# Roles and responsibilities in

# Integrated Care for dementia

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# Abstract

**PURPOSE**

Effective integrated healthcare systems require capable, trained workforces with leadership, shared governance and co-ordination. This study aimed to provide additional understanding of roles and responsibilities in relation to integrated care from the perspective of massive open online course (MOOC) participants.

**METHODOLOGY**

MOOC discussion board posts were analysed using Framework analysis consisting of transcription, familiarisation, coding, developing an analytical framework and application of the framework.

**FINDINGS**

Boundaries and key issues surrounding roles and responsibilities were highlighted and participants suggested a number of enablers that could remove barriers, thereby enhancing integrated care.

**ORIGINALITY/VALUE**

Enablers included introduction of shared communication and IT systems to support continuity of care. Awareness and understanding of dementia was seen as crucial to promote person centred care and care planning. The roles of education in, and experience of, dementia care were highlighted. Barriers affecting the roles and responsibility professionals exercise include funding, role conflicts, time constraints and time-consuming paperwork.

**Introduction**

People living with dementia require significant ongoing support and care from individuals and teams who work across a wide range of services and organisations (Miranda-Castillo, Woods and Orrell 2010). There has been increasing pressure in the United Kingdom since the Health and Social Care Act of 2012 for health and social care services to restructure and integrate. Health and social care transformation has been driven by the challenge to deliver over £22 billion cost savings in efficiency measures by 2020/2021 (Dunn, McKenna and Murray 2016). Increased pressure, restructuring and efficiency measures, alongside the rising cost of care, have placed increasing pressure on healthcare providers to ensure their services are fit for not just current care demands, but also those in the future. Health and social care organisations are facing financial deficits, worsening referral waiting times and increased demand for health and social care services (Kings Fund 2017). These challenges compound the issues of providing adequate numbers of staff to implement effective care.

Integrated care is an approach which integrates services for the benefit of patients, efficiencies and value from health delivery systems (Shaw, Rosen and Rumbold 2011). Successful international integrated healthcare systems exhibit effective leadership, clear and strong communication, shared governance between organisations and care navigation roles who assist in breaking down barriers and facilitating collaborative working (Royal College of Nursing 2014). Care navigation is a process or intervention, rather than a specific role and all staff should be involved (Health Education England 2016). Sustainability and Transformation Plans (STPs), a response to improve health and care, have led to 'area' plans with focused resources and services in particular places, rather than the organisations in which care is delivered (NHS

2015); a development which will require flexible working across boundaries (Alderwick 2016)

and may promote integrated care for dementia.

Effective integrated care for dementia represents a significant priority, and this need will only

rise as "baby boomers" approach older age and develop diseases, including dementia (Forbes

and Neufeld, 2008). Integrated dementia care pathways are already in development and being

implemented with positive effect (Timmons et al, 2017). Minkman, Lighart and Huijsman

(2009) argue the factors for successful integrated care include expert knowledge, strong

provider networks and inter-organisational co-operation. This approach may under value the

contribution of individual people who perform various roles and have responsibilities in

relation to integrated dementia care.

This article presents a major research theme emerging from a Framework Analysis study of

integrated care from the perspective of participants of a massive open online course on

dementia. The aim of this study was to explore experiences of integrated care from the

perspective of carers, people living with dementia, healthcare professionals and researchers. A

major theme emerging from this analysis related to the roles and responsibilities people

performed or undertook in relation to integrated care for dementia, rather than the specific

professional or non-professional role they inhabit.  This theme is reported here.

**Methods**

**Design**

This study reports the views of Massive Open Online Course (MOOC) participants'

perspectives on the roles and responsibilities of staff involved in delivering integrated care for

dementia in a variety of contexts. Robertshaw and Cross (2017), in the wider study, identified

the general views and experiences of integrated care for dementia from the perspective of carers

and families of people with dementia, healthcare professionals and researchers. Data were analysed using Framework Analysis of massive open online course (MOOC) participants' discussion board contributions to an activity on integrated care. The study utilised a MOOC on dementia which was available to learners in 2015, 2016 and 2017. The course had 3,058 learners from a diverse range of backgrounds, countries and professions. MOOCs are becoming an established methodology for crowd sourcing ideas to social issues (Robertshaw and Cross 2016). The course was open to the general public and did not have any entry criteria. It included both accessible easily-understood information as well as technical information about dementia, and was intended to be a transformational intervention to change participants' perceptions and attitudes about dementia. Participants studied a unit of learning on understanding integrated care and its importance in relation to dementia. Participants were then asked to reflect on their own definitions of integrated care, as well as its strengths and limitations from their experiences.

**Participants**

Discussion boards prevent determination of exact demographic data of activity participants, however MOOC participants overall were mostly female (83%) and there was variation in levels of previous study with 57% of participants who had previously completed at least a two-year University course. Participants represented an international sample, with a large proportion of participants from Western Europe (45%). There were 3,058 learners from a wide variety of professions and backgrounds.

**Data collection**

This study was designed to be compliant with the British Psychological Society Code (2014) for Internet Mediated Research. Ethics approval was granted by the University of Derby Online

Learning's ethics committee. All MOOC participants were contacted via email with information on the aims and purpose of the study and contact details should a participant wish to withdraw their forum responses from analysis. All data was downloaded in a spreadsheet and analysed by both researchers (AK and DR) using Framework Analysis. Participant comments are quoted directly without modification or editing for spelling and grammar, other than removal of identifying information.

**Data analysis**

Framework analysis (Ritchie & Spencer 1994) was used to identify themes and patterns in the data, and a framework chart was created for this purpose. Framework analysis has the capability of systematically organising and analysing participants' views and experiences from interview data. It is used for analysis in policy and service development research. The development of a 'framework' allows users to examine themes and inconsistencies in opinion between participants. This benefitted the exploration inconsistencies or contrasting experiences between carers/families and health care professionals. Framework analysis consisted of five key stages (table 1).

- Stages one and two: transcription and familiarization which involved analysis of 847 discussion board posts exported to Microsoft Excel.

- Stage three: coding which involved defining and refining the thematic framework

- Stage four: Developing an analytical framework involving development of codes, comparing them and applying them.

- Stage five: Applying the analytical framework: subsequent transcripts were indexed using the categories and codes according to Robertshaw and Cross (2017).

  Table 1: the Five stages of Framework Analysis (Adapted from Ritchie and Spencer, 1994)

**Results**

A major theme emerging from the data set was the importance of roles and responsibilities in relation to integrated care for dementia and this theme is explored here through sub-themes and their associated quotes. As per Framework Analysis, surrounding discussions are included in these results. Quotes included here are indicative of responses and are attributed to individual professional roles, gender and location to protect anonymity. They are unaltered from their original written comment, which is why some quotes include spelling and grammar errors.

Discussion board participants recognised that acollaborative and inter-disciplinary approach to working was needed for effective integrated dementia care. However this collaborative and inter-disciplinary approach alone was not considered to be adequate to achieve integrated dementia care. Participants stated delivering effective integrated dementia care requires deploying holistic principles of care into practice, ensuring a holistic approach and collective responsibility. Person centred and holistic care were mentioned throughout.

This theme was separated into six subthemes (table 2), and each theme's results are presented here.

1. Consistency and continuity of care

2. Hierarchy

3. Leadership and coordination

4. The need for advocacy within integrated care

5. Boundary conflict and responsibility within integrated care

6. Need for dementia training and upskilling

Table 2: Themes relating to roles and responsibilities identified from analysis

## Consistency and continuity of care

Participants discussed the role of services within the context of integrated care, including dementia cafes, memory clinics and reminiscence groups and the functions these services perform. Participants argued that in all these services people with dementia receive person-centered support from a range of professionals and carers. There was concern some of the functions these services performed were duplicated. Integrated care was thought by participants to prevent duplication and improve allocation of resources whilst also providing consistent care.

> *"Integrated care should prevent duplication of services, inadequate service provision, cessation of services and reduce costs. The outcome should be delivery of ongoing high quality patient centred care"*
>
> - Layperson, female, UK

Participants saw information as providing power to its holder however seeking, identifying and using patient information was suggested as a challenge. Participants believed there was a need for re-assessment of patients throughout their journey with dementia, but this had to be balanced against patient frustration when being asked the same questions repeatedly by different service providers. Getting the right information at the time from the right person was seen as difficult due to personal barriers and resistance to share information:

> *"The difficulty lies in getting the information, and staff accepting what they are told. many people are reluctant to admit to some health conditions, especially those with a stigma attached. Depending on who is available to corroborate information, we don't always get an accurate picture."*

- Medical student, female, UK

Participants identified tools to manage and enhance information consistency and continuity of care. One example of these tools was 'This is Me', a tool to provide information about a person with dementia's needs, wishes and preferences that was designed to enhance choice, personalisation and individualised care and in widespread effective use in dementia care (Alzheimer's Society, 2017).

*"I use tools such as a ' this is me' form, which aids the individuals to gain empowerment to state what they would like for the present and the future"*

- Psychologist working in an MDT learning disabilities team, female, Greece

Use of technology by various care providers was seen as a way to enhance consistency of care, to ensure care records are up to date and accurately represent the person's needs and record episodes of care. Integrated care record systems were highlighted as a way to enhance consistency in addition to ensuring records are safely stored. In this way different professionals can read each other's notes and comments to enhance care.

*" I do believe that in a technological age we should be looking at integrating the different medical records systems in some way, though that sparks new rows as to whose system is the best and should be adopted by others!"*

- Community Psychiatric Nurse Assistant, Female (location unknown)

Where staff did not have access to patient records they resorted to alternative means for information transfer. This was perceived as being difficult due to geographical dislocation and

disconnection between staff. Integrated electronic care records were posited as an answer to enhance care consistency, leading to shared responsibility by various roles.

> *"I do not have access to my patients record in primary care, or on hospital admission or social and voluntary care, therefore it all relies upon telephone calls. This is difficult when people are busy, work different hours, are out and about and just miss each other. For integrated care to truly work, we either all sit together in the same building or we have computer systems that link together."*

> - Lead Mental Health Nurse, Female, UK

Dislocation and disconnection in rural areas for people living with dementia was particularly noted by participants in Australia where staff work across very large areas. Participants felt technology provides a potential solution for enhancing integrated dementia care.

> *"Limitations of this would be that it is difficult to find times when all health professionals needed would be available at once or the same day. This would result in multiple trips to hospitals, which in Australia can be very troublesome as some people need to travel 1000's of KM's from remote areas and communities to recieve specialised and allied health input. These people often miss out or health professionals in remote areas learn to incorporate aspects from other professions into their practice to accomodate this."*

> - Registered Nurse, Female, Australia

Continuity of communication was considered to be important, facilitated by using a variety of technologies such as integrated care record systems. These ensure an overview of the whole

patient journey. Computer systems that do not communicate with each other were a concern, which caused perceived delays in treatment.

*"Integration of care, especially between mental health authorities and social services, is frequently 'not joined up', with different computer systems that don't ' talk' to each other and problems in accessing care packages. This can cause clients spending longer than necessary in eg hospital awaiting discharge, which deskills clients with dementia, making return to home more likely to fail."*

- Community Support Worker, Female, UK

New ways of working to promote consistency in care delivery were discussed, in particular the care navigator role. Care navigation is an essential component of delivering integrated person-centred care and these functions exist to help people chart a course with purpose and direction (Health Education England 2016). Participants seemed to use the word care co-ordinator and care navigator interchangeably.

*"I work as a Care Co-ordinator and care co-ordination would be much simpler if all services used one patient record.  Currently, there are GP practices, Community staff (District Nurses, Community Matron's, Therapists), Mental Health staff,; Social Services staff all using different systems and that doesn't include when the patient goes to A&E or see's a Consultant - it will never be integrated until there is ONE patient record."*

- Layperson, Female (location unknown)

**Hierarchy**

Hierarchy, a common issue for businesses and large organisations, was a theme of discussion by participants. They shared their concerns about fear of changing health and social care services leading to inefficiencies in care delivery. They also were afraid of their own approach to care changing.

*"Sadly, in practice, many professionals fear having to change their own approach which often leads to any integration of services being nigh on impossible to achieve efficiently and effectively."*

– Layperson, female, UK

Participants thought hierarchies not only existed amongst people but also between organisations. They shared their experiences of different organisations and how they work together; many held the belief that these activities could be improved.

*"I work with a charity that provides social events for older people, many with early onset dementia, reducing isolation. Sometimes we come across safeguarding issues and my colleagues and I are often shocked at how difficult it is to communicate with all the different organisations that are supposed to be 'caring' for vulnerable individuals."*

- Educator, Female, UK

Hierarchy exists not only between organisations, but also between health care and social care. Despite improvements to promote parity participants considered this inequality to remain.

*"integrated care can work well when the patient receives the best care but there still remains a vast divide with health and social care*

- Occupational Therapist, Female, UK

Some participants constructed their experiences of services as being managed and operating

like businesses, rather than as a care service. Although many National Health Service (NHS)

services are now privatised, most care homes in the UK are privately owned and run as

businesses. Participants shared their experiences of this tension and the adverse effects of

commercialised healthcare.

> *"I also feel with dementia, integrated care is needed as the majority of care homes is*
>
> *run as business. this is one of the main causes of the quality of life of the patient being*
>
> *overlooked in my opinion and in my experience having seen this hierarchy division*
>
> *working in practice"* - Day Centre worker, female, UK

**Leadership and coordination**

Participants recognised the need for new roles and functions such as the care coordinator and

care navigation, which could provide valuable leadership and co-ordination. Whilst it was

recognised that the creation of new roles would entail substantial training needs, the roles were

important for the facilitation of effective part of integrated care for dementia. The care

navigator role is embedded in the integrated care model, and promotes partnership working to

promote optimum healthcare outcomes (McMurray and Clendon 2015).

> *"Each service user should be appointed a care coordinator: an intermedia tort who*
>
> *could liaise between service users and service providers. The weaknesses is that is*
>
> *requires case managers, who may not be available or who are not qualified. I have*
>
> *witnessed the latter, which means, needs go unmet. Positives are that time should be*
>
> *reduced, good communication networks so that repetition is reduced. Negatives are*
>
> *that, sometimes, the person's main need is not met as they are being case managed by*
>
> *a different discipline. Not all social workers understand nursing issues and vice versa"*

- Daughter of a person living with

dementia, location unknown

Some participants noted barriers that prevented interprofessional and collaborative working such as time constraints, lack of funding and awareness. They felt there was a need to have time for case discussion and meetings with other professionals. Conversely, short visits or disconnected working was identified as having a negative impact.

> *" However from experience most none private health and social care professionals have such big case loads that taking time to meet other people including the patient is often very difficult. Supporting people however integrated a team may be by providing care in short 15 minute visits by many different carers cannot be beneficial to the patient or the families."*

- Professional dementia carer, Female, UK

**The need for advocacy within integrated care**

Participant discussed the importance of social care and its advocacy role, which was considered to be often forgotten or at least underfunded. Participants believed there could be rapid improvement in the National Health Service (NHS) if social workers were employed in a wider range of care environments, which could improve access to and awareness of social care services. They highlighted the importance of social workers and social care in general to support integrated care for dementia. .

> *"I think that patient experience would be hugely improved if the NHS employed social workers and each team could access one with ease. Despite health and social care*

*trying to sing from the same hymn sheet in reality the structures and processes in place*

*really do make this very difficult." - Occupational Therapist, female, UK*

**Boundary conflict and responsibility within integrated care**

Participants shared their experiences of working in complex teams with diverse ranges of roles. Each role has its own ontology, area of responsibility and focus. When bringing teams together there can be blurred boundaries and where overlap exists there can be risk of inaction or failure to recognise issues as they 'fall through the cracks'. These factors can lead to boundary conflict however participants generally found working in teams as a rewarding process despite these challenges.

> *"I work as part of a community team consisting of a GP, Community Matron, District Nurse Team, Mental Health Community Worker and CPN, Social Care Worker, Local Area Coordinator and a Care Coordinator. As a team we can discuss the whole patient care. It also enables all the different agencies involved in a patients care to communicate with each other on a regular basis. It can be difficult to get all these health/social care professionals together at the same time, but we have all found it a worthwhile and productive process."* - Care Coordinator, Female, UK

**Need for dementia training and upskilling**

Participants believed integrated care was contingent upon appropriately trained people being present and available at the right time. This was in addition to an understanding of the specific roles such as occupational therapists and physiotherapists who work alongside other staff. Some participants believed there was an overwhelming medical focus, and that alternative perspectives were not always considered. Despite this, there was a desire for a 'joined up' (integrated) approach with individuals working as part of teams able to discuss the patient's

care as a whole. There was also a sense of doing something worthwhile, which could prevent

burnout and reduce stress.

Some participants compared dementia care with other professional roles; noting this particular

area presents unique challenges. They reported that some staff may be unaware of the

professionalism and time management requirements for their roles. Staff entering new roles are

required to complete induction and competency packages, including the Care Certificate (Skills

for Care 2016), which may mitigate this lack of skills.

> *"Dementia care is challenging itself and people thinks this is a mental issues and often*
> *subtle their needs and feelings. Most of them are unaware of treating in good manners.*
> *In fact, many caring homes are aware of dementia but lacking staff with limited time*
> *management strategies and struggling to manage their daily routine only leaving*
> *behind their mental, emotional feelings"*

- Geriatric care worker, Female, location unknown

**Discussion**

The aim of this study was to explore experiences of integrated care from the perspective of carers, people living with dementia, healthcare professionals and researchers. A major theme emerging from this analysis was related to the roles and responsibilities people performed or undertook in relation to integrated care for dementia, rather than the specific professional or non-professional role they inhabit. This study has therefore provided additional understanding of the roles and responsibilities people perform in relation to integrated care.

MOOC participants desired a tailored, person-centred, holistic and inter-disciplinary approach to care complementing rather than restricting professional roles. Care coordination was seen as a challenge. However implementation of dedicated coordinator roles was seen to lead to a diffusion of responsibility, consistency and trust, with managed boundary conflicts. Care navigation and co-ordination can improve patient journeys and promote independence (McMurray and Cooper 2017). Participants questioned which professional roles should be involved and how these facilitate shared ideas; a care coordinator could prevent separation and ensure involvement of relevant individuals around the person requiring care. They could prevent duplication of effort and rationalise resources by ensuring care is provided when it is needed.

Perceived enablers included introduction of shared communication and information technology (IT) systems to support continuity of care and consistent record keeping to facilitate the integration and co-operation of roles. These IT systems were thought to be challenging as there are many systems which are not interoperable. Records held on these systems should be accessible and useable by all. Until such time as this is possible, it may be more practical to have patient-held records which have been shown to prevent carer strain and allow patients to maintain a locus of control (Simpson et al 2006). There is recent increase in the use of IT

systems, particularly telemedicine (Munro et al 2014; Vahia et al 2014; Weiner, Rossetti and Harrah 2011) which may enable integrated dementia care. Minkman, Lighart and Huijsman, (2009) saw inter-organisational working and technology as promotional factors for integrated dementia care, which correlate with these findings.

Awareness and understanding of dementia was seen as crucial to promote person centred care and care planning. The role of education was consistently highlighted, in addition to experience.

Perceived barriers preventing effective roles and suitable responsibility include funding, role conflicts, time constraints and time-consuming paperwork. These barriers could lead to care fragmentation. Communication continuity was particularly seen as a challenge due to time constraints. Participants argued that funding constraints are a result of the division of health and social care, therefore as organisations integrate funding may become more available. Concerns about conflicts and overlaps of roles were shared; these could prevent direct responsibility for individuals leading to failures in recognising and dealing with problems. Healthcare professionals historically are not in favour of change (Melnyk et al 2012) yet they have a primary role as a leader and change agent and have the greatest potential to promote better care (Wall 2013).

This course has demonstrated that MOOCs and online learning can be a useful platform to gain insights into perspectives of roles and responsibilities. It is known that learning in this type of environment with people from other backgrounds and roles is beneficial (Hallin et al 2011), and the course was designed with an emotional thread throughout which Helmich et al (2011) report is important for learning. Service users were involved in the development of the MOOC and participants were able to directly observe their experiences which further promote learning (Morgan and Jones 2009).

This work has some important limitations which must be acknowledged. This study used MOOCs to crowd source the data. MOOCs use online fora, and this method of data collection can result in groupthink, whereby conversations and comments can be influenced by other members of the group, preventing authentic discussion (Tsikerdekis, 2013). However, online fora are places where participants can be honest and open about their responses without fear of retribution due to the anonymity afforded in this space. The data were analysed by two researchers with different professional backgrounds. This increased the level of confidence in the thematic analysis, however each research may have brought their own bias when reading and coding comments. This may have resulted in bias during the allocation of themes. Respondents were from a large number of countries. Whilst this brought diversity in discussion, it often prevent direct comparison and discussion about integrated care for dementia as societies and communities were not directly comparable, due to differences in health and social care systems.

**Conclusion**

This article has explored participants' perceptions of roles and responsibilities in relation to integrated dementia care from the perspective of MOOC participants. They believed effective integrated care for dementia not only relies upon a well-designed system, but also the individuals who work and operate within it who must be adequately prepared resourced and funded to do their roles. The current financial climate and uncertain future of care services means this is unlikely to be resolved soon, despite dementia now being a leading cause of death (Office for National Statistics 2016). It is recommended that all organisations consider developing care navigation and co-ordinator roles and functions; they develop interoperable IT systems with electronic records and that all staff involved in dementia care access education and training to promote skills and knowledge development. Knowledge and understanding of

the roles and responsibilities of people and organisations needs to be embedded into future professional programmes to give professionals of the future an awareness of their potential, although it is often difficult to define what these roles and responsibilities should be. Further research is recommended to understand the factors and successful activities which 'work' to promote integrated dementia care so that these can be effectively implemented.

**Implications for practice**

- Care co-ordination and care navigation are important functions but are not currently fully embedded in all integrated care systems. These roles could improve approaches to joined-up care.

- Shared care records facilitate interprofessional working and collaboration and should be considered for implementation. These shared care records could be enabled with technology and electronic solutions.

- Further research is recommended to understand the factors and successful activities which 'work' to promote integrated dementia care so that these can be effectively implemented.

- Knowledge and understanding of the roles and responsibilities of people and organisations – and their functions in the provision of integrated health and social care – needs to be embedded into pre-registration professional programmes.

- MOOCs, although they have limitations, may be a useful method of conducting social research in health and social care by 'crowd sourcing' solutions to deliver effective integrated dementia care.

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