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Bellass, Sue, Balmer, Andrew, May, Vanessa, Keady, John, Buse, Christina, Capstick, Andrea, Burke, L, Bartlett, Ruth and Hodgson, James (2018) Broadening the debate on creativity and dementia: A critical approach. Dementia, 18 (7-8). pp. 2799-2820. ISSN 1471-3012

DOI: https://doi.org/10.1177/1471301218760906

Publisher: SAGE Publications

Version: Accepted Version

Downloaded from: https://e-space.mmu.ac.uk/619947/

Additional Information: This is an Author Accepted Manuscript provided by SAGE Publications of a forthcoming paper accepted for publication in Dementia.

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Broadening the debate on creativity and dementia: A critical approach

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Abstract

In recent years there has been a growing interest in person-centred, 'living well' approaches to dementia, often taking the form of important efforts to engage people with dementia in a range of creative, arts-based interventions such as dance, drama, music, art and poetry. Such practices have been advanced as socially inclusive activities that help to affirm personhood and redress the biomedical focus on loss and deficit. However, in emphasizing more traditional forms of creativity associated with the arts, more mundane forms of creativity that emerge in everyday life have been overlooked, specifically as regards how such creativity is used by people living dementia and by their carers and family members as a way of negotiating changes in their everyday lives. In this paper, we propose a critical approach to understanding such forms of

creativity in this context, comprised of six dimensions: everyday creativity; power relations; ways to operationalise creativity; sensory and affective experience; difference; and reciprocity. We point towards the potential of these dimensions to contribute to a reframing of debates around creativity and dementia.

Introduction

Important research in the biomedical sciences has been conducted on the disease process of different dementias, but limited progress has yet been made in developing pharmacological interventions. Against this background, there has been a growing interest in person-centred, 'living well' approaches, often taking the form of important efforts to engage people with dementia in a range of creative, arts-based interventions such as dance, drama, music, art and poetry. Such practices have been advanced as socially inclusive activities that focus on the remaining strengths of the person (Kinney & Rentz, 2005; MacPherson et al., 2009; Camic et al., 2014) and speak to the artist in us all (Campbell et al., 2017) thereby affirming personhood and redressing the biomedical focus on loss and deficit (Beard, 2011; Chancellor et al., 2014; Zeilig et al., 2014; Selberg, 2015). The benefits of arts-based practices, which often take place with small groups of people with dementia in care homes, civic institutions or community centres, have been found to include comparatively high levels of engagement (Eekelaar et al., 2012), improved subjective well-being (Johnson et al., 2015), learning (Bannen & Montgomery-Smith, 2008), the opportunity to exercise autonomous choice (Melhuish et al., 2017), and enhanced quality of life (Hannemann, 2006).

Although creative practices have thus begun to gain in importance in the care of people living with dementia, the more mundane forms of creativity that emerge in everyday life have been overlooked in terms of how these are used by people living dementia and by their carers and family members as a way of negotiating the impacts of dementia. In part, this lack of attention paid to everyday forms of creativity may be due to the widespread association of creativity with formal arts such as painting and music (Richards, 2007) and limited attention to capturing the in-the-moment experiences and contributions made by people with dementia (see for example: Dowlen et al., 2017). Furthermore, creativity as a general concept is often associated with originality, genius and notable contributions to public life – what has become known as 'Big-C' creativity (Beghetto & Kaufman, 2007). Such Big-C creativity stands in contrast to ordinary

creative practices involving imagination, improvisation and inventive problem-solving that form part of navigating everyday life. Whatever the cause, it remains the case that there has been a far more limited recognition of creativity as a distributed phenomenon that occurs across various domains of human experience (Csikszentmihalyi, 1996) and, as a consequence, there exists little information on how this kind of creativity emerges, persists or changes in the context of dementia. This article, therefore, proposes a broadening of research and practice agendas to bring greater attention to, and understanding of, the myriad forms of "little-c" creativity (Simonton, 2013) that occur in everyday life with dementia[1].

In proposing greater emphasis on this domain, we in no way wish to demean the value of arts-based interventions, which can clearly have significant positive effects, as outlined above. Instead, we wish to broaden understandings of what it is like to live with dementia and to reconceptualise creativity as also being situated within everyday practices that are lived and negotiated relationally, that is, in the context of relationships and together with other people. This broader view of creativity promises to generate insights into spontaneous creative acts that take place in familiar everyday situations and spaces. Such situated, mundane creativity may, depending on the interests of the person with dementia, include traditional arts practices such as music, art and dance. However, situated, mundane creativity can also comprise creative work that people do as part of caring relationships, for example, generating neologisms when memory loss affects word-finding, using jokes and humour as a creative response to difficulties, inventing new forms of self-expression, adapting intersubjective processes to suit changing embodiment, and making practical adaptations which enable people with dementia to successfully navigate ordinary routines and social encounters. In this way, an everyday creativity perspective focuses on how creativity emerges and is negotiated in the context of the ordinary, everyday practices of the person with dementia, their family members, friends and carers.

To extend the debate on creativity and dementia in this direction, we first review examples of arts-based work to develop an argument for a critical approach to creativity and dementia that foregrounds everyday creativity. Then we explore the ways in which creativity is theorised and how these conceptualisations might contribute to developing an appreciation of everyday creativity in the context of dementia. Finally, we outline a critical approach which comprises six dimensions: everyday creativity; power relations; ways to operationalise creativity; sensory and

[1] We use the terms 'everyday creativity' and 'little-c' creativity interchangeably in this article.

affective experience; difference; and reciprocity. We point towards the potential of these dimensions to contribute to a reframing of debates around creativity and dementia.

Researching arts-based interventions for people with dementia

Over the last two decades, arts-based interventions have become an increasingly popular activity within dementia care environments (Zeilig et al., 2014). The general consensus is that arts practices provide positive outcomes for people with dementia (Selberg, 2015). As Beard (2011) has noted, there are two distinct orientations underpinning such interventions - art as therapy, and art as activity. The former has a biomedical focus, emphasising clinical outcomes, such as the reduction of the behavioural and psychological symptoms of dementia (BPSDs), whereas the latter emphasises person-centred outcomes, such as providing a source of pleasure and enhancing quality of life.

A further division within the field is how the effects of arts-based practices should be understood, with some researchers favouring objective measurement using standardised scales (e.g. Gross et al., 2015; Camic et al., 2017) while others privilege more qualitative approaches to access the subjective experience of engagement with the arts (e.g. Aadlandsvik, 2008; Petrescu et al., 2014). These different approaches have prompted commentary from some authors who have argued that the nature of arts-based creativity is incommensurable with and thus fundamentally unsuited to positivistic research using standardised scales (Beard, 2011; de Medeiros & Basting, 2013).

Despite these reservations, quantitative study designs which measure constructs pre- and post-intervention (e.g. Johnson et al., 2015), or compare an intervention with a control group (e.g. Fritsch et al., 2009) continue to form a prominent strand within research on arts-based interventions with people living with dementia. This is, perhaps, partially driven by ambitions to evidence the effectiveness of specialised visual arts dementia programmes, such as Memories in the Making©, Opening Minds through Art and TimeSlips©, a storytelling activity (Kinney & Rentz, 2005; Phillips et al., 2010; Gross et al., 2015; Sauer et al., 2016). In particular, researchers favouring concepts such as quality of life (Lawton, 1997) and subjective well-being tend to employ scales such as the researcher-completed Greater Cincinnati Chapter Well-Being Observation Tool (Kinney & Rentz, 2005; Gross et al., 2015; Sauer et al., 2016) or the

participant-completed Canterbury Well-being Scale (Johnson et al., 2015; Camic et al., 2017). Other quality of life scales for people with dementia such as DEMQoL and QoL-AD have also been used (e.g. Phillips et al., 2010; Camic et al., 2011) and with varying degrees of 'success' when the arts-based trial is unblinded (see for example: Woods et al., 2016).

The ways in which arts-based activities are assessed in terms of their effects on people with dementia, and the strengths and limitations of such objective measurements and subjective assessments, are a source of continued debate within the field (e.g. Beard, 2011; de Medeiros & Basting, 2013). However, there are other facets of this growing body of knowledge that have received less critical attention. For example, while several studies attest to the benefits of socialisation brought about by arts activities (e.g. Bannen & Montgomery-Smith, 2008; Camic et al., 2017), and note improvements in relationships between either informal or formal carers and people with dementia (e.g. Phillips et al., 2010; Camic et al., 2011), the focus of arts-based interventionist research, whether conducted in the qualitative or quantitative domain, is predominantly individualised. Where family members are involved, their role often amounts to little more than providing proxy data on the benefits of an intervention for the person with dementia. The person-centred paradigm, while enacting a welcome shift in emphasis from the biomedical features of dementia to the person living with the condition, has arguably concretised an individual, rather than relational, focus. We propose that viewing the self as a social, relational process (Jenkins et al., 2015) rather than as an atomised, interior phenomenon, may offer a broader perspective on creativity which could be usefully adopted in a critical approach.

An emphasis on the individual also tends to erase the relation that the person has with their creative work. Although some studies exhibit or publish the creative poetic or artistic products created by people with dementia (e.g. Aadlandsvik, 2008; Ullán et al., 2011), in general the effectiveness of arts-based activities is assessed in terms of the impact of the engagement process on measurements of well-being rather than on the meaningfulness of the products as legitimate, acknowledged outcomes owned by participants with dementia and symbolic in important ways. However, it might be that research ethical committee conventions that seek to preserve anonymity constrain the public recognition of creative outputs of people with dementia. Moreover, a lack of attention to the material, sensory and embodied nature of creating, means that much of what makes creativity so *vital* goes missing in the assessment of these practices. And it is this vitality that our approach, outlined below, understands as a crucial aspect of everyday forms of creativity.

Additionally, power relations in arts-based activities remain unexplored. While increasing recognition has been given to the need to challenge the discrimination faced by people with dementia, by affording them more power in research processes and public arenas (Wilkinson, 2002; Bartlett & O'Connor, 2007, 2010; Bartlett, 2014), there is no indication within this group of arts-based interventions that participants with dementia were able to influence how the activities or the studies were conducted. The choice of cultural arts intervention, the public space in which the activities were facilitated and the ways in which their effectiveness was assessed, were decisions made by researchers; the participants with dementia therefore appeared to be positioned as passive subjects in the research process. In contrast, a focus on everyday creativity means paying attention to the creative ways in which people with dementia live with the illness in their day to day lives.

The existing body of research thus tells us more about the experience of creative interventions than it does the experience of being creative in daily life with dementia. It might focus on the individual in creative activities, but it tells us very little about that individual's experience of creativity. Csikszentmihalyi (1996, p. 110) for instance, has described the creative experience as an atemporal sense of 'flow', an 'effortless yet highly focussed state of consciousness'. Similarly, Richards (2007, p. 47-8) argues that engaging in creative practices induces a more vivid experience of life; during creative moments, we are connected 'more meaningfully to our world.' With regard to this connection to life, and deep engagement, it is important to note that such experiences may not always be pleasurable, particularly in the context of living with a progressive illness such as dementia. A focus on subjective well-being as a desired outcome, therefore, is likely to obscure experiences of negative affect in the context of creativity which are likely to be a part of such deep engagements with self and world.

Finally, existing studies tend to focus on people living with early and middle stage dementia, and the samples tend to predominantly comprise white women. Demographically, most people with a diagnosis of dementia in the UK are white women, but it remains important to understand how differences in ethnicity, sexuality and gender, as well as type and stage of dementia may structure the experiences of creativity in the context of dementia. As such, whether arts-based activities are explicitly intended to reduce undesirable behaviours, or whether they are designed to enhance individuality, pleasure and enjoyment, they remain structured practices that are, to varying degrees, arranged for people, reproducing existing caring patterns and obscuring much

of the vital, relational nature of everyday creative work. This has repercussions for the exercise of agency and highlights the experience of creative interventions which are structured, rather than the more common experience of being creative in the day-to-day context of negotiated relationships. It overlooks the highly-skilled nature of such everyday creative work. A broader approach is required to better attend to creativity as it occurs in the everyday lives of people with dementia.

Creative methods used to study the experience of dementia

A burgeoning interest in creativity in the context of dementia has also manifested in a growing and diverse body of studies that have used innovative research methods to develop understandings of the subjective experience of living with dementia (e.g. Aadlandsvik, 2008; Bartlett, 2012; Gjengedal et al., 2013; Capstick & Ludwin, 2015; Jenkins et al., 2015; Buse & Twigg, 2016; Keady et l., 2017; Kontos et al., 2017). Examples of these include co-creational arts-based research methods such as poetry (Aadlandsvik, 2008), drama (Jenkins et al., 2015) and participatory film-making (Capstick & Ludwin, 2015), diary methods (Bartlett, 2012) and methods privileging material and embodied experience (Buse & Twigg, 2014, 2016, forthcoming; Kontos et al., 2017).

This body of work offers a critical insight into dementia as a condition, foregrounding the limitations of the biomedical emphasis on managing challenging behaviours rather than troubling perceptions of otherness (Aadlandsvik, 2008; Sabat et al., 2011). Exploring notions of place, for example, Capstick and Ludwin (2015) describe how medicalisation emphasises the ways people with dementia become disorientated in space, rather than exploring the strategies that they creatively put to work in making sense of the care environments they inhabit. In a similar vein, Gjengedal et al. (2013) argue that clinical spaces are structured by the authority of health care practitioners, demanding particular kinds of performance from people with dementia which might not best help them to express their experiences. In contrast, their study showed more egalitarian relations emerged in the theatrical environment established by the researchers, opening-up opportunities to better understand their lives. Such research that has used qualitative, creative methods, has shown that dominant paradigms which shape the field of dementia research and care have important effects on people's abilities to participate fully in their care and to demonstrate capacities.

Engaging with people with dementia and their family members through innovative methods typically facilitates a more participatory approach than is traditionally found in biomedical studies of dementia, offering people with dementia and their family members greater control over their engagement with the research process and the creative outputs. In part, this engagement and control is afforded by the ways in which the various creative methods open up alternative modes of expression and analysis, overcoming some of the limitations of qualitative research which has traditionally privileged text and the interview form.

Our approach builds upon such creative approaches to studying dementia which have offered important insight into the experience of dementia as a condition and into the lives of people with dementia. They have helped to challenge taken-for-granted assumptions about selfhood, relationships and power – a challenge we aim to further develop by offering a critical focus on creativity as a thing in itself, in the context of dementia, something that has not yet been adequately developed in the literature on creative methods and dementia. In the following sections of the paper we explore how creativity has been conceptualised more broadly, link this to the context of dementia research, and develop six dimensions which might form the basis of a robust, critical approach to researching creativity and dementia, and furthermore underpin therapeutic interventions that emphasise creativity.

Expanding the scope of 'creativity' in the context of dementia

We have so far discussed the two existing strands of research that fall under the broad banner of understanding 'creativity and dementia', namely interventionist studies of arts-based practices for people with dementia and methodological creativity in dementia research. In this section, we start to build our 'everyday creativity' approach by exploring extant theoretical frameworks in creativity scholarship.

Historically, creativity was viewed as a divine phenomenon (Kara, 2015) and while contemporary scholars locate creativity within the human mind, there remain unknown elements in the creative process. Csikszentmihalyi (1996, p. 98), for instance, noted that at least some of the creative process can occur subconsciously; there can be periods of 'incubation', when, released from the constraints of the rational conscious mind, connections can be made which subsequently catalyse

waking creativity (Schredl & Erlacher, 2007). Moreover, while it is an over-simplification to position creativity in a dichotomous relationship with rationality, there is neurological research to suggest that the increased creativity sometimes witnessed in people with fronto-temporal dementia may be associated with the impairment of the brain tissue that plays a key role in analytic processes (Mendez, 2004; de Souza et al., 2014).

However, there are more dimensions to creativity than intrapsychic processes. Csikszentmihalyi (1995, p. 28), one of the most influential creativity scholars, has defined creativity as 'any act, idea or product that changes an existing domain, or that transforms an existing domain into a new one'. According to this view creativity is social and involves a complex systemic interplay of domains of knowledge, such as in mathematics or art; fields of accomplishment comprising experts who judge the validity of innovations; and individual creativity. The domain changes as creative individuals make and remake products, processes and norms which are subsequently acknowledged by experts. This domain-changing form of creativity has become known as 'Big-C' creativity, a form which emphasises eminence and genius and is often characterised by a tangible, influential legacy (Beghetto & Kaufman, 2007). In this context, creativity is not viewed solely as the activity of a single person but as a process that occurs when a creative individual is familiar with, and able to influence, the rules, modalities and symbols of a particular cultural domain of knowledge.

Developing alongside the 'Big-C' conception of creativity, a broader view of creativity as an everyday activity experienced by all rather than something confined to a 'lucky few' (Beghetto & Kaufman, 2007, p. 74) has gained foothold. Referred to as 'little-c' creativity (Kaufman & Beghetto, 2009; Simonton, 2013), this conceptualisation provides a micro-level view of distributed creative practices that are unlikely to have an enduring legacy but are nonetheless meaningful in the context of everyday lives, such as making a new addition to a recipe or creating a humorous anecdote (Richards, 2007). Little-c creativity has garnered less empirical attention than Big-C creativity (Silvia et al., 2014), despite its widespread role in ordinary lives, as people use their capacity for improvisation, innovation and flexibility, creating original and meaningful adaptations to their environment (Richards, 2010). While offering a different view of creativity, this body of work tends to valorise little-c creativity as a beneficial psychological phenomenon rather than exploring how creativity emerges from and is negotiated within the complexities of everyday life and interpersonal relationships. Even when the social context of everyday creativity is considered, it is in terms of how the social world responds to 'creative' individuals that

dominates, rather than how everyday creativity may emerge and be negotiated in a relational context. A deeper appreciation of the multi-faceted nature of creativity in everyday life is therefore required.

Efforts towards recognising the relational dimension of creativity have been made by Glăveanu (2010a, 2010b), developing a cultural psychology approach to better attend to how creativity emerged from within everyday contexts. The importance of social relations in creativity is also a key focus for McCabe and de Wall Malefyt (2015) in their exploration of how creativity figures in home cooking practices of US mothers. Beghetto and Kaufman (2007; Kaufman and Beghetto, 2009) also offer a more nuanced way of conceptualising creativity, arguing that the Big-C/little-c model is ill-equipped to theorise the nuances of such forms of creativity. They advocate the addition of two further categories: 'Pro-c' and 'mini-c' creativities (Kaufman and Beghetto, 2009). Pro-c creativity, they suggest, adds necessary breadth to the conceptualisation of creativity, and accounts for creativity that has the potential to leave a short-term legacy, such as a well-received play or novel, yet may lack eminence. Positioned between Big-C and little-c creativity, Pro-c creativity requires domain-specific expertise acquired over time, but which may not have sufficient impact to change that domain in the way that Csikszentmihalyi (1996) attributes to Big-C products.

Mini-c creativity, according to Beghetto and Kaufman (2007), offers a useful way of understanding the everyday internal creative processes that are central to an individual's learning and development. This moves away from the dominant product-orientated conceptualisations of creativity that characterise the field more broadly - what Beghetto and Kaufman (2007, p.74) term the 'fossilized outcomes of creativity'. It draws attention instead to the dynamic processes of 'creativity-in-the-making' (Moran & John-Steiner, 2003,p. 61). Mini-c is 'the novel and personally meaningful interpretation of experiences, actions, and events' (Beghetto & Kaufman, 2007,p. 73) meaning it differs from little-c in that it is understood to be a purely intrapsychic process in contrast to little-c creativity which occurs in shared space. The internal mini-c phenomenon has been described by Vygotsky as follows:

> any human act that gives rise to something new is referred to as a creative act, regardless of whether what is created is a physical object or some mental or emotional construct that lives within the person who created it and is known only to him (cited in Moran & John-Steiner, 2003, p. 7).

Beghetto and Kaufman's model offers a broader perspective on creativity, which incorporates the association between creativity and a domain-changing legacy, but also recognises more modest contributions to public life, everyday little-c creativity and intrapsychic processes. For instance, drawing attention to creativity as an everyday practice, Selberg (2015, p, 157) punctures inflated notions of extraordinary creativity:

> by honoring creativity as a banal process of the everyday rather than as heroic or genius, we might lessen the social insistence on creativity's value while still allowing for and honoring minor, humble performances of self... perhaps here individuality will lose some of its social relevance, and creativity might be reborn as a mode of social collaboration and play.

In the context of dementia, such a broader view of creativity is welcome. Although there is a general consensus that arts-based activities are meaningful to people with dementia, we propose that a broader conceptualisation can precipitate a shift in thinking about creativity in the context of dementia. Drawing attention to spontaneous enactments of ordinary creativity in the context of everyday life can offer new insights into the ways in which people with dementia and their families and friends adapt to the changes brought about by the condition, for example, word-finding difficulties, temporal desynchronization and behavioural changes. In addition, using Beghetto and Kaufman's model draws attention to how different Pro-c creativity may emerge in the context of dementia, for example activism as expressed through campaigning for a change to services and/or writing a published account of living with dementia (e.g. *When it gets dark* by Thomas DeBaggio).

Capturing forms of creativity that emerge in everyday life with dementia through creative methods that, for example, make use of observation, audio, video and visual tools, or diaries and walking methods, offers a different way of understanding dementia that does not rely wholly on traditional interviews, which may serve as a 'cruel reminder' (Hubbard et al., 2003, p. 356) of study participants' linguistic and memory difficulties. Proponents of such methods in other contexts argue for more detailed observation of the creative process as it happens in everyday life, or what Glăveanu (2010b, p. 155) calls 'process observation'. In a similar way, McCabe and de Waal Malefyt (2015) employed ethnographic methods to record the experiences of US women as they cooked, so as to reduce emphasis on a creative end product and focus attention

on the creative activity itself. Engaging in daily activities alongside people living with dementia and those around them offers ways to explore, for example, the everyday or little-c creativity that emerges in daily life with dementia. For instance, in observing the ways people may adapt their homes, make efforts to retain mental agility and memories, enable a person with dementia to 'pass' in a public space, make adaptations in the home and change their use of language and communication. Such an approach explores creativity as a set of relational and negotiated practices that does not focus solely on positive benefits but also incorporates areas where tensions and challenges can emerge, for example others' creative practices undertaken to minimise the risk of a person with dementia leaving the home alone or not taking their prescribed medication.

Thus, a critical approach to creativity and dementia offers a broader understanding than individualist or interventionist studies which tend to focus on the person with dementia as an atomistic self. An everyday relational approach pays more attention to the contextual factors of living together with dementia, recognising the self as developed in relation to and in relationships with others, and understanding the importance of these relationships for a person's continued sense of self throughout their lives (May, 2013; Burke, 2014). In the following section, we begin to outline some of the dimensions that such a critical approach might encompass.

Broadening the scope of creativity and dementia: six dimensions of a critical approach

A critical approach to creativity in the context of dementia has implications for how dementia is researched, how arts practices are enacted, as well as how people with dementia are understood and their experience is shaped and valued. We present six dimensions of a critical approach and discuss what these can add to existing academic work, healthcare and governance. These are not intended to be exhaustive, but to stimulate debate about how to begin the work of expanding the remit and repertoire of creative practices in this area of study. Our aim is to open up a new research agenda to be further developed in empirical studies on living with dementia.

First, we outline how understanding forms of creativity in everyday life allows for new ways to operationalise and hence notice and make use of forms of creativity. This helps us to re-think the measures that are customarily used in researching creativity and dementia. We also argue that a

critical focus on everyday creativity can point to the importance of negative and ambivalent emotions, as well as highlighting difference, power and reciprocity as important dimensions in how everyday acts of creativity are conducted, negotiated or stifled. Adopting this approach also allows us further to challenge the deficit model that still dominates dementia research and practice (McGovern, 2011).

1. Everyday life and creativity

A critical approach to creativity and dementia might attend to the way people with dementia and those around them are creative as part of their everyday lives, in everyday spaces and places and in the context of their ongoing, complex relationships. Such creativity falls into two broad categories. The first, instrumental creativity, comprises pragmatic responses to particular difficulties, such as the use of written instructions to make coffee or the addition of latches to doors (Lach & Chang, 2007). Small acts of improvisation in daily routines could also be considered within this category, such as those that take place in cooking (McCabe and de Waal Malefyt, 2015). The second category is non-instrumental creativity, which speaks to more artistic or joyful aspects of life, such as the spontaneous use of music, sound, body and voice. In a study by Capstick et al. (2015, p. 245), for example, a resident of a care home described a solitary plant in the garden as 'one little chap all on his own' and, in a life memoir, Elizabeth Cohen (2004) reports how her father (who lives with Alzheimer's disease) describes her toddler as 'the person who brings hurricanes'. Attending to the use of metaphor and allusion, the creation of neologisms and the use of humour makes such everyday creativity visible.

Following from Glăveanu, who argues for the importance of examining context when studying creativity, we also argue that *where* everyday creativity takes place is of significance. Many of the arts-based interventions we explored above included research participants living in the community. However, many of the activities were conducted within institutional spaces (residential care or civic buildings such as museums or galleries) rather than in 'everyday' spaces such as outdoor communal spaces such as parks, private homes, family gardens or a local supermarket. The topic of space does, nevertheless, emerge within the research accounts discussing the use of arts-based interventions. For example, Camic et al. (2017) argue that museums and art galleries offer stimulating, non-clinical and non-stigmatising places for people with dementia, which is important. But the extent to which such spaces could appear intimidating and exclusionary, rather than empowering, is given less attention (Camic et al.,

2014). Gjengedal et al. (2013) are rare in explicitly recognising the influence of space and place, by arguing that there is something intangible embedded in a room that communicates with the individual, and that the use of a theatrical as opposed to a clinical space may be appreciated by people accustomed to unequal power relationships between clinicians and service users.

The setting of the care home, a place that is often not chosen by the people with dementia themselves, is particularly salient for Capstick and Ludwin (2015, p. 158), who focus on strategies that people with dementia may create to 'make an imaginative retreat to a more hospitable or personally meaningful remembered environment'. Capstick and Ludwin (2015), Buse and Twigg (2014) and McColgan's (2005) studies of people with dementia living in care homes reveal the ways in which care home residents reconfigure either their material or their psychogeographic environments to create private spaces in the public environment of the care home. For instance, Buse and Twigg (2018) described how residents with dementia used handbags and material props to create privacy within the care home lounge, as well as their clothing strategies such as putting on a coat or packing a suitcase to express their desire to leave the care home. McColgan (2005) describes how residents with dementia employ 'resistance strategies', including attempts to leave the care home, distancing themselves from the identity of a 'care home resident' through foregrounding other aspects of place identity, and using strategies such as feigning sleep to avoid unwanted conversations. Other research suggests ways in which little-c creativity might be employed by people with dementia in care home settings. Research on narrative illustrates how storytelling may be used spontaneously by residents with dementia to sustain aspects of their identity which may be threatened within the context of care (McColgan, 2004; Hyden & Oruluv, 2009). The work of Kontos (2004) demonstrates how people with dementia living in care settings can exercise agency through spontaneous engagement in various activities at an embodied level, including re-enacting religious rituals, singing and moving to music. Little-c and mini-c creativity are thus evidenced in the navigation of place, change and power relations as people with dementia adapt to (or resist) living in the care environment. Capstick and Chatwin (2016) demonstrate the use of everyday creativity in language and social interaction, for example around the management of norm breaches and institutionalisation. This work also points to the importance of the home, garden, street and so forth as locations in need of greater study, for these are largely absent from the literature (for an example of a recent exception see: Ward et al., 2017), the focus of which remains set on institutional environments. Everyday creativity clearly happens wherever someone is, but how this occurs, with what skills, to what ends and through which struggles will differ from context to context.

With few exceptions, arts-based research conducted with people with dementia has an individualist orientation. Therefore, how creativity in everyday life is negotiated relationally has garnered little attention in the literature and needs to be better studied. However, Buse and Twigg's (forthcoming) study of dementia and dress is an exception. They observed that new routines and dress strategies were co-created by the person with dementia and their family members in order to adapt to the disruption caused by dementia. Furthermore, some creative adaptations, such as a family member reordering a wardrobe to place colour-coordinated clothes together could potentially constrain the aesthetic and self-presentation choices of the person with dementia. Little-c creativity in the context of dementia is likely to be shaped by such instances of relational power dynamics, and a critical approach to researching creativity and dementia that adopts a relational approach could offer further insights into these processes.

Although it has rarely been the explicit focus of such work, there are, therefore, existing rich studies which provide insight into how creativity can form part of everyday practices in the lived experience of dementia. However, our contention is that not enough is known about such forms of creativity that take place among people with dementia who do not live in care institutions. Especially lacking is a relational characterisation of creativity employed and experienced as they traverse their everyday spaces of home, work, neighbourhood and community. Since the majority of people with dementia live at home (Alzheimer's Society, 2014), it is important to gain an understanding of these everyday, distributed forms of creativity if we are to better understand what it is like to live with dementia, how people cope with or embrace change, how dementia affects everyday practices and what it is that might constitute 'living well' with dementia when set within this mundane setting.

2. Power relations and creativity

In the body of arts-based intervention research, there is scant evidence that people with dementia were able to influence the study design or exercise autonomous choice over the creative modality. Additionally, how people with dementia experience their involvement in the research process is often under-reported. In contrast, within the group of studies using creative methods to research the experience of dementia more broadly, there were at least some considerations of how people with dementia might exercise more control and, potentially, resist participation. Bartlett (2012), for example, elected to use a diary method which enabled people

with dementia to have more control over the data collection process. Additionally, in a study where elder clowns attempted to interact with people with later stage dementia, Kontos et al. (2017) found that one participant, a former artist, exercised his agency by resisting the clowns' attempts to engage him when they were mimicking the action of drawing. However, when there was practical, reciprocal involvement the participant chose to interact by taking turns drawing a picture with the clowns. In the context of embodied selfhood, the authors suggest, creative action is 'not an intellectual operation but rather it arises from practical involvement' (p. 189). It is incumbent on researchers, then, when working with participants with dementia, to attend closely to embodied expressions of resistance and to explore the creative methods people may adopt to resist engagement with research and arts-based therapy. Such practices should both enable resistance and have the potential to develop understandings of why the resistance was invoked and what can be learnt from such challenges to research (and treatment) agendas.

Furthermore, in contrast to imposing arts practices on participants with dementia and measuring their responses, future research employing a critical approach to creativity and dementia could devise methods that are consonant with the creative practices that people with dementia and their families and friends already use or wish to engage in. This approach might honour participants' everyday creativity and empower them to influence the activities and any research being conducted through these.

A neglected dimension of creativity and dementia is how social inequalities may structure daily experiences. Recent research on social citizenship (Bartlett & O'Connor, 2010; Birt et al., 2017) has broadened discussions from a predominant focus on the personhood agenda to highlight the ways in which the experience of dementia affects social status more broadly. Socio-political 'discourses of deficit' (Birt et al., 2017, p. 200) stigmatise people with dementia and negatively impact on recognition of them as citizens with rights. This discrimination can be enacted at a number of levels (Bartlett & O'Connor, 2007), as people with dementia become less able to access social, health and economic resources, communities become impoverished by the invisibility of people with dementia, and, in the context of everyday practices, people with dementia may feel less able to act with agency.

As Birt et al. (2017, p. 206) note:

> People with dementia may be striving to be active in their families and communities but the actions of others constantly constrain their opportunities for agency. This can generate feelings of being disempowered when others take over tasks, and restrict opportunities for access to meaningful or enjoyable activities due to others perceiving them to be too risky.

Linking this together with the literature reviewed above, it becomes clear that there might be ways in which little-c and mini-c creativities arising from everyday life might be treated as troubling to institutional arrangements. A growing body of work has demonstrated, for instance, that legitimate walking or exploration may be negatively positioned as undesirable, counting either as 'wandering' or being lost (Brittain et al., 2017). Or, in another example, clothing choices by residents of care homes living with dementia may be deemed inappropriate by staff (Buse & Twigg, 2014).

Discriminatory practices and differential access to resources may constrain the creative agency of people with dementia, and lead to creativity being construed as inappropriate or risk-taking activity rather than being recognised and acknowledged as a rightful expression of embodied agency, as a form of legitimate resistance or a means of coping with a situation of inequity. A critical approach to studying creativity and dementia remains mindful of such power dynamics and focuses attention on *whose* creativity is at stake, how this is negotiated in the context of personal and professional relationships, and with what consequences.

3. Operationalising everyday creativity

Understanding the way everyday creativity is constructed and operationalised is an important dimension of a critical approach to creativity and dementia. In another context, Glăveanu (2010b, p. 153) has noted the importance of local definitions of creativity, and stressed that creative products should be assessed 'in relation to a certain time and a certain group of reference'. For our purposes, there are two key aspects of this dimension, which include how the notion of everyday creativity can be used to provide deeper insights into living with dementia, and how the existing everyday practices of people with dementia and those around them may be adopted in research to develop understandings of the value, potential and challenges of creativity.

Everyday creativity, according to Richards (2007, 2010), relates to the ways in which we make positive, meaningful adaptations in daily life, demonstrating flexibility, innovation and improvisation in response to the daily challenges that arise. In the context of dementia, daily challenges are likely to become increasingly profound, as the ability to live independently becomes troubled by difficulties with memory loss, spatial and temporal orientation, verbal fluency and behavioural change. Many of the creative practices that people with dementia and those around them engage in are likely to be hidden or obscured by an emphasis on loss of capacity. People's creativity might only explicitly be considered 'creative' when they involve practices relating to traditional arts activities. People with dementia might not themselves recognise the hugely creative energies they use in developing jokes, new words, material arrangements, new relational practices, and so forth. Similarly, a family member who arranges mealtimes for a person with fronto-temporal dementia in a way to minimise dysphagia may not view their actions as 'creative'. But this needs to be acknowledged and supported. At the same time, we have to attend to participant's claims to or refusals of creativity as a definition of their actions. The use of everyday creativity as a construct, therefore, while enabling a broader academic understanding of how creativity is distributed across various domains of human life, and specifically how it is involved in the life of people with dementia, must also critically reflect on who defines creativity and to what ends. Furthermore, we must be mindful of whether everyday creativity always leads to positive psychological outcomes, as Richards (2007, 2010) notes. Nonetheless, there is a rich set of everyday forms of creativity in use in the lives of people with dementia and their families, friends and carers which opens opportunities to better engage with such creativity in academic studies.

A focus on such everyday creativity should also adopt an approach to methods which explore 'what it looks like in people's natural environments as it happens' (Silvia et al., 2014, p. 183). In terms of critical research into creativity, we propose that it is possible to take this a step further, by not just observing creativity as it emerges in everyday life, but also by making use of participants' everyday practices as research methods. For example, if a person with dementia creatively arranges ornaments, the researcher could use this as a form of object elicitation and as a form of art, to understand more about such actions and about the experience of dementia. Similarly, a researcher could identify and partake in any traditional creative practices that the participant enjoys, observing their sensory engagement not only with the process, but also with the outputs of the creative work. Indeed, with few exceptions (e.g. Petrescu et al., 2014; Capstick & Ludwin, 2015), creative outputs are rarely used as a form of knowledge in and of themselves;

nor are they treated as having the potential to provide further insight through a formal analysis. But they do hold such potential, for example drawings can be used in health care research to gain deeper insights into illness experiences (Guillemin, 2004; Keady et al., 2007; Williams & Keady, 2012a,b). There is, therefore, an opportunity to consider how people's everyday creativity and its material outputs, whether these derive from instrumental or non-instrumental creativity, may be used to develop more nuanced understandings of the lived experience of dementia. We can operationalise everyday creativity to better understand dementia (and creativity) not only for academic purposes but to reflect our findings back into the use of arts-based therapy or other treatment processes.

4. Affective Ambivalence

A value implicit in much of the interventionist research is that for creativity to be worthwhile it should engender positive affect to improve quality of life. Looking for the outward signs of subjective well-being has led to a focus on demonstrations of interest, pleasure and attention. However, as we have shown, some of the literature using creative methods to study the experience of living with dementia evidences the complexity of embodiment in this context and the relational nature of care, as well as offering a broader perspective on sensory and material dimensions of living with dementia. Work on political context and the power relations of institutional environments also points to the complex articulation of feeling, resistance and subjugation at work in the lives of people with dementia. To integrate insights from these literatures into arts-based therapy practices, and in the development of a broader approach to creativity in this context, means taking heed of the ambivalence which might characterize creativity in everyday life, particularly where health and illness are at stake. A critical approach to dementia and creativity must recognise that working creatively may inspire both 'positive' and 'negative' emotions, 'good' and 'bad' affect.

A key challenge in considering affective and emotional dimensions more holistically will be to accept and take seriously the fact that sadness, hopelessness, fear and so forth are legitimate and important affective and emotional experiences to be acknowledged and explored rather than always to be overcome or attenuated. In this regard, the outcome of creative engagements, whether in the home or in care, in a museum or a hospital, may not be improved happiness or liveliness (as is the aim of arts-based interventions), as such.

The surfeit of human feeling should not be reduced for people living with dementia any more than it should be for people without such a diagnosis. Of course, arts-based therapies are intended to help people to have positive experiences given the likelihood that at least some of their everyday experience has become painful and sometimes unbearable. But 'living well' might mean much more than 'feeling good'. Art, perhaps especially amongst forms of self-expression and political action, is characterised by its capacity to represent, examine or conjure all parts of human life. A critical approach to arts-therapy and creativity offers a chance not just to counter bad feeling but to explore it, gain comfort in the sharing of it with others, aim it appropriately and challenge its sources collectively, and, yes, to let it go when possible and healthy.

Wetherell (2012, p.139) argues for an approach to affective and emotional practices that understands subjectivity as the 'organising site contributing pattern and order' to their experience, in such a way that they gain their 'textures, shapes, potentialities, repetitions, creativities, and find their limits in relation to animate and inanimate others.' This has important bearing for a critical approach to creativity when considering the affective ambivalence that it will likely attend. It means that we must ensure that even where we consider common experiences like anger and happiness, anxiety and passion, that we do not forget to place them in their relational context, understand them as textured through relations of power, material forms, and so on. As Freund (1990, p. 472) has argued:

> Power, its distribution and its exercise through various social control activities, affects the likelihood of encountering 'pleasant' or 'unpleasant' states of emotionality. They 'reconstruct' embodied subjectivity in such a way as to protect those in power and lower emotional dissidence and resistance among those who are powerless. The body is a part of this construction process. To the extent to which this reconstruction and the stress of distressing experiences are chronic and encountered at junctures of biographical vulnerability, they may affect our health.

Power, feeling and health are entangled, and thus political. As we seek to engage creativity as a practice in the work of supporting people with dementia to live well, we must ensure that we do not forget this critical dimension. By doing so, we reduce the risk of arts-based therapies simply closing down legitimate and important expressions of frustration, sadness, melancholy and so on, as might happen if we emphasise only those 'positive' feelings. Instead, we can support the

creative use of affective ambivalence towards whatever personal, political or cultural ends are sought by people with dementia, their friends, families and carers.

5. *Difference*

Within the body of work on creativity and dementia there is a dominant focus on people in the early or middle stages of dementia. While some studies included people without mental capacity (e.g. Capstick & Ludwin, 2015; Buse & Twigg, 2016) only a few authors (e.g.; Gross et al., 2015; Sauer et al., 2016; Swinnen, 2016; Kindell et al., 2017; Kontos et al., 2017) explicitly stated that they included people with advanced dementia in their samples. In terms of diagnoses, unsurprisingly given its prevalence compared to other dementias, many study participants were living with Alzheimer's. People with rarer dementias, for example fronto-temporal dementia, may experience symptoms other than memory loss (Oyebode et al., 2013) and it is important that arts-based therapy and creativity and dementia studies ensure that people with less-common diagnoses are represented in activities and samples and that their different experiences are taken into account when planning how creativity will be implemented.

Furthermore, existing research samples are skewed towards white women. Although dementia is more prevalent in women (Alzheimer's Disease International, 2015) it is important to ensure that men's voices are heard (exceptions include Aadlandsvik, 2008; Bartlett, 2012; Johnson et al., 2015 and Camic et al., 2017). In addition, marginalised groups who experience the intersection of more than one type of discrimination, for example those from an ethnic minority or LGBT community, are almost entirely overlooked in the body of interventionist studies. It has been suggested that people from minority groups have delayed access to dementia care services and a lack of tailored service provision (Price, 2008; Regan et al., 2013; McGovern, 2014; Parveen et al., 2017), and it may be that studying everyday creativity with marginalised groups will offer holistic insights into their daily lives with dementia and shed light on experiences of exclusion.

A critical approach to creativity and dementia must attend to difference. In terms of diagnosis, stage of illness, marginal experiences, and so forth, the modes of creativity which might be appropriate to explore, elicit or deepen within a study could change.

6. Reciprocality

A critical approach seeks both to contribute to understandings of dementia, but also to explore what the experiences of dementia can tell us about creativity, socio-political order, practices and everyday life. For example, dementia troubles the everyday by disrupting taken-for-granted relational practices, and, as Garfinkel (1967) argued, it is through the breaching and subsequent repair work of everyday social life that we can become conscious of the constructive and reconstructive processes underpinning the social world. Therefore, as people living with dementia might sometimes breach the norms, rules or power relations embedded in everyday practices, and as people seek to repair the breaches, we might be able to learn more about the construction and reconstruction of social organization and how this might shape and constrain the lives of people with dementia. Thus we can learn from Buse and Twigg's (2014) work, for example, that the creative clothing choices made by residents with dementia in a care home illuminate constructions of acceptable clothing in public and private spaces more generally, pointing towards ways in which reconfigurations of 'normal', taken-for-granted practices might open up new avenues for support of people with dementia, and those who support them. Or, in Burke's (2014) work, where changes in intersubjective processes are seen not simply as problems to be overcome through narratives of dementia, but *vital* moments in which the nature of intersubjective processes, such as emotion, ethics and memorialization, are opened-up, questioned and (re)composed.

The creative work exposed in the management and negotiation of change in the context of dementia offers potential to explore everyday life more broadly and reflect on how we might all 'live well' together. In the body of research looking at dementia and creativity, for instance, engagement in the cultural arts is constructed as a valuable, acceptable and healthy form of self-expression for people with dementia, in a way that other behaviours, which are also arguably demonstrations of embodied creative agency, such as non-normative walking, vocalisations, and scatolia, are constructed as problematic, inappropriate forms of behaviour (e.g. Barton et al., 2005; Ata et al., 2010). Thus using the lens of dementia it is possible to gain insights into how normative creativity is constructed and accounted for, and with what impact upon health and illness experiences and inequalities.

Conclusion

We have argued here that creativity needs to be understood not just as partaking in traditional cultural arts practices but as something that takes place in the everyday. We have provided examples of such creative everyday practices in the context of dementia, for example, creative clothing choices and reordering wardrobes. This broader understanding of everyday situated creativity will allow for fresh insights into the lives of people with dementia, and will require something of a re-think when it comes to how dementia is studied and the methods employed to do that.

In addition to research that focuses on the effects of various arts-based interventions and research that has used creative methods to study the lives of people with dementia, we argue for the importance of taking a critical approach to the study of everyday creativity in the context of dementia. This means being attentive to and studying little-c and Pro-c forms of creativity that people with dementia and their friends and family members engage in.

As Richards (2007, p.48) has noted, everyday creativity 'far from being trivial...and only intermittently of relevance...represents a pervasive and dynamic way of being and knowing, and of encountering the world'. Understanding dementia through an everyday creativity lens, then, has the potential to offer profound insights into the relational and embodied experience of dementia. Importantly, this approach places the person with dementia and their family members and friends centre-stage, enabling them to identify their ability to innovate, invent, and problem-solve in both instrumental and non-instrumental ways. Such an approach highlights the relational nature of the experience of dementia, challenges prevailing narratives of deficit and loss (McGovern, 2011; Birt et al., 2017), enables fresh insights into everyday life with dementia and develops understandings of constructions of acceptable creativity.

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