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Guest Editors

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International perspectives on the
development of research-guided practice
in community-based arts in health

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The UNESCO Observatory refereed e-journal is based within the Graduate School of Education at The University of Melbourne, Australia. The journal promotes multi-disciplinary research in the Arts and Education and arose out of a recognised need for knowledge sharing in the field. The publication of diverse arts and cultural experiences within a multi-disciplinary context informs the development of future initiatives in this expanding field. There are many instances where the arts work successfully in collaboration with formerly non-traditional partners such as the sciences and health care, and this peer-reviewed journal aims to publish examples of excellence.

Valuable contributions from international researchers are providing evidence of the impact of the arts on individuals, groups and organisations across all sectors of society. The UNESCO Observatory refereed e-journal is a clearing house of research which can be used to support advocacy processes; to improve practice; influence policy making, and benefit the integration of the arts in formal and non-formal educational systems across communities, regions and countries.

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International perspectives on the development of research-guided practice in community-based arts in health

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THEME

Health has become a recurrent topic in discussion of the role of the arts in society, fuelled by a growing body of research into links between culture and flourishing. In community arts in particular there has been a widespread development of projects addressing health issues. This is a distinct area of activity operating mainly outside of acute healthcare settings and is characterised by the use of participatory arts to promote health. There are indications that this work is developing in response to health needs of communities in differing cultures and healthcare systems around the world, but so far there is little mutual knowledge or connection of the work at an international level.

This issue aims to draw together well-researched case studies of community-based arts in health projects from different parts of the globe. Each case study should explain the motivation for the work undertaken and its sensitivity to context and cultural diversity, the partnership structures and ethos developed in its delivery, and the research methodologies used. Submissions are particularly invited that reflect multidisciplinary knowledge of the application of arts development to health and flourishing communities from the perspectives of applied arts, public health, anthropology, social geography, education and other disciplines.

‘A Window Opening Up?’ The Contribution of Arts Programmes to Quality of Life for Older People Living in Care- Homes in Ireland

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ABSTRACT

This study examines, primarily from the perspectives of residents, how participating in professionally-led visual-arts workshops impacts on quality of life within long-term care. This study compared findings from studies into arts participation by older people with studies into quality of life in care.

Interviews were conducted with residents of three long-term care facilities who participate in visual-arts workshops, and with artists and staff. Relevant Irish public policy was considered, including a new inspection framework established since 2009 by the Health and Information Quality Authority.

The study concluded that arts participation can significantly enhance quality of life across the domains recognised as determining quality of life in residential care by providing opportunities for enjoyment and engagement, enhancing self-efficacy, self-expression and relationships. It also points to how residents, including highly disabled people, enjoy high levels of challenge from participation in visual arts workshops, something that itself challenges a culture of passivity and lack of autonomy inherent in traditional models of care.

KEYWORDS

arts, older people, residential care, quality of life, visual arts

1. INTRODUCTION

The ageing of the world population and of the Irish population, is one of the contexts for this study. In Ireland, those over 65 are projected to treble from 462,000 in 2006 to around 1.3 million in 2041, assuming zero migration (Central Statistics Office (CSO), 2008). Those aged 80+, will rise even more dramatically, showing a four-fold increase regardless of the underlying assumptions (CSO, 2008). In Ireland, just over 4 per cent of people aged 65+ live in long-term care representing approximately 22,500 people (Department of Health, 2012b; CSO, 2009). The likelihood of living in residential care increases with age, and nearly 23 per cent of all people aged 85+ do so (CSO, 2007). Significant growth in those requiring a level of long-term care is envisaged by 2032 (Interdepartmental Working Group, 2008).

Time spent living in care can be considerable. When discharged or deceased in 2008, almost 47 per cent of residents had stayed for between one and ten years and a further 2.7 per cent more than ten years (Department of Health & Children, 2008). More recent figures suggest that when discharged or deceased in 2011, nearly 10 per cent had stayed between one and ten years, and 0.7 per cent had stayed for more than 10 years (Department of Health, 2012a).

This study addresses some challenges involved in the culture of long-term care and the extent to which residents can participate in activities, particularly in visual arts programmes.

Quality deficits in long-term care are known internationally (OECD, 2005) although attention focuses more on poor care than poor quality of life (Cooney, Murphy and O'Shea, 2009). Townsend (1981) argued that Victorian workhouse values continued to influence life, depreciating individuality and fostering passivity and dependence. Miller and Gwynne identify a medical or 'warehousing' institutional model of care that encourages dependence, and depersonalizes 'inmate-staff' relations (1972: 85). Agich references how nursing-home care effaces rather than enhances residual autonomy, with medically defined objectives ignoring the resident as 'an experiencing subject and person' (2003: 60).

In Ireland, while it is known that care for older people should be ‘person-centred and holistic, based on autonomy, respect, choice and the promotion of independence,’ evidence is that routines dominate and care is not focused on individual needs, engendering helplessness (Murphy, 2007: 478).

A survey of activities offered within Irish care homes concluded that some provided nothing, some integrated them within everyday life, some did not focus on residents’ particular interests, and understandings of staff varied from those who saw activities as key to quality of life to those who felt that providing activities was not a priority (Murphy *et al*, 2006). In another study, involving 140 residents of public and private care homes, over half reported that they were bored (OCS, n.d.).

A qualitative study in Irish care-homes found that while residents were concerned about basic needs (like food and comfort), what was most difficult was lack of mental stimulation and lack of respect shown by staff with consequent loss of dignity and independence (Timonen & O’Dwyer, 2009).

2. BACKGROUND – PUBLIC POLICY

A number of strands of public policy are relevant to the study. These include those relative to quality of life for residents of long-term care-settings and those promoting their access to activities, especially participatory arts opportunities.

Until recently the official policy framework for older people related to health and care services only and dated from 1988. It recognised the importance of quality of life, but provided no definition (*The Years Ahead: A Policy for the Elderly*).

A new national strategy on ageing, the National Positive Ageing Strategy, published in April 2013, includes a commitment to develop opportunities for engagement in the arts (Department of Health, 2013: 20). No detail is yet available as to how this will be pursued. The Strategy has many references to quality of life although none in the context of residential care. An implementation plan for the strategy is awaited.

As regards long-term care provision, legislation from 1964 and subsequent regulations set minimum standards for care in private nursing-homes, but not for quality of life. It was 1993 before regulations required ‘opportunities to participate in activities appropriate to [residents’] interests and capacities,’ (SI No 226/1993, Clause 5e). These did not reference quality of life. A voluntary Code of Practice for Nursing Homes from 1995 referenced involvement in meaningful activities but remained unmonitored (Murphy *et al*, 2006).

In 2007 the introduction of legislation establishing the Health Information and Quality Authority (hereafter, ‘HIQA’) was significant, with power to inspect and, if necessary, to fine and close down residential facilities. Regulations now require care-homes to provide opportunities for participation in activities and make several references to quality of life, though it is not defined (SI 236 of 2009).

This was followed in 2009 with the introduction of standards on residential care for older people (hereafter, the ‘HIQA Standards’). Five standards deal with quality

of life, including one requiring individualized opportunities for meaningful and purposeful activity (HIQA, 2009):

Each resident has a lifestyle in the residential care setting that is consistent with his/her previous routines, expectations and preferences, and satisfies his/her social, cultural, language, religious and recreational interests and needs.

Criteria specified under Standard 18 require that:

The resident is given opportunities for participation in meaningful and purposeful activity, occupation or leisure activities.....that suit his/her needs, preferences and capacities.....

The HIQA Standards and enforcement powers represent a landmark development. Yet evidence from other countries is that regulations alone do not always lead to good outcomes (OECD, 2005) suggesting that regulation needs augmentation with initiatives that support care-staff to enhance residents' quality of life. The arts are not mentioned specifically in the HIQA Standards.

According to Matarasso (1997) participatory arts practice can help tackle social problems and disempowerment:

'[they] are essential components of successful social policy, helping to turn houses into homes.'

As far as public policy and the arts is concerned, neither the current nor previous Irish Arts Council strategies mention older people or residential care (2010a, 2005), but the Arts Council recognises ways of working across art-forms, and 'older people' are mentioned in this context (Arts Council, n.d.). An Arts and Health strategy recognises arts work within residential care-settings, whose aims may include promoting quality of life (Arts Council, 2010). This strategy also recognizes that arts programmes taking place in care-settings occur with limited resources and within a fragile infrastructure, highly dependent on key individuals and one-off projects. The strategy calls for a partnership to build a strategic framework between the Arts Council and the Health Service Executive, the Irish statutory body that runs the health services. To date no formal framework has been established.

Access to arts resources is distributed unevenly across Irish society (National Economic and Social Forum, 2007), and participation in mainstream arts provision is particularly limited for residents of care homes (Russell, 2007).

3. THE STUDY

3.1 AIM

The study explored how participating in ongoing visual-arts workshops impacts on the quality of life of older residents of long-term care-settings, primarily from the residents' perspective, and made recommendations for public policy.

3.2 RESEARCH METHODS

The main research method used was interviews with residents, staff and artists.

In addition, there was also:

- A Review of reports published by the Health Information and Quality Authority (HIQA) relating to 10 per cent of the country's long-term care units for older people. This sought to obtain an overview of (1) the extent to which professional artists are working within long-term care facilities, and (2) whether the available activities are meeting residents' needs.
- Literature: Reviews were conducted on (1) quality of life for older people living in residential care, and on (2) arts participation by older people. Reviews aimed to establish if arts participation can be said to impact on recognised domains of quality of life for residents.

3.3 REVIEW OF HIQA REPORTS

3.3.1 Review

Since July 2009, HIQA has been inspecting residential centres and publishing reports based on records, observations and interviews. This inspection regime is relatively new and analysis is only beginning to emerge of the data being captured by reports. To provide some up to date context for this study, a random sample was reviewed of reports published by HIQA. The aim was to explore

- whether professional artists are working within residential care-settings, and
- whether the activities provided within residential care meet residents' needs.

A random sample of inspection reports published on the HIQA web site from the first 18 months of the new inspection regime were reviewed (that is, from July 2009 to December 2010). This involved ninety-five reports, relating to 60 facilities (34 private, 19 public and 7 voluntary), representing just under 10 per cent of Irish residential care facilities based on the then available figures (Department of Health and Children, 2008). Each report was searched for the words 'artist,' 'art' and 'arts.' Also noted were Inspectors' comments on the activities available to residents, whether recommendations were made for improvement, and whether there was evidence of subsequent improvement.

3.3.2 Review of HIQA Reports - Findings

The review suggested little input by artists (whether professional or otherwise) into life in care: this was identified in only two out of the sixty care-settings included in the review. Both were public facilities. Although references to 'arts and crafts' were common, they seem not to involve artists.

Recommendations for improvements to activities across all types of facilities were found to be typically made where Inspectors' observations or views of residents or relatives suggest lack of opportunities for activity. High levels of boredom, and

sometimes loneliness, are reported in some cases. In one case, Inspectors noted, for example, that ‘some residents sat for long periods of time with no stimulation’ (Public Facility). Another report quotes a resident seeking more interesting opportunities:

‘some [activities] are simple and not interesting; we need more things to do’ (Private Facility).

Sometimes recommendations for improvement were made where activities were not informed by resident choices, or because more dependent residents could not participate. For example, one report noted that no recreational activities were planned for a blind resident (Private Facility).

On the other hand, reports from some facilities indicated that residents enjoyed activities of their choice even in high dependency units.

Recommendations for improvements to activities were made for 35 of the facilities included in the review (or 58 per cent of the sample). In twelve facilities, subsequent reports indicate that issues raised had been fully or partially addressed – and this tended to be the case where a subsequent report was available within the cut-off period set for this review (end 2010).

A picture emerges of flux, with Managers sometimes acknowledging that they are engaged in a change of culture from a medical model of care to a person-centred model.

3.4 LITERATURE REVIEW

3.4.1 Literature - Quality of Life and Older People Living in Care-Settings

The term ‘quality of life’ came into popular usage from about the 1950s. Definitions are numerous as are methods of assessment, and the original focus on objective indicators (like material possessions) has been broadened to include subjective factors (like satisfaction with life) (Farquhar, 1995). Increased interest in measurement is reflected in initiatives such as the World Health Organization quality of life index (WHOQOL-100).

There has also been an increasing focus on quality of life of older people. In this context, Walker and Lowenstein (2009) conclude that this is a dynamic, multifaceted and complex concept, which must reflect interactions of objective, subjective, macro, micro, positive and negative influences. It tends to be considered ‘pragmatically as a series of ‘domains’ (Walker & Lowenstein, 2009: 63).

Studies based on interviews with residents of long-term care-settings from Ireland, the UK and the USA evince considerable consistency as to how the domains of quality of life are defined. These include resident-autonomy, relationships, individuality and activities (Kane *et al*, 2003, Age & Opportunity, 2003, Tester *et al*, 2004, Murphy *et al*, 2006, Cooney, Murphy and O’Shea, 2009).

Two large-scale studies - one from Ireland (Cooney, Murphy and O’Shea, 2009) and one from the UK (Tester *et al*, 2004) articulate the concept in terms of four similar domains. In the Irish study, 101 residents of 12 facilities were interviewed. The UK

study involved guided conversations with 52 residents of seven Scottish facilities, observation and focus groups. The four domains identified in both studies are:

- I. Ethos of Care/ Care Environment: This includes routines, as well as choice and control over decisions like time of waking and sleeping. For some residents, routines dominated, and they felt just one of a number (Cooney, Murphy and O'Shea, 2009).
- II. Sense of Self and Identity: This includes maintaining a sense of self through personal appearance and possessions, spirituality and personal space. Acknowledging skills and contributions enhances self-esteem (Cooney, Murphy and O'Shea, 2009). Sense of self is influenced by meanings made of one's own and others' frailties, and finding ways of asserting oneself could/ compensate for frailty (Tester *et al*, 2004).
- III. Connectedness and Social Relationships: Relationships mattered with other residents, with families and communities and with staff. Relationships were facilitated by getting people with similar interests together (Cooney, Murphy and O'Shea, 2009).
- IV. Activities: Activities facilitated relationships and helped to confer a sense of achievement and maintain a sense of self (Tester *et al*, 2004). Some activities are more valued than others, characterised as 'meaningful.' Key to this is integration into everyday life, comprehending individual interests in small groups (Cooney, Murphy and O'Shea, 2009).

Domains overlap: having some control over activities of daily living and being able to make choices helps maintain a sense of self (Tester *et al*, 2004).

Communication was a cross-cutting theme, essential to forming and maintaining relationships, to maintaining sense of self, participating in activities, and making meaning of experience. Non-verbal, emotional expression was considered valuable along with verbal-expression (Tester *et al*, 2004).

These four domains are used to in this study to provide a framework against which the literature on arts participation and the results of the empirical research will be considered. Other studies will be referenced to illuminate particular points, but the four domains outlined in Cooney, Murphy & O'Shea, 2009 and Tester *et al*, 2004 will be used to structure the analysis. This approach is taken because these studies are both relatively large in scale, identify a common approach to quality of life of older people in care-settings, and are broadly-speaking consistent a range of studies from different countries.

3.4.2 Literature - Impact of Arts Participation in Older Age

Many benefits of arts participation have been identified (Matarasso, 1997), but as a research area, that of health and quality of life impacts of arts participation is considered underdeveloped, with those studies that exist having limitations (Galloway *et al*, 2005). A particular limitation is acknowledged about studies carried out in care-settings because of their scale and of the lack of randomised controls.

Creativity has been characterised as a key factor in adaptation to ageing (Smith & Andersson, 1989). Maintaining or widening activity levels was found to lessen some of the negatives associated with ageing like functional decline (Silverstein & Parker, 2002).

Cohen *et al* (2006), authors of a large randomised controlled study on the benefits of arts participation in older age, theorise that health and quality of life benefits result from providing meaningful social engagement (shown to increase quality and length of life, Glass *et al*, 1999) and conferring a sense of 'control,' meaning of self-efficacy and competence, which has a positive affect on health and wellbeing, something *heightened* in older age particularly for people living in care (Rodin, 1989).

This review included studies of arts participation by older people living in the community and those living in care-settings, concentrating on psychological and social benefits. Studies were reviewed to see if participation impacted on the four quality of life domains for residents of care-settings (identified by Cooney, Murphy & O'Shea, 2009 and Tester *et al*, 2004 and listed above):

- I. Ethos of Care/ Care Environment -The literature review does not evidence a strong impact on this quality of life domain. However, it is also true that this domain was defined in a particular way by Cooney, Murphy & O'Shea, 2009 and Tester *et al*, 2004 as organisational approaches and exercise of choice in daily routines. In that relatively narrow sense, it was not a particular focus of any of the studies reviewed, many of which were not studies within care centres. Improvements in communication reported between residents and staff resulting from arts-programmes (Basting, 2006, Roush *et al*, 2011) may, however, contribute to an improved social environment.
- II. Sense of Self and Identity - Increased feelings of self-esteem, more optimism or morale and enjoyment of life are typically reported from the arts-participation literature (Cohen *et al*, 2006, Greaves & Farbus, 2006, Hayes & Minichiello, 2005). Participation was associated with increased self-efficacy, conferring a sense of independence (Hayes & Minichiello, 2005), or a willingness to engage more in life (Greaves & Farbus, 2006, Wikstrom, 2004, Cohen *et al*, 2006).

Participation provided opportunities for engagement in life at a deep level, involving 'transformational' changes for some participants like increased sense of meaning in life (Greaves & Farbus, 2006). In one study this was associated with giving a sense of timelessness and space-lessness (Wikstrom, 2004).

Increased self-esteem applies also to people with dementia (Kinney & Rentz, 2005, Basting, 2006). Basting (2006) instances how engaging in different art-forms leads to the production of works in which residents and the community take pride, and how arts participation enables people with dementia to give meaning to experience and feelings.

- III. Connectedness and Social Relationships - Studies consistently confirm that participating in arts programmes leads to less loneliness, and to building social networks and relationships. This was found in large-scale studies

carried out in the community (Silverstein & Parker, 2002, Cohen *et al* 2006, Wikstrom, 2004, Greaves and Farbus, 2006), and in smaller-scale studies in care (Basting, 2006) or sheltered-housing (Wikstrom, 2002).

While it may seem obvious that participatory arts are sociable, *of themselves* the arts were found to promote more socialization (Wikstrom, 2002), and were associated with increased *quality* of social interactions (Greaves & Farbus, 2006). Improved communication was emphasized, particularly in studies relating to care-homes, where participation facilitated non-verbal communication often in a non-rational, emotional way important for people with dementia (Bastings, 2006). Participation also facilitated connection between residents, between residents and family, and between residents and caregivers (Basting, 2006, Roush *et al*, 2011).

- IV. Activities - In the quality of life literature, not all 'activity' was perceived as valuable, and only activity considered 'meaningful' improves quality of life in care (Cooney, Murphy and O'Shea, 2009, Tester *et al*, 2004). The benefits reported in the studies on arts-participation suggest that participation was valued, with increased morale (Cohen *et al*, 2006) and greater enjoyment of life reported (Greaves & Farbus, 2006). As discussed, participation was also found to enhance sense of self and relationships. Thus the literature suggests that arts participation can provide 'meaningful activity.'

The literature evinces outcomes from arts programmes that can improve quality of life of older residents of long-term care settings across three of the quality of life domains identified by Cooney, Murphy and O'Shea (2009) and Tester *et al* (2004). Little impact from the smaller scale studies on arts participation within care-settings was evidenced, however, relative to the first domain, 'ethos of care or care environment,' which is defined in the two quality of life studies in a relatively narrow sense (related to routines and organisational approaches).

3.5 QUALITATIVE RESEARCH

3.5.1. Participants

A purposeful sampling strategy was employed to identify Irish care-homes where professional artists facilitate programmes. Managers and artists within a number of facilities were invited to participate, and information was made available. Three public facilities agreed to participate. Managers were asked to identify residents who regularly participated in arts programmes and who met certain criteria intended to exclude residents who, for physical or psychological reasons, would not be able to communicate sufficiently. From within that group residents self-selected.

In-keeping with a research tradition in quality of life studies that privileges the perspective of older people (Bond & Corner, 2004), one-to-one qualitative interviews were conducted with residents. Interviews with artists and staff were undertaken to augment the resident interviews. Interviews occurred between April and June 2011. A semi-structured format was used flexibly to allow for a conversational style, and to facilitate adaptation so as not to exhaust frail residents.

It is acknowledged that the sample size was too small to be representative of the population living in care-settings, but the purpose of the study was to explore the experience of participating in visual arts programmes and to make a contribution to theorising its contribution to quality of life. The study was done from a social perspective, not a medical one, and no attempt was made to assess health status of residents, although it was obvious that all were significantly affected by disability and/or frailty. Resident interviews lasted between 15 and 40 minutes.

Interviews involved eight residents from three facilities, three staff, and three artists. Residents interviewed included five women and three men, aged from their 60s to their 90s. The length of time they had lived in care varied from about six months to over ten years. They participated in long-standing visual arts programmes for one half-day per week. Only one had painted prior to contact with the care home. The routine and physical environments of the homes meant that most could only paint once per week during the workshop, although one had erected an easel in the ward/bedroom that she shares with others, and painted there beside her bed at different times of the day.

The staff interviewed were a Manager, an Activities Co-ordinator and an Activities Care Assistant. Three professional Artists working on a freelance basis in the care homes were also interviewed.

Informed consent was obtained prior to interviews and consent forms were signed. As the resident sample is defined as a vulnerable group (Polit & Beck, 2004, cited in Murphy *et al*, 2006), residents were assured in the information pack, and just prior to the interviews, that they might withdraw at any time. Ethical clearance was obtained prior to data collection from the appropriate Ethical Committee.

3.5.2. Data Analysis

Interviews were recorded with permission, transcribed verbatim and participants' perspectives reported as accurately as possible. Pseudonyms were used.

The analysis of the data followed the steps outlined by Braun and Clarke (2006). Following transcription, interesting features were systematically coded and the data was collated. Different codes were sorted into potential themes and all the relevant coded data extracts were collated. Further analysis resulted in the identification of four interlinked themes. Themes established from the interviews with residents were confirmed by analysis of interviews with staff and artists.

Although the literature review informed development of interview schedules, coding did not attempt to fit within the identified quality of life domains in order to allow for an open-ended analysis across the entire dataset. In this sense the approach was data-driven and inductive (Braun & Clarke, 2006).

3.6 FINDINGS

3.6.1 – Interviews with Residents

The findings suggest that participation in visual-arts programmes result in outcomes in four areas that can be characterised as enjoyment and engagement, self-efficacy,

self-expression, and enhanced relationships. These interlinked themes illuminate the nature of the impact of arts participation from the perspective of residents and of how participating enhances residents' quality of life across the domains identified in the quality of life literature discussed earlier, particularly that of sense of self and self-identity. The four domains identified by Cooney, Murphy & O'Shea (2009) and Tester *et al* (2004) are again used as a framework in which to present the findings:

I. Ethos of Care/Care Environment

This domain is characterised by Cooney, Murphy & O'Shea and by Tester *et al* to mean organisational approaches, including choices about routines. For most of the residents interviewed, they participated in an arts-workshop for one half-day per week and had no ability to paint outside the scheduled workshop. The potential impact on this domain, as so defined, is therefore limited.

However, this study's findings suggest some impact on ethos of care/care environment. This can be seen in how residents described time passing quickly when engaged in art-making, and, in particular, in how one resident, who has installed an easel in her ward paints when she chooses (within reason). She reported how this transforms her ability to take control of the experience of long-days and of what she perceives as uninteresting activity choices. For this resident as well as conferring a sense of self-efficacy, it represented a means of asserting a level of autonomy:

'I want to do something else besides sitting here all day doing nothing. Only bingo. Sure I don't want that. Bingo. BINGO. Stand there looking at the walls.. .that's no good to me..... Thank God I've art to go to...'
Joan

Thus, access to opportunities to participate in the arts outside of the weekly two-hour workshop improved this resident's experience of the ethos of care/care environment.

II. Sense of self and identity

The participants derived enjoyment and were engaged in art-making, they developed a sense of self-efficacy and they found a means of self-expression. Thus their 'sense of self and identity' was enhanced, and the study illustrates a number of ways in which arts participation achieved this.

Enjoyment and Engagement: Residents looked forward to workshops, gained satisfaction and felt that they would miss them if they weren't available. High levels of enjoyment and engagement, of being absorbed, of time passing quickly were reported along with the sense that the activity was interesting and valuable:

'You get interested in what you're doing ..caught up and it's good like that...'

James

'You're happy doing it.... You could spend a full day.'

Patrick

Self-efficacy: Participating was associated with a sense of pride and achievement, with engaging in a process that was challenging, that facilitated making choices and taking control of time, and thus helped participants to maintain/develop self-efficacy. Residents described making choices about artworks already completed and discussed works that they were planning:

*'I'm not dependant on any other body.....
.... it'll come to me in a flash.'*

Patrick

'I done it out of my own head'

Molly

Persevering, learning, overcoming difficulties and challenges evidenced a process that motivated and gave a sense of purpose, but that at times could also be frustrating:

*'It can be disastrous or it can be successful.....
I might be mad at myself.....because
I could have done it better.'*

Patrick

Participation was sometimes understood as possible when other things were not. For some, painting represented a valued skill acquired despite serious disability. People who had learned to paint with their left hands following strokes that disabled their right sides were surprised that they had done so and were engaged in an ongoing process that challenged them:

'I never dreamt that I'd be able to paint with my left hand. if I could sew or knit... I can't do it at the moment. .. you have to persevere.. you have to persevere and get into it...'

Joan

'I'd try anything.'

Daniel

Self-expression: Participants also described a process of self-expression, often based on experiences or loved objects. Several talked about memories or things that they love as the source of their paintings. Others chose to paint from pictures rather than memory, but expressed a high level of engagement with the process involved:

[Talking about a painting] 'And we didn't forget the poor old donkey.... We had them when I was a lad.... They were light. They could walk on soft bog.'

James

[Talking about a painting] '[That's] the view from the home place – mountains and the gap.'

Daniel

'The paints now... that's the thing... to get my right mixture... .. just to see the, what do you call it.. the style.. the mixtures... beautiful.. yeah.. the colours...'

Joan

All participants talked about loving participating, but few could articulate why they did so. One man, who could, described an engagement that involved self-expression and self-realization, making sense of the world, and transformation:

'Well it does me good to think of something like that and paint it and see it before me eyes there..... Because I like to put it on paper, but in a nice way.'

'The kick I get out of it; you're transforming something from your brain onto paper. Do you know?'

'You're telling the world what it should be like.'

Patrick

One woman couldn't articulate it, but with a gesture seemed to indicate that it reached her at a deep level:

'I don't know what it isit's just something from here [pointing to her chest]...that's just... I don't know what effect it has on me..... Yea I love it .. absolutely.. I do.'

Phyllis

III. Connectedness and Relationships:

Participating led to particularly warm relationships with artists and to some extent with other residents and staff. The relationships with artists were those most emphasised by residents:

'I'll always be waiting on him. And we do have a good shake hands.'

Patrick

' [Artist's] so kind to anyone.. you know .. She makes it....she has a nice way about her'

Phyllis

Some participants described getting to know other residents at workshops or staff taking an interest in the work and engaging more with them. However, these relationships were not as stressed by residents as they were by the staff and artists (see below). One resident explained that the room where workshops took place, which was narrow and fitted only two wheelchairs at a time, limited interaction. Another described a serious approach to the work that didn't result in chatting.

IV. Activities:

Arts-participation clearly provides 'activities.' Importantly, it does so in a way that residents perceive as interesting and valuable, involving high levels of engagement, and leading to a greater sense of self and of identity. Participation was also understood in a context where boredom could be the alternative, and where it, by contrast, offered the chance to do something purposeful:

'You've done something. You prove something. You realise something. And.... at least you succeeded in doing something. You didn't waste time.'

Patrick

Thus, it can be said to constitute 'meaningful' activity, which is how activities must be experienced if they are to enhance quality of life (Cooney, Murphy and O'Shea, 2009, Tester *et al*, 2004).

3.6.2 Interviews with Staff and Artists

Interviews with staff and artists about their perceptions of the impact of participation on residents confirmed the importance of the themes identified from resident interviews: enjoyment and engagement, self-efficacy, self-expression and enhanced relationships, with 'self-expression' being the area most stressed. Interviews also explored the approach taken by the artists to facilitation.

3.6.2.1 Perceived Impact on Residents

Staff and artists talked about residents looking forward to workshops and about witnessing pride in creating and exhibiting. One artist articulated how participation added a dimension to their perception of themselves:

'They are not just a person, they are an artist now and they're painting and... exhibiting.'

Artist 1

The area of 'self-expression' was that most emphasised. Many examples were given of art being an outlet, especially for those unable to communicate verbally:

'I would say its primary purpose.. is a vehicle for expression.....if you have some outlet for your frustrations... it will always automatically improve your quality of life... ..it will take you to a more serene place.'

Manager

'... it gives them a chance to express themselves. If they are in bad humour or good humour... that will come out when they are painting.'

Activities Care Assistant

'for somebody whose world is closing down, it's a window opening up.'

Artist 1

Artists pointed to enhanced relationships and instanced residents being encouraged and supported by other residents, and how the art works provide an opportunity for staff to engage with residents in a way that didn't happen during the everyday routine. Artists and staff referred to how this could lead to a different appreciation of the residents on the part of staff:

'[staff] fall into that pattern of 'that's such and such, he's very nice but he can't do anything'. Then.... he actually can do something, something that the staff wouldn't be able to do.'

Artist 2

'... there was an exhibition and it was only then that I really sat up and took notice and people that I never even thought would be capable of producing anything...their individual styles and all that kind of thing, really impressed me.'

Manager

3.6.2.2 Approach to Facilitation

The artists, and to an extent, the staff, described an approach to the facilitation that can be described as 'participant-led' or 'person-centred,' in which getting to know the residents and their interests was the starting point. The approach can also be characterised as open-ended, with an emphasis on quality and equality. For example, artists talked about engaging in the process in an open-ended way that challenges and involves a journey for artist and participant alike. One talked about the process involving the 'potential for something else to happen.' He said:

'...you get that buzz and then the [residents] are getting a buzz off your buzz, and it's all kind of exciting...I am genuinely interested in the work...that honesty is always interesting.'

Artist 2

Artists talked about ensuring a quality experience for residents, treating them as artists and expressing this in the use of good materials – the same materials they use for their own work. This was understood as ensuring that:

'participants ..understand that they are being taken seriously'

Artist 3

All artists were used to working with residents' high levels of disability and to adapting materials and processes. For example, one artist had previously found a way

of working with a resident who had lost most of his fingers. Yet they did not focus on the issue of disability *per se*:

'...it involves the whole person no matter how able or disabled they are and.....allows them to express themselves...'

Artist 1

'I'm kind of blind to it [disability], you know, it just isn't an issue.'

Artist 2

4. DISCUSSION

4.1 QUALITY OF LIFE

As outlined above, the findings confirm that participating in arts programmes improved the quality of life of the residents concerned under the domains identified in the quality of life literature, particularly the domains of sense of self and identity, relationships and meaningful activity. Findings open out how arts participation enhances the domain of sense of self and identity through facilitating enjoyment and engagement, and building/maintaining self-efficacy and self-esteem. The domain of ethos of care/care environment was impacted on for a resident who was able to paint outside of the weekly workshop on whom it conferred a means of taking control of time and of boring routines, and points to how this quality of life domain are enhanced when more open-ended opportunities to participate are facilitated.

In a study previously cited, residents identified lack of stimulation and lack of respect by staff and consequent loss of dignity and independence as the most difficult thing about life in care (Timonen & Dwyer, 2009). Approaches to public health now posit a connection between dignity creating and sustaining health and wellbeing (Mann, 1998; Jacobson, 2012). This study's findings suggest a number of ways in which arts participation enhances the dignity and independence of residents. These include facilitating non-verbal communication and meaning-making, developing a sense of control and resilience, partially transforming the meaning made of disability, and resulting in a physical object that can reinforce a sense of identity:

Non-verbal communication and making-meaning:

Quality of life studies reference how communication enables several domains of resident quality of life, including maintaining a sense of self and facilitating meaning-making (Tester *et al*, 2004). Findings of this study show arts participation facilitating non-verbal self-expression and making-meaning – encapsulated in one resident's statement:

'You're telling the world what it should be like' (Patrick).

This also testifies to the ability of the arts to offer opportunities for deep levels of engagement and not just for 'distraction' or occupying time. It facilitates engagement

with objects or experiences (like childhood landscapes) that are loved and valued. As such it enables reinterpretation of experiences. And reinterpretation of experiences helps residents to continue to live meaningful and coherent lives (Cooney, 2011: 8).

'Control' and Resilience:

Findings show how arts participation motivates and engages residents, including highly disabled residents, about past and future projects, and involves high levels of challenge and learning. It facilitates making decisions, and exercising 'control,' something that has been shown to be particularly important for both health and wellbeing of older people living in care (Rodin, 1989). Faced with disabilities, it also demonstrates how creativity both expresses and strengthens resilience.

That residents, including highly physically dependent people, enjoy this level of challenge is of itself a challenge to the dominant ideology of care-homes, characterised as 'care and attention' (Townsend, 1981:20) and as 'tending to engender helplessness' (Murphy, 2007: 478).

This building of self-efficacy and self-esteem are especially valuable outcomes for people dealing with multiple disabilities and the change and loss associated with moving to long-term care.

Transforming Disability/Frailty:

The literature on quality of life suggests that health status and dependency level is one of the mediating factors that may affect quality of life domains in any individual case (Cooney, Murphy and O'Shea, 2009), and that the domain of 'sense of self' was affected by meanings residents and others make of their disabilities and frailties, with finding ways of asserting oneself a means to counter or compensate (Tester *et al*, 2004).

Three interviewees had learned to paint with their left hands following strokes that paralysed their right sides. In each case they had not painted before living in the care setting, and they persevered to acquire the new skill when other activities were no longer possible. In this way, they partially transcend their disability and the meaning they made of it, as it no longer precludes them doing everything they value.

Manifestation and Transformation:

Participation facilitates engagement with memories and objects that are loved and valued, and it does so in a way that does not simply situate participants in the past. Instead it transforms that experience into an object that exists in the present. As one of the staff interviewed described it:

'you have an end product...a tangible element for your feelings'

Manager

Having a physical product provides a tangible outcome to self-expression or aesthetic engagement, to overcoming challenges, or to reinterpretation of memories or experiences. These are manifest in an object to which other people can react, further potentially reinforcing a sense of identity and self-esteem.

It is also produced as part of a creative process, involving objectivity and planning and engagement with future projects. These aspects might be termed ‘transformative’ aspects of participation. (*‘...you’re transforming something from your brain to the paper,’* as one resident (Patrick) put it).

5. CONCLUSIONS AND RECOMMENDATIONS

Residents participating in ongoing visual arts programmes experience as a result high levels of enjoyment and engagement, maintain/develop self-efficacy and self-expression as well as relationships that they value highly, especially with artists. Characteristics of visual-arts participation (including providing opportunities for exercise of decision-making, planning and challenge, facilitating non-verbal expression and making-meaning) make it particularly appropriate for residents within long-term care.

What the study draws out in particular are the ways in which participating in visual arts workshops can enhance the domains of quality of life as understood in quality of life literature on older people living in long-term care. The study’s findings are striking in how the learning and challenge involved enhances the lives of residents who are otherwise highly dependent, something that itself challenges the passivity engendered within existing models of long-term care.

Yet the study’s review of inspection reports from the first 18 months of the new inspection regime established by HIQA suggest that there are relatively very few instances of involvement by professional artists within long-term care in Ireland. That review also found reports of boredom and loneliness on the part of residents, but pointed to the situation frequently improving following HIQA recommendations.

The approach taken by the professional artists interviewed is characterised as person-centred and as maximising the capabilities of residents, even highly disabled residents.

The study points to the need for overarching Government policy to give more direction on quality of life in long-term care and the implementation plan for the National Positive Ageing Strategy should do this. Consultation with residents should be the starting point for development of policy and practice to ensure that it is informed by their preferences.

In relation to regulatory approaches, it is considered consistent with HIQA’s approach to person-centred care, that a definition of resident quality of life be included in the HIQA Standards and that the role of activities (and within that, arts participation) in enhancing quality of life be made more explicit.

The recommendation of the Arts Council Health Strategy (2010) should be implemented to develop a partnership with the Health Service Executive to build a strategic framework for arts practice in residential care, and to give support to existing arts-in-care programmes.

Development of training using existing experience of practitioners, is also recommended for artists and for care staff (activities coordinators, nurses and other

care-workers). For the latter group, the aim would be to develop an appreciation of how activities promote quality of life, including awareness of the particular contribution of the arts

An investment in quality arts participation for residents of care-homes would be one way to promote dignity for the last chapter of life, the one that should make sense of what has gone before.

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Ann Leahy worked for many years at a senior level at Age & Opportunity, Ireland's national organisation promoting greater participation by older people in society. Ann has fulfilled various roles within Age & Opportunity, including Assistant CEO with responsibility for the organisation's arts work. She contributed to the development of a range of the organisation's programmes, including the Bealtaine festival, celebrating creativity as we age, and Creative Exchanges, a course in creativity for staff of care centres for older people.

She now works as a researcher on social policy. She was the lead author of a study into the impact of the financial crisis over the past five years on five European countries (Greece, Ireland, Italy, Portugal and Spain) published by Caritas Europa in February 2013. She is undertaking a second study in the same series.

She has received a Hume Scholarship from National University of Ireland, Maynooth, where she is a PhD candidate in sociology (from January 2014).

She writes poetry and amongst the awards received is a Patrick Kavanagh award for her first collection.

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