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| Institution: Ulster University | | |
| Unit of Assessment: Allied Health Professions, Dentistry, Nursing and Pharmacy (3) | | |
| Title of case study: ICS-7 Changing policy, culture and understanding in dementia care | | |
| Period when the underpinning research was undertaken: 2004 - 2020 | | |
| Details of staff conducting the underpinning research from the submitting unit: | | |
| Name(s): | Role(s) (e.g. job title): | Period(s) employed by submitting HEI: |
| Assumpta Ryan | Professor of Ageing and Health | 1992 - present |
| Hugh McKenna | Professor of Nursing | 1988 - present |
| Claire McCauley | Lecturer in Health Sciences | 2015 - present |
| Debbie Goode | Lecturer in Nursing | 2001 - present |
| Kevin Moore | Lecturer in Nursing | 2001 - present |
| Marie O'Neill | Lecturer in Nursing | 2003 - present |
| Sarah Penney | Lecturer in Nursing | 2014 - present |
| Period when the claimed impact occurred: 1 August 2013 - 31 December 2020 | | |
| Is this case study continued from a case study submitted in 2014? N | | |
| <p>1. Summary of the impact</p> <p>It is estimated that one in three people born in the UK will develop dementia. Research from Ulster University has directly changed policy and practice in dementia care, and raised public understanding of dementia, across Northern Ireland (NI).</p> <p>I1: Change to adult safeguarding policy: Ulster research has influenced the Department of Health's (a) reform of adult care and support, (b) policy development in adult safeguarding, and (c) health and social care digital transformation programme.</p> <p>I2: Change to care home culture: Our research has also resulted in significant improvements in care home culture across the region through the delivery of Ulster's My Home Life Leadership Support and Quality Improvement Programme.</p> <p>I3 Change to public understanding of dementia: Incorporating our research into a play ('The Songbirds') has led to increased public understanding of dementia across NI (in over 2000 audience members).</p> | | |
| <p>2. Underpinning research</p> <p>There are 885,000 people living with dementia in the UK, 22,000 of whom live in NI. Dementia is characterised by a deterioration in memory, thinking, behaviour and the ability to perform everyday activities. It is the leading cause of disability and dependency and can be extremely challenging and distressing for family carers. For over 15 years, Professor Ryan and colleagues at Ulster have investigated ways to better support people living with dementia by translating their research into impact on policy, culture and understanding. This has been underpinned by two interconnected research programmes focusing on: 1) the experiences of people living with dementia and their carers before, during and after the move to a care home (R1, R2, R3, R4); and 2) the impact of technology in supporting home-based reminiscence using an iPad app to store photographs, music and film which can be easily retrieved to prompt conversations about past experiences between people living with dementia and their carers (R5, R6). Our underpinning research has been supported and developed by funding to Ulster totalling GBP2,639,168 from a range of sources (including the care home sector), examples of which are highlighted in Section 3.</p> <p>Approximately 70% of care homes residents have dementia or severe memory problems and these individuals are some of the frailest and most vulnerable members of society. We used mixed methods and qualitative approaches in a range of studies to explore the impact of the move to a care home and ways of improving quality of life for residents, relatives and staff (R1,</p> | | |

R2, R3, R4). Our findings highlighted the impact of the move on older people “*I am so lost here*” and the key role of health and social care staff in supporting people living with dementia during this difficult transition (**R1**). Having a “*sense of familiarity*” with the nursing home history, staff, residents and local community was a key factor influencing a more positive transition in rural areas (**R2**). Shared decision-making was central to developing and maintaining positive relationships (**R1, R2, R3**) as residents frequently referred to being “*at the mercy*” of others who made decision about their care. The significance of “*the little things*” (e.g., food preferences, accommodating former routines) and the creation of a homely environment were found to be underrated in care homes (**R3**). A recurrent finding in our research was that although care home staff played a pivotal role in maximising quality of life for residents, they had limited access to leadership support and quality improvement initiatives (**R3, R4**)

Our research (**R5, R6**) also investigated how technology could be used to support people living with dementia to live more independently in their own homes. Our quasi-experimental study on the impact of home-based reminiscence, facilitated through an iPad app (Inspired) on people living with dementia (n=30) and their carers (n=30), showed that people living with dementia used the app independently and more frequently than their carers. We found statistically significant increases in mutuality, quality of caregiving relationship and emotional well-being ($P<.001$ for all 3) from baseline to endpoint for people living with dementia (**R5**). Participants perceived the intervention as a positive experience which focused on gains rather than losses in the context of memory retention and learning new skills and which helped them realise that “*There’s still so much inside*” (**R6**).

3. References to the research

The following outputs have been blind peer reviewed by internationally-based editorial boards.

R1 O'Neill, M., Ryan, A., Tracey, A., & Laird, L. (2020). ‘Waiting and Wanting’: Older peoples’ initial experiences of adapting to life in a care home: A grounded theory study. *Ageing and Society*, 1-25. doi:10.1017/S0144686X20000872.

R2 Ryan, A & McKenna, H. (2013) Familiarity as a key factor influencing rural family carers’ experience of the nursing home placement of an older relative: a qualitative study. *BMC Health Services Research*, 13:252. DOI: 10.1186/1472-6963-13-252

R3 Ryan A & McKenna H (2015) “It’s the little things that count”. Families’ experience of roles, relationships and quality of care in nursing homes. *International Journal of Older People Nursing*, 10, 38-47. DOI: 1111/opn.12052.

R4 Penney S. & Ryan A (2018) The effect of a leadership support programme on care home managers. *Nursing Older People*. 30 (1), 35-40. DOI: 10.7748/nop. 2018.e979.

R5 Laird E, Ryan A, McCauley C, Bond R, Mulvenna M, Curran K, Bunting B, Ferry F, Gibson A. (2018) Using mobile technology to provide personalised reminiscence for people living with dementia and their carers: An appraisal of outcomes from a quasi-experimental study. *JMIR Mental Health*. 5(3): e57. DOI: 10.2196/mental.9684

R6 Ryan A, McCauley C, Laird E, Gibson A, Mulvenna M, Bond R, Bunting B, Ferry F, Curran K. (2018) “There is still so much inside”: The impact of personalised reminiscence, facilitated by a tablet device, on people living with dementia and their family carers. *Dementia: The International Journal of Social Research and Practice*. Published online September 7, 2018. DOI: 10.1177/1471301218795242

Grants

G1: Ryan A (PI) & Taggart L. Health & Social Care Research and Development Division of the Public Health Agency. *Improving quality of life in nursing and residential homes by implementing an evidence-based programme of best practice and person-centred care*. 01/06/14 - 31/12/18, GBP96,870.

Impact case study (REF3)

G2: Ryan A (PI) & Moore KD. *The advancement of knowledge and evidence-informed practice in Irish nursing homes*. 01/05/14 - 30/04/19, GBP36,803.

G3: Clelland I (PI) Ryan A, McIlpatrick S, McCance T, Moore G, McChesney, I, Nicholl P, Zhang, S, Nugent C, Wallace J & McClean S. *Connected Health Living Lab*. Department of the Economy-HERC Funding. 20/03/18 - 30/09/18, GBP184,266.

G4: Ryan A (PI), Mulvenna M, Laird E, Bond R, Ferry F, Bunting B, Curran K, *A feasibility study of facilitated reminiscence for people with dementia*. Health & Social Care R&D Division of the Public Health Agency and Atlantic Philanthropies 01/09/15 - 30/04/19, GBP320,364.

G5: Martin S (PI) & Ryan A *Technology enriched supported housing-a study into the lived experience of older people with dementia and their carers*. Health & Social Care R&D Division of the Public Health Agency and Atlantic Philanthropies. 13/01/15 - 31/10/19, GBP385,490.

4. Details of the impact

The impact of our research (**R1, R2, R3, R4**) on care home culture as described in this case study refers to the impact of Ulster University's My Home Life (MHL) Leadership Support and Quality Improvement Programme (hereafter referred to as the MHL programme). This 10-month programme commenced in 2013 and continues to be used as a conduit for changing care home culture through the translation of our research into practice.

In planning our impact strategy, Ulster University was one of the original partners in My Home Life, an international initiative and registered charity (No. 1187498) which promotes quality of life and delivers positive change in care homes. Each partner organisation works independently, and research findings and resources are shared with the care home sector and with other partners and stakeholders through the MHL website.

I1: Impact on policy

In 2018, the Permanent Secretary, DOH (NI) referenced our research when he outlined measures to address "*unacceptable failings*" in safeguarding and restore public confidence in care homes by supporting the "*implementation of initiatives aimed at improving the quality of life for people living in care homes such as the My Home Life initiative*" (**C1**). The significance of our policy impact is further evidenced by extra funding from DOH (NI) in 2020, to support care homes to participate in the MHL programme during the COVID-19 pandemic and to appoint a Project Manager to engage with 100 new care homes as part of the regional implementation of the MHL programme across NI (**C1**).

The reach and significance of our research impact (**R1, R2, R3**) is evidenced by buy-in from the care home sector and partnership funding from its umbrella organisation Independent Health and Care Providers. This resulted in an increase in the uptake of the MHL programme from 15 managers in 2013 to 67 managers in 2020 from a diverse range of care homes (urban, rural, residential, nursing), representing approximately 1 in 7 care homes in NI (**C1**). The MHL programme was cited as an example of best practice in the Report of the Expert Advisory Panel on Adult Care and Support (DOH NI, 2017) and was recommended as a catalyst for remedial change in adult safeguarding in the report of the Independent Review Team commissioned by the DOH (NI) to investigate care home abuse and neglect in the region. "*The HSCTs should explore ... how change programmes demonstrate approaches to care and support which reflect human rights ... and projects such as My Home Life at the University of Ulster would enhance this work*" (**C2**). Our research (**R1, R2, R3**) has directly influenced DOH (NI)'s Reform of Adult Care and Support policy resulting in a request from DOH (NI) to submit a funding bid (GBP2.6m) for the regional implementation of Ulster's MHL programme across all 484 care homes in Northern Ireland (**C2**). In 2017, our research on the concept of a nursing home as 'home' received extensive media coverage and was commended by the Irish Minister for Health and raised during parliamentary questions leading to an increased focus on the need to create a more 'homely environment' in care homes (**C3**). Since 2013, the MHL programme (**R4**) has received unwavering support from AgeNI who provided partnership funding for our programme and whose CEO described it as making "*a positive impact on the quality of care experienced by residents in care homes*" (**C4**). The impact of our research (**R2, R3, R4**) has also been

recognised by the Chair of Northern Ireland Regulation and Quality Improvement Authority (RQIA) who described the MHL programme as “a great fit with RQIA’s aspirations for excellence in the care of older people” (C4) and by Care Home Advice and Support (a voluntary organisation in NI) who stated, “We want the DOH to use these findings to make the necessary improvements” (C2).

I2: Impact on culture in dementia care

Results of questionnaires completed by participating managers since 2013 showed a significant positive change in 89% of the responses measuring the impact of the MHL programme on care home residents, relatives and staff (C5). Significantly, there were marked improvements in the quality of interaction between staff and relatives (54% of respondents agreed), quality of management and leadership (51%) and satisfaction with practice (49%) in care homes caring for 2,268 residents (C1, C5). One participating manager commented: “I’ve been a care home manager for 20 years and this has been the most rewarding programme for me as a manager. I would do it all over again!” (C4). Another commented “I think the My Home Life programme should be the standard. I think all managers should take the opportunity to do it. In fact, I think it should be part of the process of becoming a registered manager” (C6). Others spoke of how the MHL programme led them to change the focus of their work to more meaningful engagement, positive risk-taking and a recognition of the importance of relationships with older people and their families. “It was... the best training I ever had for managing, leading and working in a care home, it was about relationships, and rights of older people, it was not just about health but about quality of lives, importance of family relationships and leading the team using these approaches has improved the staff and more importantly the care and support offered to older people” (C2).

The reach and significance of the impact of our research on culture is evidenced by the introduction of a range of research-based quality improvement initiatives (R1, R2, R3) across the 67 care homes which implemented the MHL programme between 2013 and 2020 (C7). These include the development of new pre-admission assessment protocols, the production of a short film on the transition to life in a care home, a new approach (‘This is Me Now’) to maintaining the dignity and identity of residents with advanced dementia, and the introduction of a ‘Decision Tree’ to facilitate the involvement of care home residents and relatives in decisions about life in their care home (C7). Based on Ulster’s research, participating managers worked with residents and their families to co-create an information booklet on the transition to life in a care home which reached approximately 17,000 individuals and organisations in the wider care home sector across Northern Ireland and provided much needed guidance as part of the implementation of the Northern Ireland Dementia Strategy (C7). In 2017 Sarah Penney (MHL Project Manager) was awarded the RCN Nurse of the Year, Learning in Practice award for the impact of the MHL programme on care home culture (C7).

I3: Impact on understanding of dementia

Our reminiscence research provided significant evidence to the NHS of the viability of mobile device apps for people living with dementia, in terms of uptake and sustained engagement (R5, R6). This led to additional funding to develop the InspireD reminiscence app which is now freely available on the Apple App and Google Play stores and in the HSC Apps4Dementia library, soft launch December 2020 (C8). One person living with dementia said of the app, “It helped me find myself again, so it did” (R6). The HSC Innovation & Digital Eco-system Lead highlighted the reach and significance of our work, and stated that the benefits described in Ulster’s research “convinced us that the app should be widely deployed across Northern Ireland and beyond” as part of a wider digital transformation programme in health and social care, which is being led by Digital Health & Care NI with the support of the DOH (NI) (C8).

Recognising the power of the arts to reflect the experiences of people living with dementia, we collaborated with a local theatre company to create a play ‘The Songbirds’ and share the findings of our reminiscence research (R5, R6). Between 2019 and 2020, the play reached an audience of approximately 2,000 people in theatres and other venues across the island of Ireland (C9). A questionnaire administered before and after the play showed a significant

improvement in public understanding of dementia across 100% of the evaluation statements. Before seeing the play, 76% of audience members agreed that people living with dementia can learn new skills and 77% understood that long term memories are often intact for people with early to moderate dementia. Significantly, these figures increased to 91% and 97% respectively after seeing the play (C10). Qualitative feedback on the play was collected via questionnaires, emails and social media tweets. A person living with dementia described the play as “*just like watching myself... It gives a 100% perfect representation of a person with dementia, that is the truth. Families need to see this; they will know then what we feel, and experience and they will understand us better*”. Another posted a message on Dementia NI’s Facebook page saying, “*It was fantastic. I would advise anyone to watch the play. What a brilliant way of getting the dementia message out to people*”. The play has been described as “*superb*” by the Alzheimer’s Society. It sold out within a matter of days at the ESRC Festival of Social Science, from where the Commissioner for Older People for Northern Ireland tweeted “*very powerful performance of #TheSongbirds in AccidentalT tonight. Great portrayal of people’s journey with #Dementia. Well done to all who pulled it together*” (C10).

5. Sources to corroborate the impact

C1: Press Release by DOH (NI) Permanent Secretary detailing a series of measures on care home standards. DOH (NI) My Home Life commissioning confirmation. Associated My Home Life reach analysis.

C2: Two DOH (NI) reports citing our My Home Life initiative: (1) Kelly, D and Kennedy J (2017) *Power to People: Report of the Expert Advisory Panel of Adult Care and Support* and (2) CPEA Independent Review Team (2020) *Adult safeguarding within a Human Rights Framework in Northern Ireland*. Associated testimonial from a member of the CPEA Independent Review Team and My Home Life funding bid to DOH (NI).

C3: Email communication from the Communications and Research Executive, Nursing Homes Ireland, detailing an opening conference address by the Irish Minister for Health and an Irish parliamentary question pertaining to our research on nursing homes as home. Nursing Homes Ireland media coverage report.

C4: My Home Life Expression of Interest flier.

C5: My Home Life pre- and post-programme participant questionnaire analysis.

C6: Three testimonials from care home managers (at Kirk House, Spelga Mews and Gngangara) who participated in My Home Life.

C7: My Home Life NI website, featuring interviews with care home managers, quality improvement initiatives and coverage of RCN Award to S Penney. Associated booklet: ‘Dementia and moving to a care home’, hosted on HSC/Public Health Agency website. Email confirming booklet distribution reach from Social Care Commissioning Lead, HSC Board NI.

C8: Testimonial from HSC Innovation & Digital Eco-system Lead. Associated InspireD app website.

C9: YouTube video of ‘The Songbirds’ play and audience numbers provided by the Director of An Grianán Theatre.

C10: The Songbirds audience questionnaire analysis (pre- and post-performance). Email communication from Empowerment Officer, Dementia NI, detailing Facebook page and member feedback on the play. Post-performance Tweet feedback from Commissioner for Older People for Northern Ireland. Email feedback on play from the Support Manager, Alzheimer’s Society.