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Item Type	Article
Authors	Robertshaw, David; Cross, Ainslea
Citation	Robertshaw, D. and Cross, A. (2017) 'Experiences of Integrated Care for dementia from family and carer perspectives: A framework analysis of massive open online course discussion board posts.' <i>Dementia</i> , DOI: 10.1177/1471301217719991
DOI	10.1177/1471301217719991
Publisher	Sage
Journal	<i>Dementia</i>
Rights	Archived with thanks to Dementia (London, England)
Download date	01/03/2022 08:02:48
Item License	http://creativecommons.org/licenses/by-nc-nd/4.0/
Link to Item	http://hdl.handle.net/10545/621809

Experiences of Integrated Care for dementia from family and carer perspectives: A framework analysis of massive open online course discussion board posts

David Robertshaw *

¹College of Health and Social Care, University of Derby, Derby, UK
Ainslea Cross

²University of Derby, Derby, UK

*David Robertshaw, University of Derby, Kedleston Road, Derby DE22 1GB, UK. Email: d.robertshaw@derby.ac.uk

ABSTRACT

Background

Integrated Care for dementia is an increasingly popular approach to supporting people with dementia, bringing services together to form a single cohesive provision for service users. This approach is still in its infancy but has the potential to improve the management of dementia, social care and to enhance the patient experience.

Aims

To understand views and experiences of integrated health and social care for dementia from the perspective of carers, families, healthcare professionals and researchers.

Methods

Crowdsourcing views and experiences from 'Bridging the Dementia Divide', a massive open online course at the University of Derby, provide a rich source of qualitative data from carers, families and healthcare professionals. We analysed 847 massive open online course discussion board posts using a Framework Analysis approach.

Results

Participants described how Integrated Care for dementia should be person-centred and holistic, involving a multidisciplinary team of health and social care practitioners, as well as the patient, the family and the wider community. The establishment of Integrated Care for dementia was viewed positively.

Keywords: dementia integrated care internet-mediated research massive open online course qualitative research

Introduction

Dementia is a complex syndrome which affects brain function, relating to an irreversible loss of cognitive ability and memory with a significant decline in behaviour, social and emotional capacity (De Bellis & Williams, 2008; Kitwood, 1997; World Health Organization and Alzheimer's Disease International, 2012). Dementia is not an inevitable part of ageing and many people with a diagnosis are able to continue a positive quality of life, live in the community and maintain their independence (World Health Organization, 2016). Dementia is a progressive disease and can reduce a person's ability to undertake normal daily activities, which can lead to dependence on family members and carers. Dementia is a significant public health issue, as currently 850,000 in the United Kingdom are living with Dementia, a figure that is predicted to rise to over two million by 2051 (Alzheimer's Society, 2014).

Delivering Integrated Care has been a concern of English health policy since the Hospital and Community Care Plans of 1962 and 1963 (Great Britain Ministry of Health, 1963; Hansard, 1962). More recent initiatives have included the development of care trusts (Department of Health, 2000), managed clinical networks (Skipper, 2010), Integrated Care pilots (Department of Health, 2009), the Integrated Care pioneers (Department of Health, 2015a) and the new care models programme as part of the Five Year Forward View Care Quality Commission, Public Health England and NHS Improvement (2014). The Whole Systems Integrated Care (WSIC) programme in North West London is the largest of

the Integrated Care pioneers where 14 areas of England were chosen to pilot different ways of delivering better joined-up care. Dementia was included in this framework (Wistow, Gaskings, Holder, & Smith, 2015). Recent drivers for Integrated Care in dementia include the implementation plan for the Prime Minister's Challenge on Dementia 2020, which set out requirements for improved diagnosis, support, independence, continuity of care and advanced care planning (Department of Health, 2015b). The National Institute for Health and Care Excellence (NICE) has called for care integration to ensure provision is person-centred and works for people with long-term conditions like Dementia (NICE, 2015) and has provided guidance to assist health and care managers to integrate and work across agencies. In particular, they advocate shared governance, information sharing and shared planning (NICE, 2016). Research into Integrated Care for dementia is important for finding new and innovative ways in which our health and social care systems may support the increasing numbers of people living with dementia. Knowledge transfer of the translation of research into practice is also vital in care and health services research and clinical research. This happens most effectively when the professionals involved in delivering care also contribute to the research into the care and services they help to provide. However, health and care professionals are able to underrepresent in the conduct of research on dementia services and care, given the size of the sector and extent of need. People working in dementia care are more likely to hold no qualifications, are less likely to be working towards any qualifications and less likely to be working in professional or managerial roles (Hussein & Manthorpe, 2012).

Recent papers such as 'No Health without Mental Health' (HM Government/Department of Health, 2011), the 'Narrative for Person-Centred Coordinated Care' (NHS England, 2013) and 'Delivering better Integrated Care' (Monitor, 2014) have pushed the integration agenda forwards. Dementia can benefit from effectively designed and co-ordinated Integrated Care, particularly as people at the advanced stages of dementia may face the challenge of being unable to communicate their needs and often have multiple co-morbidities such as diabetes and hypertension (Gage et al., 2012). Accordingly, people with dementia are at increased risk of hospitalisation following chest and urinary tract infections and frequently experience pain, anxiety and swallowing problems (Vandervoort et al., 2013). Black et al. (2013) showed that 99% of people living with dementia and 97% of carers have one or more unmet need with 85% of this figure accounting for unmet needs in resources and education. Despite complex needs, people with advanced dementia often receive fragmented and suboptimal care at the end of life (Gage et al., 2012; Goddard, Stewart, Thompson, & Hall, 2013), and anticipation of future needs or care planning does not occur routinely. The recent White Paper on the provision of optimal end of life care for people with dementia argues for multidisciplinary care in order to best meet multiple needs (van der Steen et al., 2014).

Integrated Care seeks to address these challenges through its ambition of achieving excellent communication between services, information sharing across disciplines and proactive anticipatory care, such as the management of symptoms in order to improve care outcomes (Wolfs, 2011). Integrated Care models have demonstrated improvements to both quality of care for those with chronic conditions (Ouwens, Wollersheim, Hermens, Hulscher, & Grol, 2005) and quality of life of those at the early stages of dementia (Wolfs, Kessels, Dirksen, Severens, & Verhey, 2008). Importantly, people with advanced dementia may need access to palliative care services (Lloyd-Williams, Abba, & Crowther, 2014), although research suggests that current palliative care teams may not be prepared for communication and behavioural problems presented by people with advanced dementia (Kupeli et al., 2016). Kupeli et al. (2016) reported further barriers to the delivery of effective integrated dementia care; they identified prevalent challenging societal attitudes towards older people which could influence service commissioning and policy delivery for people with dementia.

With an ageing population and increasing dementia prevalence, dementia is now the leading cause of death in the UK (Office for National Statistics, 2016). It is essential to build the resilience of carers and people with dementia so that they can remain in the community for as long as possible. This must be done in a way that facilitates independence, recognises citizenship and the right to participate fully in society. The Prime Minister's dementia challenge (Department of Health, 2015b) emphasises the need for changes in policy and service delivery to account for the challenges provided by these population changes. General Practitioners (GPs), for example, should play a leading role in ensuring coordination and continuity of care for people with dementia, as part of the existing commitment that from 1 April 2015 everyone would have access to a named GP with overall responsibility and oversight for their care. The Prime Minister's dementia challenge outlines its commitment to commission and develop more research to inform effective models and pathway developments to enable intervention implementation (Department of Health, 2015b).

The aim of this study is to identify the views and experiences of Integrated Care for dementia from the perspective of carers and families of people with dementia, healthcare professionals and researchers. Carers are defined as "anyone

who cares, unpaid, for a friend or family member who due to an illness, disability, a mental health problem or an addiction cannot cope without their support” (Carers Trust, 2015).

Methods

Design

The study aimed to explore experiences of Integrated Care from the perspective of carers and families with dementia, healthcare professionals and researchers by providing a Massive Open Online Course (MOOC) on Dementia during 2015 entitled ‘Bridging the Dementia Divide’. This methodological approach was chosen for its potential to crowd source ideas from large numbers of people who represent a multitude of roles in dementia care internationally, whose perspectives have been underrepresented in previous research. The course consisted of six units of learning, covering all aspects of dementia care. The course was open to the general public and did not have any entry criteria, including both accessible and technical information about dementia, and was intended to be a transformational intervention to change perceptions and attitudes about dementia. Participants studied a unit of learning on understanding Integrated Care as a principle and its importance in relation to dementia. Minimal information was provided on the definition of Integrated Care, so as not to influence participants or introduce bias into discussion board responses to the question. Participants were then asked to reflect on their own definitions of Integrated Care, as well as its strengths and limitations from their experiences.

Participants

The course had 3058 learners from a wide variety of professions, backgrounds and locations. Due to the large number of participants and protection of anonymity, it was not possible to delineate this number into categories of learners. Participants in the MOOC were predominantly female (83%), with significant representation between the 35 and 44 and 55 and 64 age groups. Participants had varying levels of previous education; however, 57% had completed at least a two-year University level course. Representation was from across the globe, with the majority of participants being from Western Europe (45%) and Australia and the South Pacific (23%).

Data collection

The study was designed in accordance with the British Psychological Society (2014) Code for Internet-Mediated Research, and ethical approval was granted by the University of Derby Online Learning Ethics Committee. Participants were contacted by the massive open online course owner via email which informed them of the aims and purpose of the study along with details of who to contact should they wish to withdraw their forum responses from the analysis. To protect individuals’ right to confidentiality, the discussion forums were then closed to those not registered on the MOOC meaning that the research was conducted in a private, and not a public domain.

Participants’ identities were removed from the transcript of participant responses; pseudonyms and/or the participant’s professional role were attached to quotes to maintain anonymity. Personally identifiable names or references to events, organisations and people or places were also removed from quotes.

Data analysis

Framework analysis (Ritchie & Spencer, 1994) was used according to the NatCen guidance to identify themes and patterns in the data, and a framework chart was created for this purpose. Framework analysis was chosen as it has the capability of systematically organising and analysing participants’ views and experiences from interview data. It is a favoured method of analysis for policy and service development research. The development of a framework allows the user to examine theme overlap and inconsistencies in opinion between participants. This was particularly beneficial for the study, as the analytical frameworks were effective for exploring inconsistencies or contrasting experiences between carers/families and healthcare professionals. Framework analysis consisted of five key stages which are outlined here.

Stages 1 and 2: Transcription and familiarisation

Both researchers (AC and DR) analysed 847 MOOC discussion board posts which were posted by MOOC participants. The posts were exported to Microsoft Excel 2013 Professional to form a full verbatim transcript of the discussion posts, with participant details removed and each participant assigned an anonymous code. Familiarisation of the transcript was achieved by reading of the data several times and making notes in initial impressions of the data. In line with

framework analysis processes, the transcript database had large margins and adequate line spacing for coding and making analytical notes, thoughts and impressions of the raw data.

Stage 3: Coding

This stage involved developing and refining the thematic framework in subsequent stages, which was completed through project meetings and through separate discussion with the two researchers working on the analysis. After familiarisation, both researchers (AC and DR) carefully read the transcript line by line, applying ‘codes’ describing their interpretation of important findings. An inductive ‘open coding’ approach was undertaken, i.e. coding anything that might be relevant from as many different perspectives as possible. Codes referred to substantive phenomena and context (e.g. particular behaviours, incidents or structures), values (e.g. those that inform or underpin certain statements, such as a belief in evidence-based medicine or in patient choice), emotions (e.g. sorrow, frustration, love) and more impressionistic/methodological elements (e.g. where the respondent showed reluctance or hesitance). Both researchers independently coded the first 50 posts in the transcripts after which saturation of themes was reached. Discrepancies in coding were discussed before agreement on the main themes which were applied consistently throughout the whole dataset. Although these themes were kept under review as analysis progressed, they did not subsequently change throughout the rest of coding. A third researcher was available for discussion in the case of disagreement, but this was not required.

Stage 4: Developing an analytical framework

After coding the first 50 posts in the transcripts, the two researchers met to compare their findings from the coding stage and to agree codes that could be used to inform the analytical framework. Codes were grouped together into categories and diagrams were drawn to establish links between main and sub themes, which were then clearly defined. This formed a working analytical framework (Table 1) which was subsequently applied throughout the remaining transcript.

Table 1. Agreed themes for analytical framework.

Theme 1: Achieving person-centred holistic care
1.1 Choice
1.2 Outcomes
1.3 Information
1.4 Experiences
1.5 Relationships and Collaboration
1.6 Doing the right thing
Theme 2: Roles and diffusion of responsibility
2.1 Consistency
2.2 Hierarchy
2.3 Leadership and coordination
2.4 Advocacy
2.5 Boundary conflict and responsibility
2.6 Education
Theme 3: Challenges for Integrated Care
3.1 Resources
3.2 Continuity and responsibility
3.3 Shared vision
3.4 Lack of evidence
3.5 Lack of education
3.6 Ignorance/awareness

Stage 5: Applying the analytical framework

The analytical framework was then applied by indexing subsequent transcripts using the existing categories and codes.

Codes from the thematic framework were used to create thematic charts of data so that it was possible to view each theme across all respondents. With 850 posts, being able to manage and summarise data was a vital aspect of the analysis process. A spreadsheet was used to generate a matrix and the data were 'charted' into the matrix. Charting involved summarising the data by category from the transcript. The charts included references to interesting or illustrative quotations to help drive the data analysis. Regular meetings were held to make notes of impressions, ideas and early interpretations of the data. Throughout these meetings, characteristics of and differences between the data were identified, and typologies, theoretical concepts and mapping connections between categories to explore relationships.

Results

This study aimed to identify the views and experiences of Integrated Care for dementia from the perspective of carers and families of people with dementia, healthcare professionals and researchers. Three main themes emerged from the data: 'achieving person-centred holistic care', 'challenges of Integrated Care' and 'roles and diffusion of responsibility'. Due to the volume of data, this paper discusses the themes of 'achieving person-centred holistic care' and 'challenges of Integrated Care'.

Participants described their vision of what Integrated Care in relation to dementia should achieve in the future, and what its key features should be in order to best meet the needs of the person with dementia. The overall aim for Integrated Care is a holistic view of care that incorporates health and social care needs of the patient living with dementia. Integrated Care was seen as a more efficient approach to dementia care delivery, involving the coordination of seamless care provision where some roles or features become more pertinent at certain points in the individuals' care:

I believe a simple definition of integrated care would be the co-ordination of seamless care provision. Right patient – right care-right time.

– Clinical Nurse Specialist, Education Facilitator and Dementia Champion (Female, UK)

Many of the participants did not have direct experience of Integrated Care, but could see its potential for implementation within the current care system. Some participants had direct experience of Integrated Care with varying experiences of models and cultures.

The strength I see within integration is the holistic aim of appropriate care with all services working towards the same objectives and goals.

– Clinical Nurse Specialist, Education Facilitator and Dementia Champion (Female, UK)

Analogies were used by participants to describe Integrated Care as a complex, but coordinated system. They also provided examples of 'best in class' approaches to working which could be used to enhance team working:

I envision integrated care as being like a race crew, for example. As the car goes around it is monitored and when it comes in or is called in for a pit stop all that information is available to every member in the pit crew. Each person has a job and they work with everyone else to get the car back out in top shape in the shortest amount of time. There may be a pit boss who oversees different jobs being done concurrently to save time or in a certain sequence. Not everything will need to be done every time, sometimes just a tyre change or refuel, but whatever needs to be done is done and things aren't done twice.

– Registered Nurse (Male, Australia)

Integrated care works when there has been nothing before it, when starting from scratch either as an organisation or as an organism. Trying to pull two beasts together to mate and produce a perfect mix of both will take generations to perfect. Joint commissioning helps so long as the commissioner was not employed by either the NHS or the LA prior to taking up the role – which is pretty rare as you would want someone in that post with either of those experiences on their CVs.

– NHS Account Manager, Dementia Ambassador and a Dementia Friend (Male, UK)

Achieving holistic care for people with dementia was seen as the key aim for Integrated Care, with emphasis given to the concept that it is 'greater than the sum of its parts'. The goal of holistic care through integration was seen as greater than the aims of all the services and professionals in totality. Furthermore, participants saw Integrated Care as conferring

advantages because it potentially addresses the person with dementia's biopsychosocial needs (for example community, family influences) in contrast to the traditional biomedical approach. Participants described how the multidisciplinary approach to care integration for dementia encompasses far more than just treating symptoms:

Integrated care is looking at the picture holistically so that a proper approach could be formulated towards the resolution of a condition. While most professionals predominantly hold a medical view when it comes to a diagnosis of cases, having a variety of professionals who work together on a case could shed light to another factor that is not related to medical aspect. This cannot go amiss and will be determined if it is contributory to any condition and be given timely response.

– Carer of a family member with Dementia (Female, Philippines)

Participants recognised that the person with dementia's community and the people within it (including family, government and clubs in addition to health professionals) could play a strong role in influencing care planning. Under this view, Integrated Care is seen as broader than health and social care but also includes the community to retain the person-centred approach that dementia requires. This was seen as important in recognition that each person with dementia has unique needs as a result of symptom heterogeneity and different psychosocial support needs:

Integrated care involves the wider community which may include government, social clubs and various health professionals to be able to have a broader knowledge of the person as an individual.

– Carer of a family member with Dementia (Female, Australia)

Integrated Care puts the person first in care planning and not the disease (person-centred). Contributors recognised that person-centred is not the same as tailored care; however, both are needed for effective Integrated Care. Participants emphasised the importance of personalised tailored care in dementia; in particular, maintaining the person's identity and priorities was perceived as important.

Integrated care is holistic – that is, the person is at the centre, not the disease or disease processes. It encompasses the biological, social and psychosocial needs of the client. Multi professional teams are the core of integrated care, and a high degree of collaboration and communication between them is required. No one health profession has “all the answers”. By incorporating the skills of a variety of health professionals, we are better able to care for the whole person – and their families/carers. Connections between acute, sub-acute and community services should be delivered in a comprehensive way, and treatment plan developed, so that all agencies involved in the person's care are aware of what other support services are providing. This helps to limit overlap, and confusion.

– Registered Nurse in Residential Dementia Care (Female, Australia)

Effective care planning was seen as an integral part of achieving Integrated Care, with a need to establish reliable communication channels and record keeping. Participants acknowledged the need for continuity of care to facilitate interprofessional working:

The advantage is that the treatment plan is provided in a unified and co-operative manner. Ideally, the concept provides more seamless care of the client, which addresses all their needs, not just their biological needs. Success of integrated care depends heavily on well-developed inter professional communication. This is not always ideal. Record keeping, inter-agency transfers, hand-overs between agencies, and movements of patients between districts, States, or local government areas can all cause communication difficulties. When communication is poor, the care pathway breaks down and the client may be put at risk. Costs of care, to the client and the taxpayer, should be lower, but this is difficult to quantify. Agencies may be forced to limit their time with a client in their part of the integrated care pathway, and be encouraged to hand the patient on too quickly. We see this in Australia where, for financial reasons, clients may be discharged from acute care settings to sub-acute, to transitional care, and on to community care agencies too quickly. This can also be frustrating for nurses who do not get to spend the time they would like with the client before “handing them on”.

– Registered Nurse in Residential Dementia Care (Female, Australia)

In order to truly achieve person-centred care, participants highlighted the importance of involving the individual in all care planning decisions, whilst ensuring they are informed at all stages of formulating and implementing the care plan. This co-produced person-centred approach to Integrated Care recognises the importance of the person with dementia as navigators of their own care:

...believe that integrated care is when services work together collaboratively to support the person and their family through the life span of their illness. The strengths should be that It make the person feel as though they are at the centre of all decisions and that they are being treated as a person all along the way. The person with dementia and the carer should be kept in the loop the whole time and decisions only made with their full understanding and agreement.

– Carer of a family member with Dementia (Female, UK)

Integrated Care was viewed positively for being perceived as promoting a compassionate approach to care planning, with a shared responsibility across all professions who have a shared ultimate goal recognising holistic whole person individual tailored care. This was perceived as reflecting the individual needs of the patient whilst also being cognizant of the heterogeneity of dementia:

Integrated care is all about pulling or drawing together all of the appropriate services or facilities available to create a type of care that surpasses any one individual area. Integrated care benefits the patient greatly in that they are supported in lots of different ways by lots of different people. I think integrated care shows a lot more compassion to the patient. The idea that the illness or whatever it may be is a shared responsibility and by working together we can achieve better results.

– Professional carer in Dementia Care (Female, UK)

The multidisciplinary approach of Integrated Care confers advantages, as it utilises professional perspectives and expertise, which was perceived to offer a consolidated problem-solving approach (e.g. for formulating diagnosis or solutions to social care issues); thus, potentially offering more options for a tailored individualised care package for people with dementia. It was recognised that with multiple parties, services and agendas involved in care integration, the role of coordinator is vital in acting as a navigator of care for the individual with dementia.

Integrated care is being able to provide a holistic approach to the person's needs which includes all formal diagnoses and takes into account the person's social background and the psychosocial care that is required to support the treatment and management of the identified diagnoses and particular issues affecting the person. Integrated care is coordinated, streamlined service provision to best meet the person's needs and situation. Strengths of integrated care approach include coordinated, holistic care, which is provided in a streamlined, efficient way, and provides the client and their carer/s with a less confusing system of care providers and care systems. Limitations of integrated care may include less specialized practitioners, the costs involved in bringing all health services on board and the ability to effectively coordinate a number of health service providers.

– Professional carer in Dementia Care (Female, Australia)

Participants acknowledged that close cross-team continuity and multidisciplinary working could achieve patient-centred care, through teams working together collaboratively with the person with dementia and their carer as navigators of their care.

It is about all healthcare teams coming together and working collaboratively and flexibly, with the service user/patient at the centre and focus of all care provided. It is about continuity of care and for all healthcare teams to have access to all the information relating to the service user/patient rather than that information being fragmented and so preventing repeating of information by the service user/patient every time they are seen. This should therefore prevent duplication and poor treatment plans. To make Integrated Care a positive outcome will rely on good communication skills and record keeping and for everyone involved in providing care to understand their roles and that of each other, as all roles are as important as each other, and so avoid the hierarchical situations that could damage the focus of care and prevent the individualised care that is so important. Sadly funding and resources available will have an impact on how effective Integrated Care will truly be.

– Professional carer in End of Life Care and carer for a family member with dementia (Female, UK)

Therefore, the coordinator role in Integrated Care was seen as ensuring a seamless flow of information and care planning across teams and care boundaries. Participants warned of silos between professionals and the need to break down such barriers to achieve Integrated Care. This would be an interesting area for future exploration to examine what causes silos in interprofessional working and how these can be improved.

True integrated care should involve a seamless flow between medical specialties, nursing teams, health and social care, along with associated administrative and managerial support. A service that has this structure will allow for a more holistic approach to caring for a patient, rather than silo working that is often commonplace. On the contrary, these silos are sometimes required to create “pockets of excellence”, however they are of no use if other services involved in that patient’s care cannot access them.

– Doctor in Old Age Psychiatry (Male, UK)

Whilst the shared goal and vision for the evolution of Integrated Care was agreed, it was acknowledged that Integrated Care is seen as the solution to ‘over-professionalization’. Over-professionalisation was seen as a symptom of professionals working in silos in order to protect their discipline from funding cuts, and that this could cause care boundary and role conflicts which could impact negatively on what Integrated Care seeks to achieve.

I believe integrated care to be an effective response to the holistic needs of individuals. All forms of reductionist thinking, which seek to break down issues into component parts, do not take account of the fact that the whole is greater than its parts. Over specialisation has caused us many problems and creates a need to put things back together. Holistic practice is essential since we present ourselves as a whole. Integrated care is the only way forward, but it needs everyone on board to believe in it and sign up to it. Funders use the weakness caused by inter-professional rivalries to divide and conquer. Integrated care is a response to bottom-up thinking, which is naturally integrated as people do not think in the artificial boxes that professionals try to create.

– Retired Healthcare Professional (Male, UK)

Although most of the participants were in support of universal establishment of Integrated Care for dementia in principle, there was some concern that Integrated Care could create artificial barriers between sub-specialisms and care boundaries.

Integrated care is a response to bottom-up thinking, which is naturally integrated as people do not think in the artificial boxes that professionals try to create.

– Retired Healthcare Professional (Male, UK)

Whilst Integrated Care is a relatively recent development, it is not a revolution but rather an evolution as a response to inter- and trans-professional working. Inter- and trans-professional working are arguably a product of silos and over professionalisation and the emergence of sub specialisms. Silos are created by each sub specialism striving to protect resources, self-justify and protect funding.

Participants argued strongly that the biggest barrier to establishing and implementing Integrated Care systems for dementia was the lack of financial support and resources attached. This was attributed to the lack of focus on Integrated Care at a time when competing demands for the same funds and resources was high due to scarcity:

No matter where in the world you are, funding is always the issue to hand. That is until some celebrity or politician is personally affected and the light is shone on the topic of Dementia. Unless people are touched by dementia in some way, they simply do not understand the constraints and their impact. It is exhausting fighting for funds all the time.

– Registered Nurse and carer of a family member with dementia (Female, Australia)

Furthermore, the division of health and social care systems was thought to contribute to the lack of resources available for Integrated Care with each system having its own systems and parties. It was recognised that although there is a strong case for the benefits of Integrated Care for dementia, there are challenges that require resolving before it can be rolled out more widely.

Having a Health and Social care system as two separate entities creates funding issues as well as duplicating many processes. It is not possible to neatly separate an individual into these two aspects so being able to deal holistically with the needs of an individual can be a great strength. However, having many different agencies involved could be complicated because they all have their own processes and there could be confusion about whose funding something will be paid from. A question will also be who will lead on care and decisions. My opinion is that it is definitely a move in the right direction but there will be many challenges to make this a smooth process in practice.

– Lay person with “little personal experience of dementia” (Female, UK)

Discussion

Integrated Care has been a subject of extensive policy, which was seen by participants as being justified, although they did not focus on policy, guidelines or law; instead focusing on practical and useful ways of working. When discussing challenges for Integrated Care they also focused on practicalities, rather than themes such as multi-morbidity or complexity of care. Participants were supportive of all healthcare professionals being involved in care provision, rather than focusing on a particular role or group as advocated by The Prime Minister’s dementia challenge (Department of Health, 2015b). Participants advocated a community of professionals, families and carers. They acknowledged the role of organisations such as the Alzheimer’s Society and although they acknowledged the existence of silos, however, discussion focused more on the relationship between the person, their carers and their healthcare professionals.

MOOCs can provide a platform for social change and this space has great potential for opportunities for internet-mediated research (Robertshaw & Cross, 2016), as opinions and experiences from a wide range of participants from hard to reach groups can be accessed through this platform. There are some significant limitations of MOOCs and research in this context, the most challenging being the lack of opportunity to follow-up and probe interesting points. The data collected were rich in terms of diverse topics, but lack the data rigour and depth of more traditional qualitative data methods. Future research using MOOC data should consider additional follow-up interviews or focus groups.

Another methodological flaw is the potential ‘group think’ by virtue of the participants being able to review other responses. AQIIT is possible there was confirmation bias on the issue of funding where a number of participants raised similar issues which may have been a result of reflecting on other responses. Despite this, the wide range of participants resulted in a diverse perspective on Integrated Care and dementia which adds strength. The large data set provided logistical issues but promotes both individual dialogue and collective international perspective. An advantage of this platform is that participants are guaranteed anonymity which permits them to be completely open. The asynchronous nature of discussion boards allows conversations to continue for extended periods and permits deeper reflection on the issues which arise.

We collected data on participants’ level of qualification, location, gender and age group; however, it was only possible to collect free-text data in relation roles and functions which limits direct comparison. Also, the study did not directly collect data about which participants had dementia or who was a carer, although where these data were missing, in the majority of cases, it was possible to ascertain this information from discussion board posts.

Participants were from different locations; 45% were from Western Europe and 23% Australia and the South Pacific which are similar healthcare systems and therefore allow direct comparison. However, the remaining 32% were from a wide range of countries which are less similar and therefore comparison is difficult. One of the advantages of learning online was the opportunity for participants to share experiences of their healthcare systems and to draw comparisons.

Conclusion

This paper has presented the experiences of Integrated Care from the perspective of carers and families with dementia, healthcare professionals and researchers who participated in a massive open online course on dementia. Participants described how Integrated Care for dementia should be person-centred and holistic, involving the wider multidisciplinary team. Despite the acknowledgement that health and social care services are becoming increasingly fragmented, participants viewed the establishment of Integrated Care for dementia as positive overall.

Participants clearly identified a number of recommendations for Integrated Care: these involve utilising the whole community of professionals and family, keeping the person at the centre, maintaining clear lines of communication and the integration of health and social care. Communication was consistently mentioned, and this is one of the most im-

portant drivers to achieve person-centred Integrated Care in dementia. This paper recommends further research to characterise the experiences of Integrated Care for people living with dementia and their carers.

Acknowledgements

We gratefully acknowledge the support and encouragement during the preparation of this paper from Professor Kath Mitchell, Professor Dawn Forman and Professor Chris Brannigan.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

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David Robertshaw is a registered nurse and registered nurse teacher, Fellow of the Higher Education Academy, Fellow of the Royal Society for Public Health and holds a BA (Hons) in Nursing and an MSc in Critical Care. He is currently the programme leader for FDsc Nursing Associate at the University of Derby and designed, developed and delivered the University of Derby's first massive open online course on Dementia between 2015 and 2017.

Ainslea Cross is a chartered psychologist, Associate Fellow of the British Psychology Society and Senior Fellow of the Higher Education Academy. She holds a BSc (Hons) in Psychology and an MSc in Health Psychology and has held a variety of teaching and research roles throughout the UK. Her current research interests include experiences of health care services and self-management, health behaviour change and psycho-oncology.

AUTHOR QUERIES

Query: AQ1 Please check whether the sentence 'It is possible there was confirmation bias on the...' is correct as given.

Response: Replace 'IT' with 'It'

Query: AQ2 Please provide text citation for the following reference: Brooker (2004).

Response: This should be 2003. <https://www.cambridge.org/core/journals/reviews-in-clinical-gerontology/article/what-is-person-centred-care-in-dementia/05526FC63B5923B299DEB2D8A57BCDC8>

Query: AQ3 Please provide URL for the following reference: Hansard. (1962)

Response: <http://hansard.millbanksystems.com/lords/1962/feb/14/the-hospital-plan>

Query: AQ4 Please provide volume and page range for the following reference: Kupeli et al., 2016

Response: <http://journals.sagepub.com/doi/abs/10.1177/1471301216636302> 0(0) 1–16

Query: AQ5 Please provide text citation for the following reference: Ritchie and Lewis (2003)

Response: Please remove - no in-text citation. This is a legacy reference.

Query: AQ6 Please provide the place where the proceedings was held and also the publisher details

Response: EMOOCs 2016, Graz Books on Demand GmbH, Norderstedt