Emerging values in participatory design and dementia: explicating, operationalising and redefining

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Abstract
In this paper, I describe how the core values of democracy, discussion and dilemmas in participatory design give rise to the emergent values of agency, skillfulness and creativity when used with persons with dementia. This "valued" approach to participatory design looks promising in the dementia context; however, it also represents a number of practical difficulties. This paper lays out these difficulties and suggests a position from which to proceed.

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Participatory design; dementia; inclusive design; psychology; methodology.

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Introduction
This paper deals with an attempt to operationalise and make explicit certain values in the context of using participatory design with persons with early- to mid-stage dementia. This attempt is central to my own research, which concerns the investigation and
delineation of a suitable participative design methodology to use with persons with dementia. Though still in its early stages, through working with the Irish Carers' Association, with a local geriatric unit and with the local branch of the Alzheimer's Society, my work is beginning to build a vision of participatory design which, while adhering to its core values of democracy, discussion and conflicts as resources in design [1], also allows for the emergence of agency, skillfulness and creativity – three values which, as I will explain, are particularly important in the use of PD methodologies with people who, through the inevitable progression of dementia, are undergoing a sense of a shifting and often a dissolving selfhood. Self- and personhood are imperative within this vision of PD; in this context they refer to a sense of self as continuing and continuous despite the progression of dementia. More than that, they refer to the self as both separate from others but also mediated through and constructed by the presence of others and are thus essentially dialogical terms.

This value-emergent, change-based view of participatory design holds within it several practical problems which are compounded by certain issues with the population with whom I hope to work. Before arriving at these issues, however, I will briefly track the history of PD, its core values, its emergent values and the benefit these values may have for persons with dementia, before finally stating the issues which have prompted the writing of this paper.

**Deterioration and democracy**

The prevailing view of personhood in early to mid-stage dementia has long been one of deterioration, destabilisation and ultimately disintegration; this loss of agency and control over present and future, rooted in reality but compounded by contemporary views of ageing selfhood, is crucially reflected in a perceived reduced ability to participate in social settings [2; 3]. For carer and sufferer alike, the experience of dementia is ultimately an isolating and disempowering one, and the question of how best to design for this vulnerable relationship has been raised time and again.

Can PD, with its roots in trade union movements for disenfranchised employees, empower people with dementia – both in eventual product design and throughout the design process? The potential value in PD for those suffering with dementia is one that is suggested by its original use in Scandinavia to “counteract the dehumanizing effects of an increasing technological presence in the workplace” [4].

By involving the vulnerable user in each stage of the design process, PD gives a voice to those who previously have been voiceless; in this way, its use with dementia sufferers seems promising. PD workshops are a social process which involve the intended stakeholders and the researcher coming together to discuss, debate and criticise. This social element of PD has the potential to prove both fruitful and frustrating for those with dementia, and in the following sections I suggest how participation theoretically gives rise to the acknowledgement and awakening of agency, skillfulness and creativity in stakeholders, and also how using these methods with persons with dementia can be problematic in relation to these values.
Agency, skill and creativity in participation and dementia

Through discussion and imaginings, PD sessions themselves inevitably include the collision of multiple perspectives; a crucial point, according to Martin and Gillespie [5], in the ontogenesis of human agency. Martin and Gillespie take up Mead’s point that distanciation from the immediate environment is at the root of human agency; our ability to recognise that others too own their own perspectives allows us to envision any number of imagined futures. At the level of PD sessions, they, in turn, can only foster this sense of agency and possibility – not only are the stakeholders being offered the chance to shape the design of a product or institution which will impact on their lives, they are also placed in a multi-perspectival, essentially social and thoroughly agentic frame.

This view of participatory design, it can be argued, thus facilitates a greater sense of agency and purpose in the stakeholder; however, considered in the context of dementia, the issue is rather a murkier one. If agency arises through distanciation from the immediate environment, what does this mean for a person suffering in the mild stages of dementia? With an increasingly reduced memory capacity, is it reasonable to expect these participants to reflect and act in accordance with their perceived perspectives of others? If agency is to be fostered through social participation, it must be in a way which allows room for the deficits of (or rather, plays to the strengths of, as we will discuss in the following section) its vulnerable participants. The question of how to do this is one which remains open.

There is a tendency in dealing with persons with dementia to attempt to supplement the weaknesses of the sufferer – John Vines [6] elaborates on this perspective, suggesting that it is a natural reaction to the cognitive literature on ageing, which characterises the ageing process as one of inevitable decline and deterioration. Vines rejects this position, offering instead the concept of senescence, which depicts ageing as a process in which there is a fundamental “misalignment” between the normally integrative processes of unconscious sensorimotor activity and the physicality of the person themselves. Ultimately, Vines proposes a reconceptualization of previous conceptions of capacity.

Similarities can be drawn from Vines’ concept of senescence to that of the enablement perspective as practiced by nurses when rehabilitating and caring for dementia patients. Enablement in gerontological nursing is defined by Dawson, Wells & Kline [7] as simply assisting the patient to use his/her abilities and/or resources.

Enablement is employed among a spectrum of abilities in patients with dementia, ranging from basic self-care abilities through to social, interactional and interpretive skills; in each of these areas enablement involves the assessment of the patient to understand how much of their original abilities in each of these areas have been preserved; for example, in the social domain, various replies to the salutation “hello” are recorded on a scale:

1) a verbal reply
2) a smile only
3) eye contact only
4) muttering or
5) no change in behaviour.
Depending on the level of ability present, nurses may then employ either ability enhancing or ability compensating tactics – where ability enhancing actions employ the use of greetings, frequent one-on-one interactions and involvement in group activities, ability compensating behaviours are used only if the patient fails to respond, and involve the use of attending behaviours and touching.

Though one is a practical approach to nursing and the other a theoretical approach to design, enablement nursing and John Vines' concept of senescence share the viewpoint that often it is not the decline in functioning inherent to ageing/dementia alone to blame, but rather an invalid definition of “ability”. In addition to this, prevalent conceptions of personhood in dementia often bolster the common conception of the dementia sufferer as a “non-person”, even in the early stages of the disease [8]; as in the previous section, there is a clear potential for these ideas to enhance already-utilised workshop methods in participatory design. The issue lies in how to make real the suggestions imparted by senescence and enablement nursing in old age and the early to mid-stages of dementia.

The creativity of the person with dementia must also be acknowledged in conjunction with the values of agency and skillfulness. Simons and Sanders (2009) discuss four levels of creativity which occur during the process of co-creation:

1) ‘doing’ – the physical act of doing something with one’s own hands
2) ‘adapting’ – making an item or artifact one’s own
3) ‘making’ – creating an object or an item which hitherto did not exist, and
4) ‘creating’ – creating an all-new idea, object or item.

The use of this ranking system is seen in its connections to the previous two sections; each involves enacting a change on the environment, and is thus agentic and enactive, while its use as a scale can be seen as a parallel to the scales used in enablement nursing.

Creativity sessions have been shown to have potential positive effects on persons with dementia [10]; importantly, Hanneman [11] found that some dementia patients used these creative sessions to define their aesthetic tastes and preferences. In this way creating and doing is seen as something defining, something that makes one element of a dialogical process such as a PD session distinct from another. Commonly accepted psychological conceptions of creativity, however, tend to suffer from over- and under-definition in turn: the problem here lies in how to reconceptualise creativity for persons suffering with dementia.

**Practical issues**

While literature and practices in design and nursing supports this conceptualisation of agency, skill and creativity in PD and dementia, problems remain in 1) making these values explicit in the process of design, 2) operationalising and eliciting these values in the process of design and c) redefining uncertainties in creative practice.
Making values explicit

Iversen, Halskov and Leong [12] examined the emergence of values in participatory design, adopting a dialogical approach to the process, positing that values emerge from dialogical processes during PD sessions. Their attempt to bring to the fore these values was to open discussion about values preceding the sessions themselves and including the values of the researcher in the discussion itself.

While discussion of values (whether explicitly or more unobtrusively) is inarguably a necessary part of any PD session, this may seem circular when considered in the light of our earlier points about the dialogical and perspectival nature of agency in social situations and difficulties encountered therein; is there a way to bring values to the fore that doesn’t involve distanciation from the immediate environment and an ability to consider perspectives other from our own? We need to imbue our methods with these values explicitly; however, it also has to be done in a way which is both unobtrusive and dialogical without being mentally taxing. This is imperative not only because of the cognitive capacity of the person with dementia, but also because PD is not simply an exercise in value-building; it is a design methodology and a means to an end.

Operationalising and eliciting values

Our examining of participative values has left us with a number of practical problems regarding the implementation of these ideologies within a participatory framework:

1) How to practically foster agency methodologically in a way which either compensates for lost or misappropriated abilities or which enhances already-there abilities in persons with dementia.

2) How to incorporate Vines’ senescence concept/practices from enablement nursing into PD methodologies – going beyond simply occupying a ‘frame of mind’ and actually implementing similar actions, and

3) How to encourage and use creative processes which allow for the demarcation of PD participants as separate from each other whilst also allowing for rich discussion and dialogicality in PD sessions.

It is my belief that these problems are ones which will surely benefit from discussion amongst others who have experience and knowledge of working with vulnerable persons, particularly using broadly participative frameworks.

Redefining uncertainties in creative practice

Although there are clear issues with this value-based view of PD, it is possible to mark out the beginnings of a position which addresses these problems practically. The idea of the person with dementia as resourceful, skillful and creative is one I have stressed throughout the paper, and this position is taken up also by Killick & Craig [13] who eschew conventional notions of creativity in the context of dementia.

Opening up creativity beyond its usual conception makes it immediately more accessible for dementia sufferers. Killick & Craig confront and acknowledge the inevitable difficulties which come along with this sort of work; however, in engaging with the practical aspects of creative sessions with people suffering from
dementia, they uncover evidence of agency, of communication and participation.

This is achieved by redefining and reconsidering what we consider creative: is it not that all utterances are communicative, even if they are the often repetitive and disjointed words of a person suffering from dementia? The challenge lies in exploring this space and in interpreting these actions and utterances as participative. In the context of PD, this may represent a significant step forward in practice – Killick & Craig write that one of the foremost functions of creative sessions in dementia is that of outward communication: "each artform has its own language." This speaks directly to PD: the variety of creative methods conventionally used in workshop sessions is extensive, as is the scope of their potential use with people with dementia. It is my hope that my research will proceed from this position of acknowledgement and exploration to explore the possibilities in the space uncovered by Killick & Craig, and to develop materials, activities and methods within a PD framework.

This will surely not be without its difficulties: at the very least, it will require reconsiderations of creativity, values, skill and agency from the researcher; it will require (however reconceptualised) communication, collaboration and participation from the patient, and must also involve carers (friends, family, medical staff) – the issue of their creativity, collaboration and participation is one which must also be considered. However new and difficult this vision of PD may seem, it is one which also represents new hope in supporting, empowering and emancipating vulnerable persons through design.

Conclusion

PD has a history of including as stakeholders vulnerable persons; those with dementia are particularly suitable here, suffering not only from the symptoms of the disease but also from conceptions of the person with dementia as being somehow less than a person. Participatory design, with its notions of democracy, discussion of values and dilemmas as resources, can be shown to engender values such as agency, skillfulness and creativity; these values, in this context, are both emancipating and empowering to the sufferer. However, difficulties arise at the level of implementing these suggestions, due both to methodological difficulties and issues inherent to the population itself. The current paper attempts to establish a position from which to proceed, and welcomes discussion and suggestions on how to overcome the anticipated practical problems.

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References


