

Institution: University of Sheffield

Unit of Assessment: 3A - Allied Health Professions, Dentistry, Nursing and Pharmacy: Dentistry

Title of case study: Enhancing Care for Older People and Family Carers: International Impacts on Practice, Guidelines and Policy

1. Summary of the impact

This case study demonstrates how programmes of research led by the University of Sheffield since 1995 have generated theoretical models and implementation tools that have had considerable significance and reach in a diverse number of areas.

There have been impacts on:

- Care and Education Practice, with over 1,250 managers/practitioners completing leadership programmes and a more widespread adoption by the practitioner community.
- **Service improvements,** with thousands of family carers and older people having an enhanced service-user experience.
- **Public and practitioner debate**, as the work has been shared with the residents and workers in 18,000 care homes.
- **International policy guidelines**, where it has informed the generation of quality standards in care homes throughout Europe.
- **Policy debates**, where the research has featured prominently in discussions about achieving dignity in care.

2. Underpinning research

Providing high quality support for older people and family carers is of global significance and reach. Recent reports have highlighted how much needs to be done to improve current practice. Research undertaken at, or led by, the University of Sheffield since 1995 developed two new approaches to work with older people and carers (The 'Carers as Experts' model and the 'Senses' Framework). Each approach has associated implementation tools (CADI/CASI/CAMI; COPE; COAT for carers; and the CARE Profiles for the Senses). These approaches have fundamentally altered thinking and practice in the field.

The empirical development and testing of the 'Carers as experts' model began with the 1996-1999 €3.3 million EU-funded ACTION project, initiated by Sheffield and involving 5 European countries. This demonstrated the practical benefits of the model delivered via the medium of Information and Communication Technology. A later EU-funded study on carers (1998-2001, €330,000), again initiated by Sheffield, involved Professor Mike Nolan (University of Sheffield since 1995), Professor lan Philp (University of Sheffield 1994-2009) and Dr Kevin McKee (University of Sheffield 1994-2009) working with 6 European partners to develop and test a short carer assessment instrument (COPE) [R1,R2]. This project resulted in the EUROFAMCARE study (2002-2005, €2.5 million, Sheffield as UK lead) that generated background reports on the state of carer policy in 23 European countries and involved institutions from 6 countries (including Sheffield) in conducting 1,000 carer surveys to further refine COPE and to develop and test carers' preferred models of service delivery [R3].

Subsequent studies undertaken in Sweden and Canada (with Nolan as scientific lead and coapplicant) further refined the application of the Carers as Experts model as a new way for practitioners to engage carers as partners and co-experts (the Carers Outcome Agreement Tool: COAT) [R6]. These studies generated funding of over 40 million Swedish Krona over 10 years (approximately £4m). COAT is now in widespread use in Sweden and parts of the UK.



Research on the 'Senses' Framework began during the influential 'Dignity on the Ward' campaign (1999-2000) funded by Help the Aged in response to the national outcry against poor standards of hospital care for older people. The study used 'Senses' Framework to identify the components of an 'enriched' care environment and for the first time turned attention to outcomes for older people, staff and family carers together. The framework was further developed in the largest ever study of nurse education in relation to older people (ENB AGEIN 1999-2004) that adopted 'Senses' Framework when defining an 'enriched' learning environment for students working with older people. This highlighted the importance of the practice placement in the formation of attitudes towards older people. Based on this Davies (University of Sheffield from 1994-2006) received a prestigious Department of Health Postdoctoral Fellowship (2002-2005) to develop and evaluate ways to introduce 'Senses' Framework into routine practice in care homes. This resulted in the practice change tool, the CARE profiles (Combined Assessment of Residential Environments). Subsequently we have completed a major SDO funded project (Dignity on the Ward, 2006-2010) that used 'Senses' Framework to explain the factors that influence culture change in acute hospitals. This has generated further practice change tools based on the CARE profiles but applied in acute contexts. This work has been used to develop a leadership programme for clinical managers working with older people [R4, R5].

3. References to the research

- R1. **McKee, K,** Spazzafumo, L, **Nolan, M**, Wojszel, B, Lamura, G and Bien, B (2009) Components of the difficulties, satisfactions and management strategies of carers of older people: A principle component analysis of CADI-CASI-CAMI. *Aging and Mental Health*, 13(2): 255-264. doi: 10.1080/13607860802342219
- R2. Balducci, C, Mnich, E, **McKee, K J**, Lamura, G, Beckmann, A, Krevers, B, Wojszel, Z B, **Nolan, M**, Prouskas, C, Bien, B and Öberg, B (2008) Negative impact and positive value in caregiving: Validation of the COPE Index in a six-country sample of carers. *The Gerontologist*, 48(3): 276-286. doi: 10.1093/geront/48.3.276
- R3. Lamura, G, Mnich, E, **Nolan, M,** Wojszel, B, Krevers, B, Mestheneos, M and Döhner, H (2008) Family Carers' Experiences Using Support Service in Europe: Empirical Evidence From the EUROFAMCARE Study. *The Gerontologist*, 48(6): 752-771. doi: 10.1093/geront/48.6.752
- R4. **Patterson, M, Nolan, M**, Rick, J, Brown, J, **Adams, R and Musson**, **G** (2011) From Metrics to meaning: Culture change and quality of acute hospital care for older people. Final report to NCCSDO.
- R5. <u>www.sdo.nihr.ac.uk/files/project/SDO_FR_08-1501-93_VO1.pdf</u>. Final report received strong endorsement from external reviewers for its quality and relevance to policy/practice
- R6. Levesque, L, Ducharme, F, Caron, C, Hanson, E, Magnusson, L, Nolan, J, and **Nolan, M** (2010) A partnership approach to service needs with family caregivers of an ageing relative living at home: A qualitative analysis of the experiences of caregivers and practitioners. *International Journal of Nursing Studies*, 47 (7), 876-887 doi: 10.1016/j.ijnurstu.2009.12.006

4. Details of the impact

Since 2008, this research has had a significant impact in a number of diverse areas:

Care and Education Practice

Leadership programmes: Over 1,250 clinical/service managers and other practitioners in health and social care have undertaken leadership programmes explicitly based on the 'Senses' Framework. Over 400 of these have been care home managers on the *My*HomeLife leadership



support and community development programme. This programme was singled out for praise in the NHS confederation 'Achieving Dignity' Report. Over 850 nurses, midwives and AHP's have been through a range of 'Senses' Framework based leadership programmes in NHS Lothian. The Head of Corporate and Clinical learning for Lothian notes that the 'Senses' Framework have been at the 'core' of their Leadership Programmes over the last 6 years and that they have become 'embedded' into practice and thinking, leading to improved outcomes for staff, patients and their families [S8].

Practitioners using the research findings in conducting their work: The carer assessment indices CADI/CASI/CAMI have been translated into over 20 languages and are in widespread use globally. As noted above, the COAT assessment model is used by practitioners in 104 Swedish municipalities and in the City and County of Swansea. It has been validated for use in French-speaking Quebec.

An indication of the significant practitioner interest in this work is apparent in the 25 invited keynote addresses given to national and international practitioner conferences in the UK, Europe and Australasia on either the 'Senses' Framework or the 'Carers as Experts' model between 2008-13.

Enhanced Service User Experiences

Over one third (104/290) of all Swedish municipalities are users of the Carers Outcome Agreement Tool (COAT). The Head of Services for Older People in Jonkoping Municipality (one of Europe's leading centres for innovation in geronotological practice) notes that COAT provides the basis for all family carer support, improving assessment of need and subsequent action [S7].

Both 'Carers as Experts' and The 'Senses' Framework have driven an extensive programme of service redesign undertaken by the City and County of Swansea. The Planning Officer for Older People has confirmed that this has resulted in major culture change and enhanced service delivery impacting on over 700 family carers, 400 older people and over 100 staff. Estimated saving in one service alone is over £150K annually [S5].

Decisions by regulatory bodies informed

The Inspection Standards produced for Care Homes by the Care Quality Commission (Scotland) and applied to all care homes in Scotland drew significantly on 'Senses' Framework in defining their quality criteria. This focussed attention to a broader conceptualisation of quality that engaged older people and carers more fully in the assessment process.

Public and practitioner debate informed

The on-going and increasingly important public debate about the future role and status of care homes is being led across all four home countries by Age UKs' 'My Home Life' campaign, impacting on 18,000 care homes and over 400,000 older people. The Executive Director of the My Home Life Programme states: 'Relationship-centred care and the 'Senses' Framework underpins My Home Life's vision for best practice which has crossed national boundaries. MHL has shared this evidence-based and relationship-centred vision with 18,000 care homes and over 400 care home managers have been supported through the MHL leadership support and community development programme'

<u>Influence on International Policy Guidelines</u>

The EU 'PROGRESS' initiative for Employment and Social Solidarity produced guidelines on indicators for the measurement of impact in care homes throughout Europe. This large-scale collaborative project synthesised the best research in the field across Europe and engaged a wide



range of experts in extensive Delphi surveys. Hundreds of pieces of research were consulted and yet one fifth (18/94) of the quality indicators generated were based exclusively on the CARE profiles developed during research undertaken at Sheffield [S3].

The model of partnership working encapsulated in the Carers as Experts model was used as the conceptual basis for the Carers National Competence Centre in Sweden. It has been highly influential in other policy developments in Sweden.

Policy debate informed

The 'Senses' Framework was provided in verbal evidence to the influential Commission on Dignity in Care and were one of only two programmes of research explicitly cited in the final report [S2], 'Achieving Dignity in Care' (Recommendation 15) produced by the NHS confederation/Association of Directors of Social Services/AGEUK. In the wake of both Francis and Keogh, debates about dignity and compassion in care have assumed ever greater import and the 'Senses' Framework represents probably the most important addition to this debate to have emerged in the last decade.

5. Sources to corroborate the impact

- S1. The *My Home Life* website corroborates the claim that the 'Senses' Framework is the main conceptual underpinning of this initiative. (http://myhomelife.org.uk/research/)
- S2. The *Delivering Dignity* final report (p.21) corroborates the claim that Sheffield research underpins the findings of the report (http://tinyurl.com/cque4ox).
- S3. The *Measuring Progress: indicators in care homes* report corroborates the claim that 18 of the 94 quality indicators were based on Sheffield Research (pp.22, 23, 51, 57-63, 74-76, 90 http://tinyurl.com/pr2v6ho)
- S4. The ACTION website (www.actioncaring.se) and that of the Swedish National Carers Competence Centre (www.anhoriga.se) corroborate the claims that the Carers as Experts model was the basis for the centre.
- S5. A statement from the Planning Officer for Older People, City and County of Swansea corroborates that the 'Carers as Experts' and 'Senses' Frameworks have driven an extensive programme of service redesign undertaken by the City and County of Swansea and confirms the accompanying benefits.
- S6. The EUROFAMCARE series of reports corroborate the claim that this was the most comprehensive piece of research yet conducted into carer need across Europe (http://www.uke.de/extern/eurofamcare/publikationen.php).
- S7. A statement from the Head of Care for Older People, Jonkoping Municipality, corroborates that COAT provides the basis for all their family carer support and has led to improved assessment of need and subsequent action.
- S8. A statement from the Head of Corporate and Clinical Learning NHS Lothian corroborates that 'Senses' Framework have been central to their Leadership Programmes over the last 6 years and that they have become embedded into practice and thinking, leading to improved outcomes for staff, patients and their families.