- and identity-affirming.

Where being in the moment occurred within the context of an interaction, a number of dynamic mediating factors were present, such as negotiation, engagement and self-reflection. The following extract helps to illustrate the dynamic interplay across and among these factors:

In study 4 (Conversation) JK was able to get to know Reg (family carer) and Sarah (who lived with advanced semantic dementia) over a number of visits to their home. During the visits, JK began to learn about Sarah's biography and, as Sarah's husband Reg had previously described to JK, JK began to understand the topics and triggers that encouraged Sarah to talk and interact. In the extract below, JK and Sarah have been talking about Sarah's job as a machinist during her working life and in line 003, when being in the moment had started to come to an end, JK used her knowledge about Sarah's biography to help her stay in the moment a little longer:

001 S But er yeah I still see them now  
 002 JK That's nice isn't it  
 003 S mmm

- 004 JK And was that the job that your mum told  
 005 you to go and get?  
 006 S Yeah she said (.)I can remember this  
 007 ((pointing)) me mum was going to work  
 008 she said right love ((pointing)) there's  
 009 a place down the road ((gesture that  
 010 way)) where we lived then which was the  
 011 place  
 012 JK ((nod))  
 013 S go and see if they've got a job there  
 014 love ((pointing away))

In line 006, Sarah's response indicated some awareness of her difficulties and that this was territory where she felt confident: 'I can remember this'. The earlier prompt at line 004 provided a positive way for Sarah to fleetingly sustain being in the moment by using a topic that she was still aware of and could discuss.

In 'being in the moment', therefore, it was not so much the length of time that was important to observe and record but, rather, the meaning that such engagement engendered for those involved in the interactive and relational process and how 'being in the moment' was subsequently supported or came to an end. As such, in 'being in the moment' time can become malleable and fluid with the multi-sensory cues being experienced differently by those involved in the encounter. In addition, 'being in the moment' can be layered with positive or negative attributes. As an illustration of the latter feature, in study 3 (Complexity), numerous examples were recorded in the data of people living with dementia residing on mental health NHS dementia inpatient wards both literally and metaphorically crying out for

‘help’ and to ‘go home’. These experienced moments could be fleeting or last a significant amount of time when the person living with dementia was more completely absorbed (perhaps understandably) in finding a way out of the situation in which they found themselves and did not understand: a moment that could be prolonged and imbued with significant distress. On the other hand, however it was experienced, being in the moment did come to an end at some point in time and it is this process that is captured in the third and next continuum step.

### **Step 3: Ending the moment**

Ending the moment could be sudden and initiated by the person living with dementia him- or herself, as the following example illustrates:

In study 1 (Atmospheres) SC described how ‘waiting for something to happen’ was a common experience for men living with dementia in the three care environments that formed the sampling frame. Once something did indeed happen, SC documented the kinds of interaction occurring between the residents and the various endings that arose, as this extract from her field notes revealed:

*‘For a few minutes Don (person living with dementia) chats making lots of words. Through the rhythm of his voice and his animated body movements he shows me that he is telling me lots of things [even if I am uncertain of what it all means]. I make out the odd word or sentence. Another man makes sounds behind Don and Don turns and looks and then [this time] says [clearly] ‘He’s alright him’, he continues making word sounds and laughs a little. He does some gesticulations and points and then does a*

*pretend punch, which feels like it is in jest about something in his story as he is laughing, smiling and is relaxed in his talk*'. (2.55pm. 23rd February 2012)

As a gesture, Don's 'pretend punch' acted as a physical and embodied ending to 'being in the moment' and enabled the conversation to quickly move on to other areas.

Alternatively, ending the moment could be a conscious and deliberate action taken by other stakeholders involved in supporting the person living with dementia to be in the moment. For example, in study 2 (Music) RD highlighted how the Manchester Camerata musicians involved in the *Music in Mind* sessions often felt frustrated when the flow of the creative improvised music-making ended. This feeling of disquiet was especially heightened when moments of musical connection were ended by family carers attending the *Music in Mind* sessions by talking over the improvised music-making in the group setting. By contrast, in study 5 (Filming), ending the moment in a cooperative inquiry (Heron 1996) required time and careful planning by the group facilitator (CS).

In study 6 (N:OPOP) ending the moment occurred when most of the walks reached the point from which they started - normally, a participant's home. However, there were other instances, such as on one occasion, when during a walk with Lily (person living with dementia) and AC, they both became lost and were unable to successfully return to Lily's home. This had happened as Lily had become engrossed in telling AC about a reading group for people living with dementia that she was attending and then, with the passage of time, had realised that she was uncertain how to get home. Out of audio-recording earshot AC asked a passer-by for directions; however, the digital recorder picked up the point at which Lily was re-orientated out of this moment, as shared below:

AC: So let's see we've gone up the [hill], we've looked at the chemist, the chip shop, we've been to the [names a large supermarket], seen the doctors, we've talked about [names another large supermarket]...

Lily: Oh, I didn't take you as far as the library did I?

AC: That's okay. Tell me a bit about the library.

Lily: The library is very handy, we use it [for a dementia support group]...and for meetings and there's always something going on you know...

AC: And you said you're in a reading group or something there as well?

Lily: I'm in a reading group...a lady called Maureen takes charge of it and she gets all sorts of stuff off the internet and she'll print it out, perhaps part of a story, and we all read it and we have one chap who's very Yorkshire...so every now and again she gets something that's got a Yorkshire accent in so he can do it in his Yorkshire accent because he loves doing that.

AC: Is the library somewhere you can walk to or would you get a taxi or...?

Lily: No, the library is actually very near to where I live.

AC: So would you walk up there?

Lily: I could if I wanted because I can cut through. I'm just trying to think whether it's near here now?...I told you I might get you lost.

AC: Don't worry, we're not that lost.

Lily: Well, that's the church we [went past].

AC: So, there's the church...

Lily: Yeah, so we get back to where I live that way.

AC: That way [points towards the church steeple], so shall we head towards there? Just watch these puddles.

The moment that ended in this interaction was not one caught up in a past time, but rather in a different geographical place. As everyone experiences at some point, Lily became disorientated because she was in another place that she did not recognise. In this instance then, 'being in the moment' was not about reminiscent or a temporal fluidity, but about being caught up somewhere else where ending the moment was facilitated by Lily re-attuning to the natural and physical environment around her, namely the church and the puddles of rainwater.

#### **Step 4: Reliving the moment**

This final step in the continuum of moments allowed for the possibility of moments to be revisited and relived once again by people with dementia and various stakeholders. Reliving the moment was seen across all the data from the six studies, for example:

- In study 1 (Atmospheres) families brought favourite objects and photographs from home into the care home in order to help connect the person living with dementia to a sense of familiarity and biographical continuity. This same phenomenon also took place on the mental health NHS dementia inpatient wards (study 1 Atmospheres; study 3 Complexity).
- In study 5 (Filming) the co-produced films enabled the outcome of the research by people living with dementia to be re-lived and re-connected to the moment of their



production. This acted as a stimulus for reminiscence as well as shared stories that connected the inquiry group together through reliving the moment.

Linked to the second bullet point above, the data also suggested that the particular social research methods used in the study enabled participants to relive the moment. For example, in study 2 (Music), the video-elicitation method enabled a reliving of musical moments outside the context of the sessions. People living with dementia were shown to react strongly to the replaying of familiar music from the sessions. As an illustration, during one video-elicitation interview with Scott (person living with dementia) and his wife Julie, the replaying of the 'Hello Song' which commenced each *Music in Mind* session - and where they were both present and captured on the digital recording - led to Scott swaying and singing along with the music. Reliving the moment also sparked a sense of joy in Julie, Scott's wife, who linked her arm through his and put her head on Scott's shoulder, perhaps enabling Julie to feel a sense of personal connectedness and closeness.

Similarly, in one of the aims of study 4 (Conversation), JK explored ways in which life story work could be used to 'relive the moment' by capturing memories and interactional abilities. In this example, Karina supported her husband Doug, who was in the advanced stages of semantic dementia, and had always attempted to keep Doug included in a conversation. Karina noticed that Doug had retained a striking ability to talk in an 'upper class' accent, even though his language was no longer decipherable. When Doug was admitted to a care home during the original study timeframe, his life story summary sheet contained the following words: *'I enjoy interaction and using my good nonverbal skills. The words do not have to make sense it's the social connections that are important to me and I can do a great posh voice, ask me about it'*. This information outlined ways others could use Doug's retained skills to relive the moment and each time he performed his 'posh voice', as his

family called it, he received a positive reaction from others (see also: Kindell, Wilkinson and Keady 2019).

As such, reliving the moment could be seen as a performance in remembering and reminiscence, reframing and repositioning past events as present moments of value, significance and meaning. Reliving the moment therefore acted as a spark that enabled creating the moment to start once again, and the continuum of moments to become cyclical.

## **Discussion**

A few years ago, a major study reviewing the literature on life story work in dementia identified the inability of current measures to capture ‘in the moment’ benefits and recommended that future studies develop innovative methods to address this research and practice deficit (Gridley *et al.* 2016). More recently, a Cochrane Review examining reminiscence and related therapies in dementia care by Woods *et al.* (2018) reached a broadly similar conclusion and suggested that future psychosocial studies needed to place an ‘in the moment’ lens against the evaluation of the lived experience. Using multiple data sources, the studies reported in this article have begun to address these set challenges by providing a consensus-driven definition of ‘being in the moment’ and has used secondary data analysis from six separate, but inter-connected, social research studies conducted between 2011 and 2019 for this purpose. Our study also developed a continuum of moments that was seen to extend over four sequential and inter-linked steps, namely: creating the moment; being in the moment; ending the moment; and reliving the moment. It was also suggested that this continuum of moments had temporal, transitional and cyclical properties that teased out what was happening and meaningful in/to the lives of people with dementia, their support networks and the environment in which moment(s) occurred.

Pointing towards the research and practice future envisaged by Gridley *et al.* (2016) and Woods *et al.* (2018), the definition of 'being in the moment' discussed in this article has drawn attention to the crucial role of 'other people' in being attuned to the atmospherics, objects and materiality of the circumstances in which moments are created and lived. For example, the importance of such attentiveness was seen in study 1 (Atmospheres) when Larry created the moment by commenting on an atmospheric shift in the care home with care staff immediately picking up on his cue to facilitate a conversation about the weather. Similarly, in study 4 (Conversation) Doug, who lived with advanced semantic dementia, was able to relive and create the moment for others through the use of his 'posh voice'; however, it required the attentiveness and responsiveness of others (family/friends/care staff) to connect Doug's performative self and 'posh voice' to an opportunity to engage in being in the moment together. Arguably, in such circumstances, moments could be constructed as relational happenings where a number of dynamic and inter-related factors, such as biography, practice, time, settings and other people, combine to create and sustain the experience of being in the moment. In such circumstances, 'other people' are not simply to be positioned as facilitators or providers of moments for people living with dementia but, instead, as part of the complex processes through which moments are created, sustained, ended and (possibly for people living with dementia) re-lived once again.

By paying close attention to the everyday lives of people with dementia, it becomes possible to recognise some of the underlying processes and mechanisms that exist to support the continuum of moments outlined in this paper. However, to do this with any degree of certainty requires the dementia studies field to see the whole range of methodologies and methods that are open to it and to more confidently embrace creative ways of getting to the (at times) fleeting and transient nature of moments. This positioning is necessary for all concerned, not simply for people living with dementia, and it therefore requires a reflexive

appreciation of the research act if researchers themselves are to be able to step outside of the moment, so to speak, and embrace what Gabb and Fink (2015) called ‘a leap of faith in the scientific imagination’ (p.983).

To meet the above challenge, the six studies reported in this article adopted a wide- range of participatory methods and social research approaches to authentically position and interact with people living with dementia and to underpin the steps involved in the continuum of moments. These approaches included, for example, the use of: sensory ethnographic observations (study 1 Atmospheres; study 2 Music; study 3 Complexity); walking interviews in the neighbourhood using mobile data collection methods (study 6 N:OPOP); co-production of digital-film-making (study 4 Conversation; study 5 Filming); the compilation of life story books to aid biographical interviewing (study 4 Conversation; study 5 Filming; study 6 N:OPOP); and the undertaking of home tour videos led by people living with dementia (study 6 N:OPOP).

The use of such creative approaches informed by emancipatory and participatory methodologies whenever possible, such as the first use of co-operative inquiry (Heron 1996) with people living with dementia acting as an inquiry group (study 5 Filming), produced a diverse range of outputs that acted as the bounded findings. These outputs were not ‘traditional’ in their presentation and were unique to the values and vision of those people living with dementia taking part in the process as equal if not, at times, lead researchers. For example, outputs included a co-produced animation (study 5 Filming), the co-production of a range of portable, biographical and digital life story books in semantic dementia (study 4 Conversations), a range of ageing-in-place films available on YouTube (study 5 Filming) and the co-production of comic-format ‘zines’ to help create accessible public awareness information about living in a neighbourhood with a diagnosis of dementia (study 6 N:OPOP). For moments to be captured in such creative, personalised and expressive formats, not only

do such outputs and methods require an inter-disciplinary mix of participants, including, in our experience, artists and film-makers, but also a more informed understanding from ethical committees about approving such work. All six social research studies included in this article encountered a variety of difficulties in gaining ethical approval to simply create the moment for people living with dementia. However, one issue stood out above all others. People living with dementia made their feelings abundantly clear in the majority of our studies that they did not always want the protection of anonymity in taking part in research projects, especially when positioned as co-researchers, co-analysts, co-producers and co-disseminators of knowledge (see also: Clarke *et al.* 2018). We would therefore suggest that the ethics of consent to participate in research, and the politics of anonymity when people living with dementia are involved in participatory research studies, urgently needs to be revisited.

One of the advantages of re-thinking and re-positioning the lived experience of dementia as a continuum of moments is that sustaining 'being in the moment' through person-centred care practices, for example, enables a suitable conceptual framework to sit behind its delivery and guide its conduct and evaluation. Adopting this approach might help to address some of the criticisms often levelled at person-centred care in the literature, such as the practice being conducted in a theoretical vacuum and with a lack of relational understanding (see for example: Harding, Wait and Scrutton 2015). Numerous examples of sustaining 'being in the moment' through person-centred care practices were seen in our data sets and some have been shared in this article, such as in study 4 (Conversations) when Joanna described 'feeding the line' to help her husband Peter, who lived with advanced semantic dementia, continue to talk and therefore be in the moment with his wife for an instant longer. However, that extra fraction of time was crucially important and meaningful to Peter and Joanna and it was the unit of analysis against which their momentary interaction and wellbeing were measured. The biographically-minded conversational technique employed by Joanna was later picked up by

the practitioner-researcher (JK in the authorship) to enable her to mirror the approach in her own interviewing technique with Peter. However, it is important to acknowledge that ‘being in the moment’ can also be stressful and anxiety-provoking for a person living with dementia, as seen in study 3 (Complexity) for example. A clinical (and/or family carer/other stakeholder) judgement as to when a moment is sustained, stopped, diverted or even created at all becomes an important part of a person-centred decision-making process.

In the context of dementia studies and person-centred care practices, the evidence-base for effective communication approaches continues to remain limited, as revealed in the most recent National Institute for Health and Care Excellence (NICE) dementia guideline (NICE 2018). However, from our work, we believe it is important to recognise that people living with dementia can be in the moment with other people living with dementia and that they can create, sustain, end and (at times) relive moments together. This is a significantly under-reported and under-researched area of the practice/communications literature in dementia studies. Nevertheless, we contend that this is where Mason’s (2018) explanation of a ‘charismatic moment’ might have most utility, offering support to the earlier arguments of Killick and Allan (2001) about the need for genuine empathetic person-to-person connection and that this is something that we are all capable of doing, whether we live with dementia or not.

Finally, to move forward in dementia studies, we must break with the dominant quantitative research paradigm of the past and, to paraphrase Gabb and Fink (2015), take a leap of faith into a new methodological and methods future that positions the lived experience of dementia and the co-production of research findings at the apex of an evidence-based hierarchy. A new ‘gold standard’ if you like. It is the steps that comprise the continuum of moments outlined in this article that could form a new conceptual framework for such exploration. If this analysis holds sway, then we would contend that it is vital to use multiple, creative ‘in the moment’

methods and measures to continually research/evaluate/analyse such moments of connection - and disconnection - among all the stakeholders involved in an engagement process.

Identifying and analysing moments over a series of time points that are constructed as meaningful to those involved in the process is not a threat to scientific rigor or identity, but is, rather, an opportunity to be embraced and applied. All we need is the courage to take that leap of faith.

### **Study Limitations**

This study used secondary data analysis where strategies for anonymisation and tools that address some of the deficiencies of contemporary technological systems for handling qualitative data are recognised as limiting the approach. However, the close-working relationship and data familiarity among all members of the authorship helped to mitigate such circumstances and enhance the credibility of the findings. All six studies reported in this article were also conducted in the north west of England which may not be representative of other regional population samples in the UK.

### **Conclusion**

As we enter the third decade of the twenty first century, we need a new force to help shape the lived experience of dementia, one in which people living with dementia can be authentically positioned as co-researchers, co-analysts and co-creators of scientific knowledge. **People living with dementia also appear to instinctively position themselves as living moment by moment (Bryden 1998) and whilst the ability remains, to also remember key moments of significance in their journey through dementia, such as at the time of diagnosis and all the feelings and emotions surrounding that experience which may, of**

course, be quite traumatic (Bryden 2005). As our emergent work has demonstrated, there is a need for greater conceptual and methodological thinking about ‘moments’ in dementia studies, especially in considering their fluid and cyclical nature, and how moments can be positioned and linked together to provide a more holistic understanding of lived experience. However, to reach this new level of understanding, participatory approaches and methods require a heightened focus in the literature and in the everyday work of practitioners and researchers in the field. Furthermore, we would also contend that the funding priorities of research councils and charities also need to buy into this new direction as without their support and motivation to change, the status quo will prevail and the moment lost. And this is the time for change.

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**Table 1: Dementia and Ageing Research Team: Values and Vision**

Established in 2009 at The University of Manchester, the Dementia and Ageing Research Team has a goal *'to conduct research into the everyday experience of people living with dementia and their care partners and find ways to engage those perspectives in transforming, shaping and leading our work'*. Membership of the Dementia and Ageing Research Team is inter-disciplinary and includes people living with dementia as part of its make-up. The Dementia and Ageing Research Team hold regular team and knowledge-exchange meetings to discuss various aspects of its work together and the innovation in social research methods used to underpin its studies.

For Peer Review

**Table 2: The six studies that comprise the empirical foundation for the article**

Study 1 [Atmospheres]: Conducted by SC, this part-time PhD study (2011-2019) explored atmospheres of dementia care and the important role played by care staff in creating restorative atmospherics to enable person-centred care to flourish in such settings. The study involved seven men living with dementia in various care environments as well as staff and family of the men with dementia. The study adopted an ethnographic approach to data collection underpinned by sensory and embodied narrative analysis and explored the role of place and gender in the lives of the men. Ethical permission to conduct the study was provided through an appropriate NHS Research Ethics Committee in the UK (for additional information see: Campbell 2019).

Study 2 [Music]: Conducted by RD, this PhD study (2015-2019) used a multiple-case study design to develop a thematic description of the ‘in the moment’ embodied and sensory experiences of people living with dementia when they engaged with music. The setting for this study was Manchester Camerata’s *Music in Mind* programme, an innovative 15-week improvisation-based music-making programme for people living with dementia in the community or in care settings. Six people living with dementia were recruited into the study, along with four family carers and two *Music in Mind* practitioners. The study used visual and sensory methods in recording group activities. Ethical permission to conduct the study was provided through the Social Care Research Ethics Committee in the UK (for additional information see: Dowlen 2019).

Study 3 [Complexity]: Conducted by LJ, this PhD study (2013-2019) adopted an interpretive description methodology and qualitative mixed methods design to explore the concept of complexity in dementia within the under-researched setting of mental health NHS dementia inpatient wards. The study was conducted over three phases: phase 1 was an on-line

electronic survey of national dementia leaders; phase 2 consisted of individual interviews and a focus group with clinicians working on these specialist dementia assessment wards; phase 3 comprised case studies of four people (patients) living with dementia whom staff had identified as having complex presentations. In phase 3, all people living with dementia were formally detained under a section of the Mental Health Act (Department of Health 1983) and all lacked capacity to consent to take part in the study. Ethical permission to conduct the project was provided through an appropriate NHS Research Ethics Committee in the UK (for additional information see: Jones 2019).

Study 4 [Conversations]: Conducted by JK, this PhD study (2011-2015) used a multiple case study design to explore everyday conversation at home with five individuals with semantic dementia and their spouses and in one case study, a daughter also took part. In the five case studies, presentations of semantic dementia ranged from early signs to living with the advanced stages of the condition. Each case study used a combination of conversation analysis of video and audio data alongside biographical interviewing in a longitudinal design. Information derived from these strands was then used to design an individually tailored intervention which focussed on the specific everyday conversation issues in each situation. This included aspects of life story work and interaction-focused therapy. Ethical permission to conduct the study was provided through an appropriate NHS Research Ethics Committee in the UK (for additional information see: Kindell 2015).

Study 5 [Filming]: Conducted by CS and RE, this participatory study on work programme 1 of the Neighbourhoods study (2014-2019) adopted a co-operative inquiry approach alongside the Open Doors Research Group in Salford, Greater Manchester, UK. The Open Doors Research Group operated as a sub-group of the Open Doors Dementia Service which is a peer support group for people living with dementia and their care partners. The co-operative inquiry group in Salford produced a suite of three locally-based cultural heritage films that

documented the 'Changing Face of our Neighbourhoods' (for additional information see: Calvert *et al.* 2020; Swarbrick *et al.* 2019; and <https://salfordneighbourhoods.wordpress.com/films/>; accessed 6<sup>th</sup> January 2020).

Study 6 [N:OPOP]: Conducted by AC and SC in the authorship, this work formed part of work programme 4 of the Neighbourhoods study (2014-2019). The overall study investigated the locally situated, lived experience of people with dementia and their care partners and sought to identify enabling and inhibiting factors to their participation in neighbourhood life across three field sites in England, Scotland and Sweden (Campbell *et al.* 2019; Ward *et al.* 2018). People living with dementia and a nominated care-partner engaged in three methods of data collection: walking interviews, participatory social network mapping and home tours. The team involved 56 participants, 29 of whom were living with dementia and 27 were a nominated care-partner. They came from a variety of backgrounds, were aged between 57 and 88 and lived with different types of dementia. Ethical permission to conduct the study was provided through an appropriate NHS research ethics committee in the UK. All examples and reflections provided in the article are drawn from data gathered from the walking interview method in the north west England field site (see also: Clark 2017).