‘Bridging the Dementia Divide: the contribution of a Massive Open Online Course on Dementia to dementia care and pedagogy’

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CONTENTS

List of abbreviations

API	Application Programming Interface
ARK	Access Research Knowledge, Northern Ireland’s social policy hub
BTDD	Bridging the Dementia Divide
cMOOC	connectivist Massive Open Online Course
COVID-19	Corona Virus Disease 2019 (the viral cause of the 2020 global pandemic)
DH	Department of Health
EMOOCS	European Massive Open Online Course Stakeholders Summit
EU	European Union
EURODL	European Journal of Open, Distance and E-Learning
FTD	Frontotemporal Dementia
HEA	Higher Education Academy
HEE	Health Education England
IT	Information Technology
LBD	Lewy Body Dementia
LIWC	Linguistic Inquiry and Word Count
MOOC	Massive Open Online Course
NHS	National Health Service

ONS	Office for National Statistics
TAGS	Twitter Archiving Google Spreadsheet
TED	Technology, Entertainment and Design (a conference first commenced in 1984)
TEDx	Technology, Entertainment and Design conferences held in local or regional venues, which share ideas and the latest research
UK	United Kingdom
USA	United States of America
WHO	World Health Organisation
xMOOC	eXtended Massive Open Online Course

Preface

This critical appraisal is original and contains independent work by the author, David Robertshaw.

The published works contain original works by the author, David Robertshaw, as well as co-authored works as named in the publications. The contribution of each author is acknowledged in attribution forms in the appendices.

Throughout this appraisal, references are made to “the author”, “the facilitator”, “the researcher”, and “the instructor”. These are references to David Robertshaw, who developed and designed Bridging the Dementia Divide.

Abstract

Dementia is one of the most important global health issues of our time due to its impact on both individuals and society. This thesis spans a 6-year programme of research and scholarship focused on developing an open platform for people to develop an understanding of the symptoms, progression, and caring needs of living with dementia with the intention that it would change their attitudes and perceptions of dementia. The vehicle for this project was a massive open online course (MOOC), known as “Bridging the Dementia Divide” (BTDD). The research and findings from BTDD were analysed, evaluated, and disseminated through ten published works consisting of the BTDD MOOC itself which has been studied more than 10,000 times, a TED talk which has been viewed more than 1,800 times, seven articles published in peer-reviewed journals and one chapter.

This body of work developed organically over time and involved an iterative methodological process. These works were driven by a pragmatic and reflexive approach to the work and research. This body of work has always had in mind the potential benefit to the end-user, service users, the public, professionals, patients, and people living with dementia. Because of this, specific aims were not set in the beginning but were developed iteratively over a period of five years. The initial aims and purposes of these works were to inform people about dementia and to make a difference to the lives of people living with dementia and their carers. The project then grew and developed into the development of the MOOC itself and resulted in the subsequent research surrounding it. The aims of the publications were developed in response to the developing research programme’s aims. The resulting aims of this thesis were: to conceptualise and implement a MOOC on dementia, to generate new knowledge pertaining to attitudes and perceptions and the lived experience of dementia within online fora; to evaluate the MOOC as a change intervention within the context of dementia and to discern the impact of dissemination of research findings for implementation in practice and pedagogy. This body of work was researched from a pragmatist paradigm.

This critical appraisal used Rolfe’s (2001) reflective model of “what, so what, now what” to consider the published works themselves, their impact, and requirements for

future research. Research originating from BTDD has contributed to dementia care by providing educational experiences, describing the experiences of integrated care from the perspectives of carers and family members with dementia, as well as identifying the roles and responsibilities people and organisations play. BTDD made a difference in participants’ attitudes towards and perceptions of dementia. The findings from BTDD have influenced University policy, practice, and programmes and as importantly the research and publications included in this thesis have influenced national and international research projects.

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Chapter 1: Introduction

“Personally, I'm terrified of it and don't want my children ever watch me ‘disappearing’ if I'm ever diagnosed with dementia. It's a terrible hopeless disease. Losing control over your life, body, nor remembering, not being able to decide…I'll certainly make advance care plans/decisions if I'm ever diagnosed.”

Bridging the Dementia Divide participant

One of the most important global health issues of our time, dementia has a large impact on both individuals and society (World Organisation [WHO], 2019). Dementia encapsulates significant human emotions especially due to loss of ourselves and our memories, loss of independence and freedom. It has been described as a “living death” (Freegard, Pond, and Forman, 2015). Although temporarily overtaken by COVID-19 in 2020, Dementia is a leading cause of death in the UK, accounting for 12% of all deaths in 2016 (Office for National Statistics, 2017). Dementia continues to affect millions of people worldwide (Prince, Bryce, and Ferr, 2011) and the focus on dementia has intensified over the last decade (Phillipson et al., 2012).

Dementia is an ‘umbrella’ term describing a complex syndrome of more than 400 diseases with an associated decline in function, memory, reasoning, and communication skills often resulting in behavioural and psychological symptoms, which complicate care (Department of Health, 2009, Health Service Executive, 2020). Recent research has provided a clearer understanding of the biological and genomic bases for some of the diseases under the umbrella of dementia, leading to some effective treatments (Harvey, Skelton-Robinson and Rossor, 2003; Rocca et al., 2014; Flicker and Ames, 2005; Matioli et al., 2017; McNamara et al., 2016; Garcia-Ptacek et al., 2016; Taylor et al., 2020). Worldwide, approximately 50 million people are living with dementia. Around 60% of these people live in low- or middle-income countries, and there are around 10 million new cases diagnosed each year. This number is projected to reach around 82 million in 2030, and 152 million by 2050 (World Health Organisation, 2020). In 2014 the projected number of people diagnosed with dementia in the UK overall in 2021 was estimated to be around 1 million people (Prince et al., 2014). NHS Digital (2021), as of 31st January 2021, recorded 429,858 people in England with a coded diagnosis of dementia. This number has decreased by 8,503 since 31st December 2020 which could be either as a result of deaths, or a delay in diagnosis. The diagnosis rate for people aged over 65 is estimated to be 61.4% (NHS Digital, 2021) meaning many go undiagnosed for a significant amount of time. In high-income countries, only 20-50% of cases are recognised, diagnosed, and documented in primary care. In some low- and middle-income countries, this number has been estimated as low as 10%. It is believed approximately 75% of people living with dementia have not received a diagnosis and therefore do not have access to treatment, resources, advice, support, help, or care (Alzheimer’s Disease International, 2015).

In 2015 the overall economic cost worldwide of dementia was estimated to be $818 billion (Alzheimer’s Disease International, 2015), or approximately 1.09% of global gross domestic product. The estimated annual cost in 2021 is more than $1 trillion (Alzheimer’s Disease International, 2021). There is a growing number of people living with dementia in developing countries, and it is likely these growing cases will account for the majority of new diagnoses going forwards.

Dementia is one of the foremost causes of disability and dependency in our world (World Health Organisation [WHO], 2017; World Health Organisation [WHO], 2018). There are significant physical, psychological, social, and economic impacts on people living with dementia, their carers, their families, and society at large (Brown, Hansnata, and La, 2017; Wimo et al., 2013). Dementia was previously observed through a biomedical lens; however, the perspective of dementia is now broadening (Cahill, 2018). People living with dementia have persistently been denied basic rights and freedoms (Kelly and Innes, 2013; Boyle, 2010; Cahill, 2018). Physical and chemical restraints have been used regularly (Wang and Moyle, 2005; WHO 2019) and people living with dementia are often not able to have the freedom, choice, and independence they not only deserve but are legally entitled to (Human Rights Act 1998). Stigma, a process whereby people are negatively labelled, lose status and power, are discriminated against, and are stereotyped (Link and Phelan, 2001; Swaffer, 2014) is a persistent issue arising from prejudicial perspectives and viewpoints. It adversely affects diagnosis, access to support, the standard of care, quality of life, and wellbeing (Swaffer, 2014; Phillipson et al, 2012). Societal attitudes towards dementia present a significant challenge, and there is a stigma attached to a diagnosis of dementia: people living with dementia do not receive the same support, interventions, or funding as people with other conditions (Swaffer, 2014). There is a “dementia divide”: a chasm between how people living with dementia are treated when compared with “normal” people concerning autonomy, freedom, choice, independence, respect, access to services, treatment, behaviour, language, support, finances, and just generally being a human being (Kane, Murphy and Kelly, 2020; Kontos et al., 2020; Bhatt et al., 2020).

UK Government and international policies have encouraged sustained international collaborative effort to achieve impact and change for people living with dementia (World Health Organization and Alzheimer’s Disease International, 2012). In 2015 the Prime Minister, David Cameron, challenged the United Kingdom to be the best country in the world for dementia care, and the best place in the world for people to undertake research into dementia by 2020 (Department of Health, 2015).

Responding to challenges: “Bridging the Dementia Divide” (BTDD)

In 2014, in response to these challenges, issues, and policy, I began a programme of research and scholarship. Its purpose was to develop an open platform for people to learn about dementia with the intention that it would change their attitudes and perceptions of dementia. The ‘vehicle’ for this project was a massive open online course (MOOC), known as “Bridging the Dementia Divide” (BTDD). A massive open online course (MOOC) is an ‘entity’ that is large (**m**assive), open to any who wish to study it (**o**pen), online and accessible through the internet (**o**nline) and is a programme or course (**c**ourse). Part of the Open Educational Resource (OER) movement although often contradictory to it, MOOCs are very large with many thousands of learners. Openness relates to the use of open-source software, open curriculum, open sources of information and open assessment processes (Rodriguez, 2012), compared with Small Private Online Courses (SPOCs) which are often delivered by Universities and training organisations with very small numbers of participants (Ding and Zhao, 2020; Ibrahim et al., 2020; Pisoni et al. 2020, Wang et al., 2020), MOOCs often have up to 300,000 participants. The biggest MOOC had over 1.1 million participants (Online Course Report, 2020). MOOCs have become a popular way of learning, providing open University-level education for free (Milligan and Littlejohn, 2017). There are many MOOCs on various topics, with varying styles or approaches are dependent upon the instructor, the institution, the platform, and the topic (Reich and Ruipérez-Valiente, 2019).

Education is a key enabler for supporting people living with dementia (Surr et al., 2017). Dementia education is widely available at different levels (Surr and Gates, 2017) however the impact of the education is questionable (Surr et al., 2017). The Dementia Core Skills Education and Training Framework identified three tiers of training: tier 1, awareness training aimed at all members of society; tier 2, aimed at people working daily or regularly with people living with dementia; and tier 3, aimed at people leading services for people living with dementia (Skills for Health, Health Education England and Skills for Care, 2015; Surr and Gates, 2017). The framework identifies content for each tier with specific learning outcomes associated with each group of individuals. Benbow et al. (2011) consulted with people living with dementia and their carers to identify knowledge and understanding required in dementia care workers. Their study found six themes: knowledge about dementia, person-centred care, communication, relationships, support, and helping people engage in activities: themes correlating with the framework. Surr and Gates (2017) conducted a review of existing training courses for Health Education England in the ‘What Works’ study and found that on average only 73% of courses fully met the learning outcomes for their level. This does mean that some courses were fully comprehensive, however other courses may have had a much lower coverage. BTDD was not reviewed as part of Surr and Gates’ (2017) exercise, however, BTDD covers 100% of the tier 1 framework requirements, and varying amounts of tier 2 and tier 3 requirements (table 1).

Table 1: Dementia core skills education and training framework mapping tool for BTDD (Surr and Gates, 2017)

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Name of training programme: Bridging the Dementia Divide	Percentage of learning outcomes met fully, partially, or not at all								
Subject area	Tier/ Group 1 Yes	Tier/ Group 1 Partially	Tier/ Group 1 No	Tier/ Group 2 Yes	Tier/ Group 2 Partially	Tier/ Group 2 No	Tier 3/Group 3 & 4* Yes	Tier 3/Group 3 & 4* Partially	Tier 3/Group 3 & 4* No
1. Dementia Awareness	100	0	0						
2. Dementia identification, assessment and diagnosis				71	29	0	33	17	50
3. Dementia risk reduction and prevention				100	0	0	40	40	20
4. Person-centred care				100	0	0	100	0	0
5. Communication, interaction and behaviour in dementia care				100	0	0	100	0	0
6. Health and well-being in dementia care				43	50	7	17	17	67
7. Pharmacological interventions in dementia care				0	20	80	0	0	100
8. Living well with dementia and promoting independence				69	23	8	40	0	60
9. Families and carers as partners in dementia care				100	0	0	33	67	0
10. Equality diversity and inclusion in dementia care				100	0	0	100	0	0
11. Law, ethics and safeguarding in dementia care				67	33	0	14	43	43
12. End of life dementia care				50	50	0	67	33	0
13. Research and evidence-based practice in dementia care				0	67	33	17	33	50
14. Leadership in transforming dementia care							0	40	60

*Tier 3/Group 3 & 4 column covers only the additional learning outcomes for that level. For coverage of all Tier 3/Group 3 & 4 learning outcomes, the columns for Tier/Group 2 and Tier 3/Group 3 & 4 should be combined

Citation: Surr, C. (2018) Dementia Training Standards Framework: Learning Outcomes Mapping Tool v3.0. Leeds: Leeds Beckett University.

There has been large variability in the quality, type and content of education programmes and they often focus on theoretical knowledge, with limitation application of this (Surr et al., 2017). BTDD was designed as a solution-focussed education tool to bring about a step-change for people living with dementia care by sharing the knowledge, theory, and practice of dementia care with everyone. BTDD focussed on the impact of diseases under the umbrella of dementia on people themselves, the social and economic impact, the impact on human rights, and the impact on stigma (WHO, 2019).

A history of MOOCs

The rise of MOOCs was rapid. The term was first used in 2008 to describe a course entitled ‘Constructivism and Connective Knowledge’, and shortly thereafter a course entitled ‘Introduction to Artificial Intelligence’ at Stanford (Rosewell and Jansen, 2014). However, the concept of a MOOC itself is not new, and this type of learning has roots in distance learning, an approach that has a long history (for example, education provided by the Open University [Harting and Erthal, 2005]). Although they have been in existence since 2008, MOOCs began their trajectory towards prominence in 2014/15. More than 800 Universities currently deliver MOOCs to 81 million students across over 9400 courses (Shah, 2018). In 2018, MOOCs in health and medicine accounted for 7.2% of those available (Shah 2018). MOOCs are a type of online learning, which is also known as computer-based instruction. This involves learning undertaken inside a virtual learning environment and can vary from basic e-learning where individuals progress through screens offering a limited learning experience to University-accredited degree courses with deep and social learning (Knight and Price, 2016).

In 2019 there were signs that interest in MOOCs may have been declining (Reich and Ruiperez-Valiente, 2019) however the COVID-19 pandemic of 2020 proved the use and value of MOOCs to quickly disseminate essential information to key groups. During the COVID-19 pandemic, FutureLearn delivered at least 16 MOOCs on COVID-19 (FutureLearn, 2020), Coursera delivered at least 10 (Coursera, 2020) and EdX delivered four (EdX, 2020). eLearning for Healthcare, the Health Education England programme, used its platform to deliver at least 14 MOOC-like courses on essential topics from personal protective equipment to critical care equipment guides (Health Education England, 2020). This demonstrates the value of MOOCs as a way of broadcasting important information to users reliably and rapidly at scale.

MOOCs as a platform for research

Since their inception in 2008, MOOCs have been an area of exploration and research for investigators. Earlier MOOC research tended to evaluate theories and models of MOOCs: examining microlearning, learner characteristics, interaction and communication in learning communities, assessment and accreditation, social interaction, and learning analytics (Bozkurt, Akgün-Özbek, and Zawacki-Richter, 2017; Kennedy, 2014; Sa'don, Alias and Ohshima, 2014; Sangrà, González-Sanmamed, and Anderson, 2015; Diver and Martinez, 2015). This earlier research focused more on the type and style of MOOCs and was small-scale focusing on experimentation with users, learner journeys, assessments, and interactions. Ebben and Murphy (2014) examined 25 publications and found an earlier phase of research focusing on cMOOCs (those focused on a connective approach encouraging social learning and interaction) and a later phase of research focusing on xMOOCs (based more on a traditional University course or programme). This is interesting because MOOCs were originally posited as connected, social environments where users could learn from each other (Siemens, 2004) however the results were more like traditional courses/programmes: probably because it is easier to prepare and deliver a MOOC replicating existing teaching material and content. It is disappointing the connected social learning of earlier MOOCs has not persisted, although social learning and interactions do still exist in MOOCs today. It is possible earlier notions may have been too experimental or idealistic, with later educators favouring more practical, pragmatic ways of delivering MOOCs (Bozkurt, Akgün-Özbek, and Zawacki-Richter, 2017). Conceptually, earlier approaches were often system- or MOOC-centric rather than being participant centric. Approaches to teaching and learning need to change as time moves on; generations have different needs, desires, and expectations of their education (Hampton and Keys, 2017) and these changes are welcomed.

Later studies have focused more on quality assurance and the wider implications of MOOCs however management, organisation, access, equity, and ethical aspects of MOOCs are still emerging areas of research (Bozkurt, Akgün-Özbek, and Zawacki-Richter, 2017). Learner interactions, learner dropout, learner behaviour and completion are still current areas of research and inquiry (Moreno-Marcos, 2019). It is positive that MOOCs are still being used as a platform for research, testing and experimentation.

Veletsianos and Shepherdson (2015) examined the authors of MOOC research and found education and computer science researchers were most prevalent, however much of the published research was interdisciplinary. Research has tended to consist of theoretical studies, case studies or examples of MOOCs and has not generally focussed on the underlying philosophies of MOOC research (Raffaghelli, Cucchiara, and Persico, 2015). Most MOOC research has originated from Europe and North America (Veletsianos and Shepherdson, 2016). Researcher perspectives of MOOCs, therefore, may not be representative of institutions, researchers, or MOOCs in all regions.

Recent research in MOOCs has adopted more novel approaches and focused on specific applications of MOOCs. Sein-Echaluce Lacleta et al. (2016) proposed a MOOC model which could intelligently change the course’s pathway and direction during the MOOC’s run dependent upon learner needs, issue individualised certificates and provide automatic feedback. This approach was interesting, however, their research focused on teaching and learning methods of the MOOC and this has been an area of research consistently since the early development of MOOCs (Zhu et al., 2020). Zimmerman, Kopp and Ebner (2016) developed the ‘Dr Internet’ project aiming to evaluate how people use the internet to answer medical problems. This research examined the patient-doctor interaction to understand patient behaviour and found that a MOOC could be employed for this because they provide simple and convenient ways of collecting data as well as present innovative options for testing on a large scale. This approach allowed testing of a novel technique in a safe environment or testing “in the wild” (Rooksby, Rouncefield, and Sommerville (2009), which permits experimentation, learning, and subsequent application to a controlled environment.

Zimmerman, Kopp, and Ebner (2016) considered the validity of research used in MOOCs. They believed general characteristics of MOOC participants may be different from the general population therefore making generalisations becomes difficult. Reich (2015) has also argued this perspective, saying that big data sets do not, because of their size, always give us answers to interesting questions. Applying the principles of pragmatism (the paradigm through which this thesis was conducted), means Reich’s

(2015) and Zimmerman, Kopp, and Ebner’s (2016) judgements have less value because pragmatists argue it is actions, values, and outcomes which matter in pragmatism rather than being concerned with complex concepts such as reality or truth (Kaushik and Walsh, 2019). Generalisations are still useful because they originate from constructed knowledge (Morgan, 2014).

MOOCs as a platform for social learning

MOOCs, by virtue of their design, are social learning environments (Anderson, Gifford and Wildman, 2020) because they use applied, informal, social, and generative learning systems (Egloffstein and Ifenthaler, 2017). BTDD and MOOCs generally are designed to be cognizant of Siemens’ (2004) theory of connectivism as well as Bandura’s social learning theory (Bandura, 1977). Connectivism and social learning theory are rooted in Vygotsky’s principles of constructivism whereby learners construct new knowledge together in networks (Vygotsky, 1978). Fidalgo-Blanco et al. (2014) felt that social learning was essential in MOOCs to develop experience and knowledge. Their study referred to ‘socialmaterial’ (the platform, pedagogical factors, learner agency – the decisions participants make) finding the most important factor in learner completion was related to the platform features rather than levels of interaction, which seems at odds with the aims of MOOCs which favour social learning and interaction over the environment. These findings have also been echoed by Tubman, Oztok, and Benachour (2016) in their sociocultural analysis of the FutureLearn MOOC platform. Anderson, Gifford, and Wildman (2020) felt that cognitive and behavioural outcomes were only able to partly explain learner outcomes. Rosé and Ferschke (2016) said the lack of social interaction in MOOCs was often a shortcoming and contributed to some of the issues around learner success in MOOCs. This is an interesting juxtaposition and identifies the link between the platform’s design and how it promotes social learning. Interactions are very important areas of MOOCs and online learning more generally (Trentin, 2000). Khalil and Ebner (2013a; 2013b) suggested that increasing interactions may be a suitable method of increasing learner completion and learner satisfaction. Involving participants in their learning happens because of the social and active process of communication (Motschnik and Holzinger, 2002; Andrews, Preece and Turoff, 2002) so this is inevitable.

Brinton et al.'s (2016) work focused on the development of social learning networks in MOOCs. These form when users share and exchange information during activities and interactions. Recent work has been focused on segmenting or partitioning users by their activity and interaction, and Wise, Chui and Jin (2017) suggested partitioning learners to build smaller individual social networks within MOOCs. They proposed that educators could then identify active participants within these networks to act as facilitators. This system also allows the identification of participants who are not engaging or who require assistance. Participants who wish to consume the content only, and not participate socially, could also do this. Some research has been focused on using social media alongside MOOCs: Egloffstein and Ifenthaler (2017) found this increased social interaction and participation and this method could be used alongside Wise, Chui and Jin's (2017) ideas of 'partitions'.

MOOCs ultimately provide a social learning network that exists because participants exchange and share information, and there are structured interactions within the community. Research on social learning within MOOCs is still emerging, however, some authors are now trying to pre-determine or model how participants will progress through MOOCs (Wang et al., 2015). Anderson, Gifford, and Wildman (2020) found that social learning is a particularly strong tool to develop and implement attitudinal or 'affective' learner outcomes.

MOOCs as a platform for social change

Attempting to answer human problems is recognised as a very difficult area of research because defining these problems, identifying their causes, and reaching possible solutions are complex (Stull, 2019). Social change is a way of addressing human problems, and this is an objective of a range of disciplines (Watson et al. 2016a). There is robust evidence for facilitation methods in the online learning environment (Moore, 2002; Salmon, 2009; Salmon, 2013) however there is less evidence for online facilitation of social change. Lee's (2017) study examined the facilitator's role in facilitating change as part of her animal and behaviour welfare MOOC. She found that instructors needed to be present, engaged, social, interactive, and collaborative.

There are limited examples of using MOOCs as platforms for social change. Watson, Kim and Watson (2016) have delivered a range of MOOCs aimed specifically at examining and changing participant attitudes (MOOCs on the Ethics of Eating, Science of Happiness, Journalism for Social Change, and Animal Behaviour and Welfare) (Watson et al., 2016a; Watson et al., 2016b; Watson, Kim and Watson, 2016). These MOOCs were designed to have attitudinal change built-in (this was the same approach in BTDD). Their approach focused on deliberate facilitation and creating dissonance by presenting media to evoke emotional responses and therefore change learner attitudes, an approach suggested by Simonson and Maushak (1996), Kamradt and Kamradt (1999) and Simonson (1979). Providing new information establishes a mind that is receptive and can be changed (Bodenhausen and Gawronski, 2013). Watson et al.’s (2016a; 2016b) work was cognizant of the three components of attitudes: cognitive, affective and behavioural aspects (Kamradt and Kamradt, 1999; Simonson, 1979) and their MOOCs attempted to tackle every component.

Hudson et al. (2019) undertook a MOOC on smart cities to address attitudinal change. They reported high levels of attitudinal change and inspired people to take up voluntary work or further study however only a small number of participants became more interested in engaging with smart cities. They believed that MOOCs could be a useful tool to support attitudinal and social change, because the environment provides an opportunity to “scaffold knowledge as the community learn together, with opportunities for critical reflection” (Hudson et al., 2019). However, further research to consider how learning materials turn learning into action is required.

MOOCs disseminate knowledge. However, very few MOOCs are intentionally designed to elicit social change within any of the three attitudinal domains (cognitive, affective, and behavioural). It could be the case that some MOOCs provoke an adverse response in attitudes, rather than a positive one. These adverse responses could be observed if a MOOC designer is not consciously aware of these possibilities or is not cognizant of MOOC design approaches to elicit change (Stibe and Cugelman, 2016).

MOOCs have been used to collect data to bring new insights about social issues needing change (McInerney et al, 2018; Annear, Eccleston and McInerney, 2016;

Rawlings, Tieman and Sanderson, 2017; Ramchandran, Fronk and Passaglia, 2016) There are only a very small number of MOOCs and extant research exploring attitudinal change effects in MOOCs where these have been designed to perform this change (Watson et al., 2016a; Watson et al., 2016b; Watson, Kim and Watson, 2016). The Understanding Dementia MOOC (Wicking Dementia Research and Education Centre, 2020) has been used to examine quality (King et al., 2015), completion and learner behaviour (Goldberg et al., 2015; Kelder et al. 2013), levels of dementia knowledge (Annear et al., 2016; Eccleston et al., 2019), and for McInerney et al.’s (2018) study about palliative care in the context of dementia. Farrow et al.’s (2018) study asked participants how they had applied knowledge and identified themes in the data, however, their conclusions were based on participant feedback and they did not conduct a pre-post survey comparison.

These are early examples of MOOCs as a social change intervention; however, this prior research has often been based on topics, ideas, concepts, and feedback rather than measurement or intentional design for change.

Dementia knowledge

Dementia knowledge has been the subject of investigation since at least the 1980s (Sutcliffe and Larner, 1988). Dementia knowledge is often assessed by a variety of scales and tools including the Alzheimer’s Disease Knowledge Scale (a 30-item questionnaire measuring what people know about Alzheimer’s Disease) (Carpenter et al., 2015; Sullivan and Mullan, 2017), the Dementia Care Attitude Scale (an 8 item tool measuring attitudes towards dementia) (Wang, Xiao, and He, 2015), the Approach to Dementia Care Questionnaire (a scenario-based tool containing 13 items which determine whether someone has a person-centred approach or reality-oriented approach (Wang et al., 2018; Normann, Asplund, and Norberg, 1998), and the Dementia Attitudes Scale (a 20-question scale which adopts a two-factor structure, with factors labelled dementia knowledge or social comfort) (O’Connor and McFadden, 2010). Knowledge and experience of dementia have been the focus of a variety of research projects which have focused on specific groups for example carers, students, and healthcare professionals.

This section has reviewed 31 publications related to dementia knowledge. Studies involving carers have found there is a high amount of knowledge and experience of dementia among this group. Quinn et al.’s (2020) cohort study demonstrated that lower quality of life ratings by a person with dementia was associated with higher care stress. They also found similar associations with life satisfaction and wellbeing: the positive aspects of being a carer were not associated with outcomes for the person with dementia. Carers have generally experienced a lack of informal support and had low confidence when requesting help. They have also reported adverse effects on their health (Wawrziczny et al., 2018). However, support groups are beneficial and supportive for their members (West and Hogan, 2020). Lamont et al. (2020), in their analysis from the IDEAL study, found that self-efficacy, optimism, and self-esteem were associated with the ability to ‘live well’ with dementia.

Pritty et al. (2020) conducted a systematic review of the experience of carers of people living with dementia. They found five themes characterising this experience: connection, informed and informing, “the facility”, “it’s what you make of it”, and sharing responsibility. Stigma is still an experience for carers, and Werner et al. (2020) explored how stigma forms by family members who are informal carers. They conducted focus groups and thematic analysis, finding that both family members and professionals experience stigma because of their association with people living with dementia. Lack of knowledge was felt to be the main causing factors, with the emotional burden being the main impact of the stigma. Being a carer or living with dementia can be seen as a stage or status, which people move into and through during the life course (Tolhurst and Kingston, 2012).

Researchers have also examined dementia knowledge from the perspective of the public. Johnston et al. (2020) conducted a systematic review finding that Dementia is not generally seen as a defined condition with progressing neurological decline. Instead, people were focused on surrounding issues such as ageing, mental illness, and cultural beliefs. Dementia knowledge is modest in the general population with higher levels of education, a care-related background, having a chronic health condition, and having direct experience of caring for someone living with dementia being related to higher levels of knowledge (Chang and Hsu, 2020). Conversely, lower levels of education, and lack of experience, are linked to discomfort in relation to dementia. Levels of literacy are related to dementia knowledge and attitudes; people with a higher level of literacy are more likely to give the correct answers to knowledge tests (Yang et al., 2021). Young people have generally tended to demonstrate positive or neutral attitudes towards dementia, however, there is still a substantial proportion who have negative attitudes or misconceptions. Farina et al. (2020a) observed a mix of experiences and knowledge of dementia. Their focus group looked at the Dementia Friends programme and considered its impact; young people spoke about the perceptions and experiences of dementia, as well as the outcomes and learning from the session (Farina et al., 2020b).

There are generally mixed attitudes towards people living with dementia, but there are signs this is changing. Leung et al. (2019) in their mixed methods study demonstrated there were positive attitudes in members of the public, but levels of knowledge remained low. Levels of knowledge are generally a result of exposure to prior learning, or having undertaken dementia education, or having direct experience of someone living with dementia for example a family member (Eccleston et al., 2019). People in the public are worried about dementia. Martin et al. (2020) conducted a survey of the public and found that worry was present, and there was a perceived dementia ‘risk’. People who reported the highest levels of worry and perceived risk had direct experience and family history of dementia. Olsen et al. (2019) explored public perceptions and understanding of dementia through the Mass Observation Project. Their study identified there was public concern with respect to caring responsibilities, the impact on relationships, and fears about developing dementia. These concerns are shared by people living with dementia. Sabatini et al. (2021) examined the relationships between self-perceptions of ageing and living well, finding that promoting positive perceptions of ageing at the societal level may give more resilience for coping with a diagnosis of dementia and give higher levels of support. Public health campaigns aimed at improving these aspects are feasible and timely (Van Asbroeck et al., 2021), and therefore this should be considered.

Dementia knowledge among health professional staff remains a challenge. Recent investigations have found that knowledge, skills, and behaviours concerning dementia are still low among general practitioners and doctors generally (Wang et al., 2020; Steiner et al., 2020). This is also observable among nurses. Evripidou et al. (2019)

conducted a systematic review examining nurses’ knowledge and attitudes towards the care of people living with dementia. They found that nurses lacked knowledge, communication skills, management strategies, and the confidence to provide dementia care. Interestingly, staff on general medical wards with better dementia knowledge are generally more critical about the extent to which they were using evidence-based guidelines and involving external specialist expertise (Scerri, Innes, and Scerri, 2020).

Overall, the attitudes of staff towards people living with dementia are positive and training/knowledge development regarding dementia has recently been shown to be related to self-reported attitudes (Keogh et al., 2020). Training has been shown to improve knowledge and attitudes (Evripidou et al., 2019; Hewards et al., 2021; Annear, 2018; Keogh et al., 2020). However, some staff groups still have significant gaps in dementia knowledge (Lawler et al., 2020; Annear, 2018). The consequence of lower levels of education is generally poorer outcomes for people living with dementia (Jacobsohn et al., 2019) and therefore an integrated approach to knowledge development is beneficial and useful for all (Bayly et al., 2018). The picture is similar among student healthcare professionals who often demonstrate poor overall knowledge about dementia, yet report positive attitudes (Wang et al., 2020; Akifusa et al., 2020; Sunaryo, Saifullah, and Mulyani, 2020). Age, class, and experience of caring for people with dementia are indicators for increased knowledge about dementia (Sunaryo, Saifullah, and Mulyani, 2020). For students, there is a strong effect of training on knowledge, confidence, and attitude (Williams and Daley, 2020). Interestingly, practitioners score higher on knowledge tests than students, but this is to be expected as a result of experience and training (Saccasan and Scerri, 2020).

Social cognition theory is based on a knowledge-attitude-behaviour/practice/skills arc of development (Conner and Norman, 2005; Godin, 1994; Donovan and Henley, 2010). It has been theorised that when a person contemplates behaviour/action they consider their knowledge and underlying attitudes before acting upon them (Fabrigar et al. 2006). However, Clore and Schnall (2005) argued that attitudes and actions can be influenced by moods and emotions, which are ‘temporally constrained’ supporting conditions and may change depending on the state of the person. They saw attitudes as being “evaluative tendencies” but recognised these may be temporary or enduring

(Eagly and Chaiken, 1993; Clore and Schnall, 2005). Studies often infer that improved knowledge means "better" attitudes for example it has been demonstrated that higher levels of education are associated with interest in politics, environmental awareness, perception of gender roles, immigration and immigrants, perceptions of welfare benefits and benefit recipients, national identity, and entrepreneurship (Brennan et al., 2015). However, these assumptions are positivist; based on a desired value- or attitudinal-perspective. In reality, attitudes are socially constructed and can form differently among different social groups depending on their function (Herek, 1999). For example, different social groups have different attitudes towards alcohol, food, and religious practices yet their knowledge may also be varied. Attitudes may be fixed or flexible and may be socially acceptable for one group but not another. This infers that attitudes are independent of knowledge, and therefore there must be some independent value in the content and formation of attitudes.

BTDD as an educational and research intervention

Early on this in this research process, I posited that a MOOC, as an education intervention, could be used as a platform to support WHO's (2012) agenda, that BTDD could play a part in promoting a dementia-friendly society, and that it could improve public and professional attitudes towards and understanding of dementia. I designed BTDD to create an open forum for international collaboration and dialogue. During each run of BTDD, members of the general public, health and social care professionals, policymakers, families, and carers of people with dementia, and people with dementia themselves engaged with the topic of dementia. BTDD was one of the earliest on Dementia, only slightly pre-dated by the 'Understanding Dementia' MOOC by the Wicking Dementia Research and Education Centre in Tasmania, Australia (Wicking Dementia Research and Education Centre, 2020). There are now at least 15 MOOCs on dementia around the world hosted by major universities and companies (MOOC List, 2020), however, BTDD was one of the first. As well as aiming to increase access to higher education and open learning opportunities, BTDD also aimed to improve attitudes towards, and understanding of, dementia and provide a platform for ongoing research into dementia. As identified earlier, there are limited examples of using MOOCs as platforms for social change (Watson et al., 2016a; Watson et al., 2016b; Watson, Kim and Watson, 2016; Hudson et al., 2019), but BTDD was one of the first to have this purpose. To date, over 10,000 people have participated in the BTDD MOOC, with the videos being watched over 76,000 times.

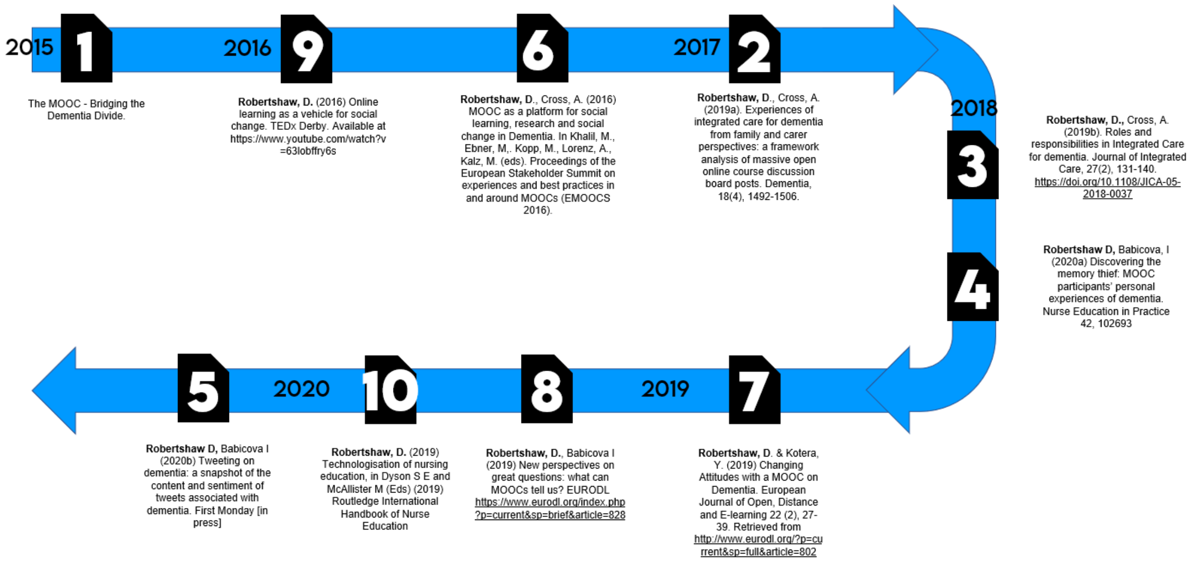
In 2014 massive open online courses (MOOCs) were a new and innovative creation and had the potential to connect with many thousands of users around the world (Zhu, Sari and Lee, 2018). Worldwide, MOOCs were a new area of development and were still experimental at the beginning of this thesis (Haywood and Macleod, 2014; Warusavitarana et al., 2014). The University of Derby had never developed a MOOC before. This project was innovative, and previous research in MOOCs was focused on learning and teaching in MOOCs and who studies MOOCs (Veletsianos and Shepherdson, 2015). BTDD was intentionally designed to collect a high volume of participant metadata each time it is delivered for research. From the outset of the design phase, research opportunities were identified for the MOOC. Rather than focusing on learning, teaching or user behaviour, this research sought to use BTDD as a knowledge generator in relation to dementia and to determine if BTDD could make a difference to attitudes and perceptions. Ethical approval was sought for these research approaches, with subsequent applications to address later research.

Aims and purpose of the research

This PhD by publication has drawn together six years’ academic research and scholarship in MOOCs and dementia. The published works included in this doctoral study sought to generate new knowledge about dementia, to characterise it as a condition, to change attitudes towards it, or to provide a novel insight into the condition from new arenas (for example, social media, online fora). Later publications were aimed at dissemination of the knowledge generated throughout the research process as well as offering guidance for practitioners. The published works consist of the MOOC itself, a TED talk, articles published in peer-reviewed journals, and a book chapter. These published works were supplemented by a range of conference presentations and workshops, as well as an invited presentation at the Palace of Westminster about the MOOC itself and the place of MOOCs within the future of professional education (Robertshaw, 2015).

This body of work developed organically over time and involved an iterative methodological process. Each publication influenced the next. These works were driven by a pragmatic and reflexive approach to the work and research. The publications presented in this thesis were completed in a different order to how they are arranged here; they are arranged thematically based on the resulting aims of the thesis (figure 1).

Figure 1: Research journey



The MOOC - Bridging the Dementia Divide.

Robertshaw, D. (2016) Online learning as a vehicle for social change. TEDx Derby. Available at https://www.youtube.com/watch?v=63lobffry6s

Robertshaw, D., Cross, A. (2016) MOOC as a platform for social learning, research and social change in Dementia. In Khalil, M., Ebner, M,. Kopp, M., Lorenz, A., Kalz, M. (eds). Proceedings of the European Stakeholder Summit on experiences and best practices in and around MOOCs (EMOOCS 2016).

Robertshaw, D., Cross, A. (2019a). Experiences of integrated care for dementia from family and carer perspectives: a framework analysis of massive open online course discussion board posts. Dementia, 18(4), 1492-1506.

Robertshaw, D., Cross, A. (2019b). Roles and responsibilities in Integrated Care for dementia. Journal of Integrated Care, 27(2), 131-140. https://doi.org/10.1108/JICA-05-2018-0037

Robertshaw D, Babicova, I (2020a) Discovering the memory thief: MOOC participants' personal experiences of dementia. Nurse Education in Practice 42, 102693

Robertshaw, D. & Kotera, Y. (2019) Changing Attitudes with a MOOC on Dementia. European Journal of Open, Distance and E-learning 22 (2), 27-39. Retrieved from http://www.eurodl.org/?p=current&sp=full&article=802

Robertshaw, D., Babicova I (2019) New perspectives on great questions: what can MOOCs tell us? EURODL https://www.eurodl.org/index.php?p=current&sp=brief&article=828

Robertshaw, D. (2019) Technologisation of nursing education, in Dyson S E and McAllister M (Eds) (2019) Routledge International Handbook of Nurse Education

Robertshaw D, Babicova I (2020b) Tweeting on dementia: a snapshot of the content and sentiment of tweets associated with dementia. First Monday [in press]

The aims of this work were not set at the beginning, they were developed iteratively over a period of five years. The process began in 2015 with the aim that this project wanted to inform people about dementia and to make a difference to the lives of people living with dementia and their carers. The project then grew and developed into the development of the MOOC itself, and resulted in the subsequent research surrounding it. The aims of the publications were developed iteratively in response to the developing research programme's aims. Throughout this development, the work has always had in mind the potential benefit to the end-user, service users, the public, professionals, patients, and people living with dementia.

Eventually, these aims developed into:

Aim 1 (A1) Conceptualise and implement a MOOC on dementia: generating new knowledge pertaining to attitudes and perceptions and the lived experience of dementia within online fora;

Aim 2 (A2) Evaluate the MOOC as a change intervention within the context of dementia and the impact of dissemination of research findings for implementation in practice and pedagogy.

This critical appraisal has used Rolfe's (2001) reflective model of "what, so what, now what" to consider the published works themselves and their impact. The aims achieved with 10 published works (table 2). A summary of ethics applications can be found in appendix 2.

Table 2: List of published works

Published work	Reference number	Where this can be found	Relevant ethics application	Author attribution form
The MOOC - Bridging the Dementia Divide (published work 1).	1	The overview of BTDD can be found in appendix 1. The content for this published work can be viewed on canvas.net or in appendix 25.	n/a	n/a
Robertshaw, D., Cross, A. (2019a). Experiences of integrated care for dementia from family and carer perspectives: a framework analysis of massive open online course discussion board posts. Dementia, 18(4), 1492-1506. (published work 2).	2	The published work can be found in appendix 6.	The ethics application can be found in appendix 3. The approval can be found in appendix 4.	The author attribution form can be found in appendix 10.
Robertshaw, D., Cross, A. (2019b). Roles and responsibilities in Integrated Care for dementia. Journal of Integrated Care, 27(2), 131-140. https://doi.org/10.1108/JICA-05-2018-0037 (published work 3)	3	The published work can be found in appendix 7.	The ethics application can be found in appendix 3. The approval can be found in appendix 4.	The author attribution form can be found in appendix 11.
Robertshaw, D., Babicova, I. (2020a) Discovering the memory thief: MOOC participants' personal experiences of dementia. Nurse Education in Practice 42, 102693 (published work 4)	4	The published work can be found in appendix 8.	The ethics application can be found in appendix 3. The approval can be found in appendix 4.	The author attribution form can be found in appendix 23.
Robertshaw, D., Babicova, I. (2020b) Tweeting on dementia: a snapshot of the content and sentiment of tweets associated with dementia. First Monday [in press] (published work 5)	5	The published work can be found in appendix 18.	The ethics application can be found in appendix 15. The ethics application modification can be	The author attribution form can be found in appendix 24.

			found in appendix 16. The ethics application approval can be found in appendix 17.	
Robertshaw, D., Cross, A. (2016) MOOC as a platform for social learning, research and social change in Dementia. In Khalil, M., Ebner, M,. Kopp, M., Lorenz, A., Kalz, M. (eds). Proceedings of the European Stakeholder Summit on experiences and best practices in and around MOOCs (EMOOCS 2016). (published work 6)	6	The published work can be found in appendix 5.	The ethics application can be found in appendix 3. The approval can be found in appendix 4.	The author attribution form can be found in appendix 12.
Robertshaw, D., Kotera, Y. (2019) Changing Attitudes with a MOOC on Dementia. European Journal of Open, Distance and E-learning 22 (2), 27-39. Retrieved from http://www.eurodl.org/?p=current&sp=full&article=802 (published work 7)	7	The published work can be found in appendix 14.	The ethics application can be found in appendix 9. The ethics application approval can be found in appendix 13.	The author attribution form can be found in appendix 21.
Robertshaw, D., Babicova, I. (2019) New perspectives on great questions: what can MOOCs tell us? EURODL https://www.eurodl.org/index.php?p=current&sp=brief&article=828 (published work 8)	8	The published work can be found in appendix 19.	n/a	The author attribution form can be found in appendix 22.
Robertshaw, D. (2016) Online learning as a vehicle for social change. TEDx Derby. Available at https://www.youtube.com/watch?v=63lobffry6s (published work 9)	9	The published work can be found on YouTube.	The ethics application can be found in appendix 3. The approval can be found in appendix 4.	n/a
Robertshaw, D. (2019) Technologisation of nursing education, in Dyson S E and McAllister M (Eds)	10	The published work can be found in appendix 20.	n/a	

(2019) Routledge International Handbook of Nurse Education (published work 10)				

Problem statement and research questions

BTDD sought to inform, challenge, and inspire people to engage with dementia, as well as bring about a step-change in the way university education is consumed. As a MOOC, BTDD had the unique opportunity of being open to everyone but at the time it was first delivered this was an untested, unknown entity. BTDD could generate new knowledge pertaining to attitudes and perceptions, and the lived experience of dementia within the online environment. The research, therefore, needed to capture this, as well as evaluate BTDD as a change intervention within the context of dementia. The findings from this research could influence MOOCs more widely, and further research could focus on assessing if this approach may affect changes in perceptions towards other illnesses, diseases, and public health issues.

These were the research questions:

RQ1 Each run of BTDD contained more than 250,000 data records. This data was immensely rich, detailed, and highly accessible. The data presented an opportunity for analysis and enabled the research group to ask the following questions: what did participants say about dementia as an experience and aspects related to it? What roles did people play and did participants feel they had responsibilities? These questions were answered by published works 2, 3, 4, 5, and are linked to aim 1.

RQ2 Did BTDD have an impact? Did people do something differently or behave differently because they studied BTDD? Were there any recordable differences because of studying BTDD? These questions were answered by published work 7 and are linked to aim 2.

RQ3 What key lessons could BTDD provide to influence MOOCs, online learning, pedagogy, and could MOOCs like BTDD be used for other applications or interventions? These questions were answered by published works 5, 6, 7, 8, 9, and 10 and remains a focus of ongoing research and work to raise awareness of open and accessible education for all. These questions are linked to aim 2.

Research philosophy

Identifying a research paradigm was essential because it is fundamental to understand the 'lens' through which the research was undertaken (Szyjka, 2012). The research philosophy identified the beliefs and assumptions about the development of knowledge and included epistemological assumptions (those about human knowledge), ontological assumptions (those about the nature of reality) and axiological assumptions (the influence of values and ethics within the system). These assumptions influenced the research questions, research methods, interpretation of the findings, and how these findings could have been disseminated to others (Saunders et al., 2015; Crotty, 1998; Burrell and Morgan, 1979).

Research conducted as part of this doctoral work was driven by action, values, active communication, change, and adopted a highly practical dynamic approach. It aimed to have a two-way channel of information with the subjects of the research, to learn from them but also to impact them. The research was highly focused on values and was initiated based on a belief and desire to improve the experience of people living with dementia. The research focused on making a difference through multiple means of distribution, adopting a pragmatist approach.

Pragmatism as a research philosophy originated in the late 19th century (Maxcy, 2003) but gathered pace throughout the 20th century. It was Richard Rorty who popularised pragmatism in the late 1970s (Maxcy, 2003; Ormerod, 2006). The founders of pragmatism were Charles Sanders Peirce, William James, Chauncey Wright, Oliver Wendell Holmes Jr., Nicholas St. Johns Green. John Dewey, George Herbert Mead and Arthur F. Bentley. This group were philosophers, psychologists, mathematicians, judges, lawyers, educationalists, sociologists, and political scientists: a mixed and pragmatic group with a diverse range of opinions and perspectives (Maxcy, 2003; Morgan, 2014; Ormerod, 2006; Pansiri 2005). Pragmatism as a movement rejects traditional assumptions about the nature of knowledge, inquiry, and reality. It rejects the idea that inquiry could access reality or truth by using a single scientific method (Maxcy, 2003).

Pragmatism is a coherent, unifying theory taking the approach that we do not have a ‘Gods eye’ view of the world: we cannot make a judgement on whether one particular stance or theory is better than another (Rorty, 1990). Instead of making judgements or taking one perspective, pragmatism seeks to reconcile objectivism and subjectivism, as well as values, knowledge, and experiences. Pragmatism refuses to be involved in complex concepts such as reality, truth or knowledge (Kaushik and Walsh, 2019), holding these to be normative concepts based on socially constructed habits and beliefs (Pansiri, 2005; Yefimov, 2004) or even that there may be single or multiple realities open to inquiry (Creswell and Plano Clark, 2011). Some pragmatist scholars believe an objective reality exists apart from human experience; encountered only through human experience (Goles and Hirschheim, 2000; Morgan, 2014; Tashakkori and Teddlie, 2008).

There is general agreement that knowledge is socially constructed, but that some constructions more closely match individuals’ experiences than others (Morgan, 2014). Human actions cannot be separated from experiences and beliefs originating from those experiences (Kaushik and Walsh, 2019). Thoughts, therefore, are linked to actions and people take actions based on the consequences of their actions and they use these experiences to influence the consequences during similar conditions in the future (Kaushik and Walsh, 2019). Pragmatists believe the meaning of actions and beliefs are found in their consequences – and these define who we are as humans, and we can shape our own experience by using our own actions and intelligence. Pragmatism sees concepts, ideas, theories, and findings as practical, consequential “instruments of thought and action” (Saunders et al., 2015). Findings and knowledge have value when they are driven by values and result in action. Meaning and purpose are not distinguishable from the human experience, but they are different depending upon the context (Dillon et al., 2000). These assumptions lead to the conclusion that knowledge cannot be separated from beliefs, experiences, and habits (Howe, 1998).

Reality is only true to the extent that it permits relationships with other areas of our experiences (James, 2000). Truth, in a pragmatist paradigm, is whatever proves good or useful or has stood the test of time, scrutiny and re-examination (Baker and Schaltegger, 2015; James, 2000; Ray, 2004). However, this does not mean that "if it works then it is true" (Boisvert, 1998) because it is the building body of evidence that is more useful. Humans may only perceive human concerns, values, interest, and ambitions – and these are the guiding reasons for all human action (Heron, 1996; Östman and Wickman, 2014). Pragmatists hold the perspective that we are not able to truly question the nature of knowledge or reality from one particular perspective or stance because there is no way to determine which theory of knowledge or reality is true. Therefore, different approaches to assumptions, perspectives and philosophies do not have value and therefore do not matter. Kelemen and Rumens (2008) believed these concepts only matter when they directly support action. Reality is never the same, it is not static: reality changes, as does the world. Pragmatists believe the world and reality are in a constant stage of becoming, and this state can be changed by actions. These actions are vital for pragmatists (Goldkuhl, 2012; Maxcy, 2003; Morgan, 2014).

As a Registered Nurse, I have strong values, and my work throughout this research was based on actions to achieve change. The research changed and grew with BTDD and the responses of its participants. This further influenced the work's value-base resulting in research focused more on practical outcomes. This has meant the research was practical, pragmatic, and adopted mixed methods approaches. These research designs and strategies were chosen because they were relevant to the problems my work sought to address as the problems were encountered. The research began with the 'problem' or 'issue' and took a pragmatic approach to design to achieve this. The research recognised there was no way to truly judge which approach was best to take because one philosophy alone does not recognise the diverse range of views or realities and can never truly determine the value of knowledge. By using mixed methods, the research tried to get as near to the truth as it could, but it also disseminated its findings in diverse ways to people who may take different philosophical stances. The research, methods, and approach have been diverse yet based on outcomes, values, and actions.

Chapter summary

Dementia is a global challenge affecting every one of us at some point in our lives and work. I began this journey as a registered nurse with a clear practice-focus, mindful of the need to educate students and the general public about the importance of dementia. The vehicle for this was a massive open online course, Bridging the Dementia Divide. The ‘dementia divide’, identified here as the chasm between the experiences that people living with dementia have when compared with ‘the rest of us’, was a key driver for this project and me personally as I led the development and delivery of BTDD as well as the subsequent research. This thesis and body of work intended to keep the research and its outcomes as applicable as possible to practice, practitioners, and people living with dementia.

Chapter 2: Conceptualising and implementing a MOOC on Dementia: generating new knowledge pertaining to attitudes and perceptions and the lived experience of dementia within online fora

“I often reflect on how one person’s pathway is like no other, varying symptoms, different stages, different levels of acceptance, then my grandfather was diagnosed with Alzheimer's and I found myself talking to him as though we were both in our fifties, fetching coal from the coal shed, tending the veggies in the garden and the attractive elderly lady in his view, I had to smile, for here somewhere was my grandfather long before I was born.”

Bridging the Dementia Divide participant

Chapter introduction

This chapter will consider research and published works to address aim 1:

1. Conceptualise and implement a MOOC on dementia: generating new knowledge pertaining to attitudes and perceptions and the lived experience of dementia within online fora.

This aim and this collection of works developed out of the desire to inform people about dementia and to make a difference to the lives of people living with dementia and their carers. Development and implementation of the MOOC provided opportunities to research participant metadata and discussion board contributions to bring new insights. These research projects developed over time in complexity, with each paper influencing the next one’s methodology in terms of technology, scale, and depth.

The published works relevant to this aim and chapter are:

- Published work 1: The MOOC - Bridging the Dementia Divide
- Published work 2: Robertshaw, D., Cross, A. (2019a). Experiences of integrated care for dementia from family and carer perspectives: a framework analysis of massive open online course discussion board posts. Dementia, 18(4), 1492-1506.
- Published work 3: Robertshaw, D., Cross, A. (2019b). Roles and responsibilities in Integrated Care for dementia. Journal of Integrated Care, 27(2), 131-140. https://doi.org/10.1108/JICA-05-2018-0037
- Published work 4: Robertshaw D, Babicova, I (2020a) Discovering the memory thief: MOOC participants’ personal experiences of dementia. Nurse Education in Practice 42, 102693
- Published work 5: Robertshaw D, Babicova I (2020b) Tweeting on dementia: a snapshot of the content and sentiment of tweets associated with dementia. First Monday [in press]

Published work 1: The MOOC - Bridging the Dementia Divide

BTDD began development in 2014. Although the ‘year of the MOOC’ was declared in 2012 (Pappano, 2012), MOOCs were still a new project for most universities, and they were for the University of Derby. BTDD was one of the first MOOCs developed by the University of Derby. This meant there was little research available to guide the course’s development. Available research demonstrated MOOCs could include student-type experiences to resemble an on-campus experience, yet the structure and content of a MOOC could be set free from traditional higher education structures and constraints (Al Dahdouh and Osorio, 2016; Robertshaw, 2016c).

BTDD was designed to be part of the public and national agenda around dementia by encouraging participation in education. BTDD consists of a single ‘module’ of six ‘units’, related to 30 hours of learner engagement over six weeks. Planned learning was for 3-5 hours per week studying. BTDD was designed to be flexible for learners, providing standard and extension activities for participants who desired to explore an issue in more depth. The curriculum was strongly embedded in the current health and social care agenda, with its design being reflective of best-available evidence and policies. BTDD was free-standing in terms of its content, teaching and assessment so that learners could take the course without any prior study or knowledge. Each ‘unit’ had associated learning outcomes and activities designed to encourage learner interaction and measure learning. These ‘units’ employed instructional design and Activity Theory (Engeström, 1999) to implement an activity-driven experience for learners. BTDD also contained informational multimedia, including interviews, which complemented the written content. BTDD was designed to be a self-paced course, with students undertaking most of the activity independently but with interaction in discussion boards and other activities. This style supported the development of communication skills, organisation skills, proactivity, professional awareness, professional development, specific technical skills, and change attitudes. Using this design, learners were able to demonstrate autonomy, pace themselves and engage directly with their peers in discussion boards.

There was uncertainty about including an assessment however during preparations for BTDD, discussion resulted in the consensus that assessment would be helpful to demonstrate learning. This consensus was supported by evidence (Chauhan, 2014;

Daradoumis et al., 2013; Staubitz et al., 2016). BTDD employed a robust approach to assessment, ensuring each assessment whether formative or summative had value and relevance to real life. Academic rigour needed to be demonstrated, testing learners to ensure they achieve the learning outcomes and can apply their learning. The assessment strategy for this MOOC accounted for the different learning needs of learners and offered a bespoke, flexible, and authentic assessment for learners to demonstrate their learning. Although the course did not offer credit and no credit was awarded, it was designed to operate within the University’s Regulatory Framework and conformed to its regulations on assessment. Because of the nature of the course, which focused on practice, rules of confidentiality were adhered to throughout the assessment. It is well recognised that assessment in a MOOC is challenging, and it was not possible for me to provide individualised grades and feedback to every learner (Daradoumis et al., 2013). BTDD recognised and identified the importance of individualised and high-quality feedback. With this philosophy, review and feedback was provided by learners themselves: encouraging critical reflection and ownership of learning. Peer assessment is defined as “an arrangement in which individuals consider the amount, level, value, worth, quality, or success of the products or outcomes of learning of peers of similar status” (Topping, 1998). Peer review implements the philosophies of active learning, andragogy, and social constructivism; whilst also promoting discourse and engagement as learners can provide detailed feedback (Falchikov and Goldfinch, 2000). BTDD asked learners to review and provide feedback on other learners’ work and offer a grade of either pass or fail. If learners ‘passed’ they received a computer-generated certificate of completion. This was provided automatically by the software platform and featured the course’s name and the logo of the institution. Learners were asked to create an artefact to demonstrate their learning, which could have been for example an oral history of a person with dementia or a video about how to support a person with dementia. Examples of these can be found in the appendix and they demonstrate high levels of engagement and learning. In addition to the main course assessment learners received Open Badges for individual course units. Open Badges are an educational technology that is an image file containing data about the learner who earned it, what they did to receive it, who issued it and optionally can link to evidence. These badges can be added to a ‘backpack’ which means learners can take badges with them and demonstrate their learning. In effect, this works as an e-portfolio and allows learners to collect evidence of studying various courses (Glover, 2013). Created by Mozilla, Open Badges decentralise learning, highlighting skills and accomplishments, encouraging learner participation (Goligoski, 2012).

Video, audio, and multimedia interactivities also became an area of focus and literature identified that direct interaction between participants and their tutor or the course team was essential (Kopp and Lackner, 2014). These principles were applied to BTDD.

BTDD consisted of six ‘units’ of learning:

- Unit 1: Introduction to dementia
- Unit 2: Communication and compassion
- Unit 3: Independence, control and quality of life
- Unit 4: Dementia as a global health priority
- Unit 5: Integrating care
- Unit 6: End-of-life care

These topic choices were guided by the Dementia Core Skills Education and Training Framework (Skills for Health, Health Education England, and Skills for Care, 2015). This framework also established the three tiers and four groups (table 3). BTDD was aimed at tier 1 and group 1.

Table 3: Dementia Core Skills Education and Training Framework tiers and groups (from Skills for Health, Health Education England and Skills for Care, 2015)

HEE Tier	Matched social care workforce group
Tier 1: dementia awareness-raising, in terms of knowledge, skills and attitudes for all those working in health and care settings	Group 1: all of the social care workforce – dementia awareness
Tier 2: knowledge, skills and attitudes for roles that have regular contact with people living with dementia	Group 2: people working in social care who are providing personalised direct care and support to people with dementia
Tier 3: enhancing the knowledge, skills and attitudes for key staff (experts) working with people living with dementia designed to support them to play leadership roles	Group 3: registered managers and other social care leaders who are managing care and support services for people with dementia
	Group 4: social care practice leaders and managers who are managing care and support services and interventions with people with dementia which includes social workers, and occupational therapists working in social care

Zengilowksi, Wadhera and Harp (2015) demonstrated that interactivities were essential in MOOCs because higher levels of engagement would lead to greater satisfaction and achievement by learners. BTDD included interactivities in the form of discussion boards, group work and assignments. One MOOC used “fireside chats”: short videos to summarise the week’s learning or a topic (Zengilowksi, Wadhera and Harpp, 2015). These principles were employed in BTDD, which used “weekly windups” focusing on the unit’s content, often including an interesting interview with a guest. These were received positively, and many participants watched these live. This approach has become more popular in recent years, with the proliferation of Facebook (Chan and Leung, 2020) and YouTube live streaming (Lam and Woo, 2020). BTDD was an early implementer of this approach and focused on the personal connections and communications of learners.

BTDD was designed with an instructional design approach, taking a methodical and intentional approach to designing learning experiences. Instructional design was developed in the early 20th century by educators and psychologists to develop military training materials (Reiser, 2001). Early MOOCs based on George Siemens’ (2004) ‘connectivism’ recognised that learners are connected individuals who interact and participate through a series of ‘nodes’. Siemens’ approach led to two early classifications of MOOCs: ‘cMOOCs’ and ‘xMOOCs’. In cMOOCs, the ‘c’ stands for ‘connectivist’, and in xMOOCs, the ‘x’ stands for ‘extension’, which reflects the purpose of extending beyond the classroom (Hollands and Tirthali, 2014). cMOOCs tend to be more social, connected, vibrant online learning communities whereas xMOOCs tend to be more like traditional on-campus courses but delivered online. cMOOCs tend to be smaller, whereas xMOOCs tend to be much larger in terms of participants (Rodriguez, 2013). Hollands and Tirthali (2014) believed that most MOOCs were xMOOCs, however, they recognised that cMOOCs were more likely to be learner-centred and encourage a deeper interconnectedness within the learning community. A criticism of xMOOCs is that they are teacher-centred, media-centred and that they focus on instruction rather than connection (Khalil and Ebner 2013a, Khalil and Ebner, 2013b). This dichotomous distinction has been challenged, with some authors suggesting higher numbers of classifications (Clark, 2013) or no classifications at all (Conole, 2013). BTDD was a hybrid model, adopting both the cMOOC and xMOOC models, adopting a connectivist approach. However, BTDD also applied constructivism as a principle, recognising that learners can individually and collectively construct their knowledge based on experiences during the course. Constructivism is linked to the work of Piaget and Vygotsky (Ackermann, 2001; Elliott et al. 2000; Vygotsky, 1978). Focusing on personal, individual knowledge construction, BTDD was designed to recognise that learners exist as part of a wider community who are all connected. There was a course instructor who focused on leading weekly windup conversations but also engaged within the fora. Rodriguez (2013) said the facilitator's role is to 'govern knowledge coherence' which was a focus of the weekly live sessions. There are great variations in the instructor role, which has been poorly defined (Yuan and Powell, 2013). There have also been limited quality assurance processes for the instructor role and content, with scrutiny often based on broadcast principles (McAndrew and Scanlon, 2013). In BTDD, the instructor role and the live sessions were both aimed at promoting knowledge coherence and this was confirmed by participant interaction and contributions to the discussion boards.

BTDD was designed to be an 'intervention': to encourage participants to act in relation to dementia. This ethos inspired the rest of the research included in this critical appraisal: the MOOC, the participants and the commitments drove a desire to seek a deeper understanding of dementia. Hollands and Tirthali (2014) believed that institutions develop and deliver MOOCs to extend reach and access, build and maintain brand, reduce costs, improve educational outcomes, innovate in teaching and learning, and conduct research on learning and teaching (Hollands and Tirthali, 2014). BTDD aimed to do all these things as well as aiming to change attitudes about dementia and have a wider institutional impact.

In discussion boards, BTDD asked participants about their experiences of dementia, as well as their views and opinions of integrated care for dementia, with the following questions:

1. What do participants of a massive open online course on dementia perceive to be the strengths and limitations of integrated care?
2. What are the personal experiences of dementia from the perspective of participants in a Massive Open Online Course on dementia?

The research and inquiry related to these two questions resulted in published works 2, 3, 4 and 5. BTDD also included a pre- and post-course survey which examined attitudes and perceptions. The resulting research and inquiries were published in published work 7.

Learners were highly engaged in BTDD and highly engaged in the research. A sample of participant assessments submitted for Bridging the Dementia Divide can be found in the appendices; this work demonstrates the high level of engagement of participants and the impact of BTDD. Learner engagement in MOOCs is difficult to assess and there are varied definitions. MOOCs often have high dropout and non-participation rates; however, this understanding may be affected by analysis of the data and by adopting traditional definitions of engagement (Veletsianos et al., 2015). Often only small numbers fully engage and end up being responsible for most leaner contributions (Cohen et al., 2018). Learner engagement in BTDD was high compared to other MOOCs, with 35.47% of active learners completing the programme (active learners represented 23.96% of enrolled learners). 43.57% of the available badges were awarded (Leech and Hadi, 2017). A large proportion of the learners followed the weekly pace of the course; however, many others did not follow the course in the sequence. Most learners completed the course in a shorter time than expected, and many studied the units in an order of their choice. However, learners still spent a similar amount of time in the course just over a shorter period. This highlights the possibility of MOOCs as microlearning opportunities where participants join a MOOC to learn about a topic that may be represented in one unit. Microlearning is become more popular and provides the opportunity for learners to engage in smaller portions of learning with full flexibility in terms of what they learn and when (Jomah et al. 2016).

BTDD had 3049 learners in 2015, 3566 learners in 2016 and 1616 learners in 2017, and a further 3,000 learners have joined BTDD since it moved to another platform in 2018. This totals more than 10,231 learners. In July 2020, video views passed 76,000 on YouTube. BTDD contributed to dementia care and pedagogy, and the other publications in this appraisal consider these contributions in greater detail.

Through the research approach, BTDD generated new knowledge relating to attitudes and perceptions, and the lived experience of dementia. BTDD was highly focused on outcomes, values, and actions: key features of the pragmatist paradigm. The following published works demonstrate how this new knowledge was generated and disseminated. This work met aim 1 and contributed to research questions 1, 2, and 3.

Published work 2: Robertshaw, D., Cross, A. (2019a). Experiences of integrated care for dementia from family and carer perspectives: a framework analysis of massive open online course discussion board posts. Dementia, 18(4), 1492-1506.

This paper was first published online in 2017 but published formally in print in 2019. 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. Integrated care is a concept involving the integration and coordination of health and care services for the benefit of the people who use them (Shaw, Rosen, and Rumbold, 2011). In an integrated care system, services provide continuous care in partnership and decisions about services are kept close to those who use the service. The NHS Long Term Plan (NHS, 2019) set out visions for partnerships within ‘places’, with services arranged locally. Integrated care should work across health and care organisations as well as other organisations including local authorities. It should involve a whole-system approach (Ham and Curry, 2011). Integrated care for people living with dementia is important because they and their families need pre- and post-diagnostic support (McHale et al., 2019). They also have ongoing complex needs which may increase over time and co-exist with other health conditions (Jones et al., 2016; Minkman et al., 2009).

This published work was based on data collected in BTDD discussion boards from a question about participants’ experiences of integrated care for dementia. This research was influenced by published works 1, 9, and 6 and used Framework Analysis, a five-step process enabling the researchers to identify themes and patterns in data through the production of an agreed analytical framework which was then applied consistently throughout the data (Ritchie and Spencer, 1994; Srivastava and Thomson, 2009). These five steps involved transcription and familiarisation, coding, developing the framework and then applying the framework. This process was manual and relied upon two researchers reading and coding a large volume of data. The project used textual data (natural language) from three years of the course running. This study was small compared to subsequent papers but was the first step into using and analysing big data, although this was undertaken manually. This approach influenced later research which featured increased automation, natural language processing and text mining.

This research identified three main themes in the data: achieving person-centred holistic care’, ‘challenges of integrated care’ and ‘roles and diffusion of responsibility’. 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. These are encouraging findings, despite recent evidence that integrated care is still fragmented for people living with dementia (Agha, Frandsen and Rebitzer, 2017; Frost et al., 2020; Parker et al., 2020).

Participants identified several recommendations for integrated care: these involved 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 important drivers to achieve person-centred integrated care in dementia.

Framework analysis, whereby an analytical framework is applied in a methodical, comprehensive, and systematic way to generate themes by making comparisons within and between cases (Gale et al., 2013) or as, in this research, comments/discussion board contributions. Framework Analysis allowed immersion and familiarisation. It was the collaborative work with others that brought the richness of analysis and discourse (Srivastava and Thomson, 2009). However, MOOC textual data was used which lacked the opportunity to follow-up and probe further, rich information submitted by users. The information could not be explored further with participants, because once the user had submitted their contribution and left the MOOC, they were not available for a further detailed discussion about their contribution. The data collected were rich in terms of diverse topics, however, ‘group think’ could have arisen by virtue of the participants being able to review other responses. It is possible there was confirmation bias on many of the issues that arose. Participants could have reflected on other responses and then reinforced these with their own (Janis, 1991). Groupthink and confirmation bias have been areas of concern throughout all this body of work, because of the nature of the communities explored, however, a pragmatist approach was taken to this, focusing more on the implications and actions of the responses and the participants themselves. The main issue with this publication was that text analysis was manual which increased the risk of human error, however, the strength of this was that the researchers could engage deeply with the data. This led to subsequent research using computational content analysis.

This research was thoroughly embedded in the pragmatist paradigm. It focused on observing and recording socially constructed knowledge from participants and took the approach that their experiences, beliefs, intentions, and actions could not be separated from their experiences (Kaushik and Walsh, 2019). This implies that participant views, experiences and contributions were highly characteristic of their actions and intentions (Saunders et al., 2015). This approach was also taken in published works 3 and 4.

Up to April 2021, this publication has been downloaded 837 times and has been cited in 11 peer-reviewed articles. This research has been cited by authors writing about palliative care in the context of dementia (McInerney et al., 2018), emergency care of people with dementia (Jacobsohn et al., 2019), drug therapies in advanced dementia (Parsons and Gamble, 2019), developing complex interventions (Backhouse, 2017), and developing a MOOC about postural and technological adaptations in paediatrics (Martin-Valero et al., 2019).

This published work contributed to aim 1 and addressed research question 1. This was my first substantive research project, and I was able to develop skills across the whole research process, including conceptualisation and design, the process of ethical approval, data collection, and analytical techniques. This published work generated new knowledge about the experiences of integrated care for people living with dementia. It also demonstrated that MOOCs like BTDD could be used to understand answers to important questions and influenced later research. This research considered BTDD as a source of information, as well as identifying key areas for action. By identifying these, BTDD contributed to the understanding of dementia and the context in which people living with dementia exist.

Published work 3: Robertshaw, D., Cross, A. (2019b). Roles and responsibilities in Integrated Care for dementia. Journal of Integrated Care, 27(2), 131-140. https://doi.org/10.1108/JICA-05-2018-0037

Published in 2019, this research also used Framework Analysis, a process whereby an agreed analytical framework is developed and applied consistently throughout the data (Ritchie and Spencer, 1994). This study aimed to explore roles and responsibilities in integrated care from the perspective of carers, people living with dementia, healthcare professionals and researchers. Data was collected from discussion boards in BTDD, and this research focused on the roles and responsibilities of people involved in integrated dementia care exploring the perceptions of MOOC participants towards these. This dataset was collected as part of a question about experiences of integrated care and dementia.

This published work built upon the research conducted as part of published work 2, and there were similar strengths and limitations to the previously published work. This research used data originating from discussion boards and involved manual analysis of text to develop the analytical framework which was then applied manually. However, the strength of this work was the volume of data included in the analysis and the clear focus of inquiry.

The data demonstrated that effective integrated care for dementia not only relied 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 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, 2017). Following analysis, the research recommended that all organisations consider developing care navigation and co-ordinator roles and functions as well as developing interoperable IT systems with electronic records. The research found that all staff involved in dementia care should have access to education and training to promote skills and knowledge development. It also demonstrated that knowledge and understanding of the roles and responsibilities of people and organisations should be embedded into healthcare professional programmes to give professionals of the future and awareness of their potential, although it is often difficult to define what these roles and responsibilities should be.

This research identified that care coordination and navigation are important functions, but they are not currently fully embedded in all integrated care systems. Shared care records, although recognised as a solution by participants, should facilitate interprofessional working and collaboration and should be considered for implementation. These shared care records could be enabled by technology and electronic solutions. Further research opportunities were identified to understand the factors and successful activities which “work” to promote integrated dementia care so that these can be effectively implemented. The research also generated new knowledge and understanding of the roles and responsibilities people have in relation to dementia, but these functions need to be developed. Participants also wanted to see these roles and responsibilities embedding into pre-registration professional healthcare programmes. It also further contributed to the notion that MOOCs may be a useful method of conducting social research in health and social care by “crowdsourcing” solutions to deliver effective integrated dementia care.

This research contributed to aim 1, and addressed research question 1. This research has been cited by authors mapping post-diagnostic dementia care in England (Frost et al., 2020) and during a study on health and social care integration in Finland (Ylitalo-Katajisto, 2019). It was also identified as part of a publication on MOOC research trends (Duggal and Dahiya, 2020). Among the body of work, this publication has some of the most significant policy and practice implications because of its findings. This published work examined the roles and responsibilities people play in relation to dementia and demonstrated how BTDD could be used as a platform for research and information. This research identified key areas for further research, as well as highlighting the continued contribution of BTDD to dementia care. These findings demonstrate new knowledge about experiences of integrated care.

Published work 4: Robertshaw, D., Babicova, I. (2020a) Discovering the memory thief: MOOC participants’ personal experiences of dementia. Nurse Education in Practice 42, 102693

This study aimed to characterise experiences of dementia in the broad population by using data collected as part of BTDD. This research focused on the data gathered as part of a question about BTDD participant’s personal experiences of dementia and arose because of discussions during published works 2 and 3. Once collected, data were analysed using Framework Analysis (Ritchie and Spencer, 1994) by reviewing, developing an agreed analytical framework, and then applying this throughout the dataset. During the first week, participants were invited to answer the question “share your own personal experience of dementia”. There were 1329 responses in 2015 (an average of 0.43 posts per registered learner), 1465 responses in 2016 (an average of 0.41 posts per registered learner), and 690 responses in 2017 (an average of 0.42 responses per registered learner). Although these numbers of responses are low, they are in line with participation expectations for MOOCs which is generally low (Leach and Hadi, 2017). This research followed the earlier projects (published work 2 and 3) and took a similar approach, yet it was bigger in scale because of the volume of data received and analysed. The analysis was manual, adding extra difficulty and time however this further informed the need to use computational analysis.

This research identified new knowledge about attitudes, perceptions, and the lived experiences of dementia from the perspective of BTDD participants, with BTDD as an example of an online forum. Four main themes emerged from the data which were representative of the experience. The first theme was “the condition”, where participants discussed their experiences of dementia itself, including diagnosis, suffering, discovering the condition and shared information about its prevalence. The second theme was “caring” which included all aspects of providing direct and indirect care for someone living with dementia. The third theme, “perception”, was identified from the discussion about the perceived positive and negative experiences. There were thoughts and phrases about the future after diagnosis including fear, hopelessness, suspicion, and vulnerability. These concepts are associated with the lived experience of dementia. The fourth and final theme was “control” and was about maintaining independence, the concept of loss and the conflicts which arise amid losing control.

Themes identified in this research align with the experiences of feeling fear, anger, insecurity, and hopelessness found by Bowes and Wilkinson (2003) and Bunn et al. (2012), and anxiety, depression, and despair reported by Bender and Cheston (1997). This research also identified a lack of knowledge about dementia and suggested this is widespread. There were some contradictions in this research when compared with others, for example, Bowes and Wilkinson (2003) found there was a “restriction on service access” which was not a theme emerging in this study. Benbow and Kingston (2014) found similar results during their investigation, transcription, and thematic analysis of recorded narratives. They found four themes of support: ‘relationships’, ‘services’, ‘prior experience of coping’, and ‘explanation for the dementia’. Three additional stressor themes were identified: ‘emotions’, ‘physical health’, identity’.

Previous research demonstrated negative connotations of dementia, which could have been due to a lack of awareness (Bunn et al., 2012). This theme arose in the research and participants often identified how a lack of awareness and education preventing them from understanding behaviours/symptoms shown by their relatives or people they knew.

This research contributed to aim 1 and addressed research question 1. The strength of this research originated from the large volume of data collected and the diverse range of participants. The large volume of data allowed us to triangulate and correlate themes and theories, and these results allowed for rich discussion and discourse. The research took the approach of sourcing answers inductively by making observations to make generalisations and theories. This research has had great personal impact; it was a difficult paper to write, but in many ways was one of the most important publications included in this critical appraisal: it spoke to the very core of what dementia is and gave an account of the personal experience of dementia. The wider impact of this research has yet to be demonstrated, however, these findings have implications for policy and practice. This publication significantly identified BTDD’s contribution to dementia and demonstrated the applicability of using a MOOC like BTDD as a source of information for research.

Published work 5: Robertshaw, D., Babicova, I. (2020b) Tweeting on dementia: a snapshot of the content and sentiment of tweets associated with dementia. First Monday [in press]

BTDD had already generated new knowledge and information through a range of datasets collected over three years. However, this research sought to compare data originating from another source to determine if the results originating from BTDD were accurate or not. This study was influenced by all of the earlier studies. It was designed to scrutinise concepts and ideas found in previous projects by comparing with data from another perspective, an approach advocated by the pragmatist paradigm (Baker and Schaltegger, 2015; James, 2000; Ray 2004). This study aimed to discover the nature, context, and terminology used by Twitter users when talking about dementia and dementia-related terms.

This study, still concerned with public understanding and perception of dementia, used Twitter as a data source. Twitter is another online social world, and this research was collected data relating to dementia, and then performed linguistic analysis to determine its content. This research used greater levels of automation and computational analysis: a direct result of previous projects. This study adopted a netnographic approach, examining people’s interactions and contributions in the online environment (Kozinets, 2009), yet was still rooted in a pragmatist philosophy. Netnography, sometimes known as digital ethnography, is an ethnographic methodological approach that provides limited access to true participant identity and demographic information, however, Kozinets (2002) saw this as a necessary and acceptable shift from traditional ethnographic approaches. This study used an inductive logic approach, where the researchers began by analysing the data then allowing conclusions to emerge organically from the analysis (Ignatow and Mihalcea, 2017).

This research used Tweets as a data source to explore the attitudes (sentiment) and themes associated with the most common types of dementia as outlined by Alzheimer's Research UK (Alzheimer’s Research UK, 2020). The five search terms used in this study were: dementia, Alzheimer’s Disease, vascular dementia, frontotemporal dementia (FTD) and Lewy body dementia. To obtain a fully rounded understanding of differences in attitudes (or, sentiments) towards types of dementia, the most common types of dementia were selected. This study used automated linguistic analysis, a step beyond the manual coding and thematic analysis of the previous papers.

A total of 860,383 tweets were gathered using TAGS which generated a total of 27,695,933 words. Just under half of all tweets (48.63%) originated from the search term ‘dementia’, and 49.95% originated from the ‘Alzheimer's’ search term. The remainder of the tweets originated from the terms ‘frontotemporal dementia’, ’Lewy body dementia’ and ‘vascular dementia’. Using the software package LIWC, each search term was analysed and investigated for the emotional tone of voice, sentiment, clout, analytical thinking, and authenticity.

The results indicated that dementia and Alzheimer’s Disease were the two search terms that had the most tweets, suggesting that these were the two topics talked about the most. Additional data investigated per term were positive and negative percentages of total words. It is interesting to note that the highest rate of used positive emotional words was used for search terms Dementia (3%) and Lewy Body Dementia (LBD) (2.2%), compared to the lowest percentage of positive words in search terms Frontotemporal Dementia (FTD) (1.2%) and Alzheimer’s Disease (1.9%). Further to this, the percentage of negatively associated emotional words were also investigated per search term. The analysis suggested that the highest percentage of negatively associated emotional words was used in tweets about Vascular Dementia, where 2.3% of all words were negative, compared to Alzheimer’s Disease, where only 1.2% of all words were negative emotion words.

This study was robust; however, data was collected from Twitter such that the results were influenced by the framework and apparatus in which the data was collected (the “assemblage” [Brooker, Barnett and Cribbin, 2016]). The Twitter application programme interface (API) does not guarantee access to all tweets related to a search term, so some tweets may not have been collected. In addition, Tweets can become clustered meaning tweets on the periphery may not be collected. The API permits a maximum of 3000 tweets per hour, and it is possible there were more than 3000 tweets per hour related to the higher frequency terms of dementia and Alzheimer’s. The risk of this was mitigated by hourly collection, which ensured a consistent and coherent body of data however it is not possible to definitively determine what effect this had on the results. Tweets on the chosen topics may not have been available because users may not have used the search terms: for example, a user may have been discussing dementia but not used the term ‘dementia’ in their tweet. The converse may also have happened: Tweets not related to the search term, but including the search term, may have been identified. Arguably though these tweets are still relevant because users are using language related to the term. These issues arise particularly when users or news events influence data: for example, in March 2019 Donald Trump referred to Nancy Pelosi as being ‘demented’. This tweet was re-tweeted many times and may have influenced the dataset and results of the research.

Software used to analyse the tweets in this publication have their limitations: both are off-the-shelf products using natural language processing algorithms that are proprietary. Of the two programmes, AntWordProfiler has a greater level of customisation as word lists may be constructed for use. This paper used the general service list of the first most popular 1000 words and the second most popular 1000 words. This word list is validated with a long history of use. It was designed by a professor of linguistics (Antony, 2008) and was, therefore, a good choice to use. This analysis, conducted by software, improved objectivity in language analysis. In previous studies using manual interpretation and coding of text, the subjectivity of researchers was an identified issue (Robertshaw and Cross, 2019a; Robertshaw and Cross, 2019b). This overall approach is highly reflective of its pragmatist paradigm, with the research focused more on the actions and outcomes rather than the complex data collection system or approach.

This study showed that people discuss Dementia and Dementia-related tweets as part of their everyday conversations on Twitter. Approaching this research from a pragmatist paradigm, the study again was focused on observing and recording contributions and experiences, and therefore contributors’ intentions and actions (Kaushik and Walsh, 2019). This research has important findings for social change interventions such as Dementia Friends, which has focused on changing attitudes towards dementia. The findings show work like Dementia Friends may be having an effect; however, the next phase of social change intervention should be focused on the other conditions and diseases part of the umbrella of dementia.

This research contributed to aim 1 addressed research questions 1 and 3. This research project allowed comparison of results from another online social world with that of BTDD and to determine if there were any similarities or differences in the results. The findings demonstrated that Dementia is a frequently discussed topic on Twitter, and data suggested people focused on their family members, the disease itself, research, and treatments. The two environments were reasonably similar. This research added value and weight to the findings of the previous research, allowing me to verify and triangulate earlier findings, and confirm that BTDD's findings were useful and applicable.

Chapter summary

This chapter aimed to demonstrate how a MOOC on dementia (BTDD) was conceptualised and implemented, as well as how new knowledge was generated about attitudes and perceptions and the lived experience of dementia. This has been demonstrated by five published works which focused on BTDD itself (published work 1), experiences of integrated care for dementia (published work 2), roles and responsibilities for dementia (published work 3), experiences of dementia (published work 4), and the conversations people have about dementia (published work 5).

Reflecting on these publications, they gave opportunities as a researcher and registered nurse to develop research skills as well as investigate issues that were important for students and members of the public. They demonstrated robust methodological analysis of large datasets and encouraged the development of research methodologies pragmatically over time and based on need. Established methodologies were developed and applied to novel areas of inquiry. The earlier publications within this chapter involved manual analysis, which was time-consuming and needed faster methods. This led to the development of skills in linguistic analysis using computational methods: techniques that have been useful in other areas, for example analysing student assignments for plagiarism.

The findings of the published works in this chapter were able to be applied to practice and dementia care. The next chapter will focus on evaluating the MOOC as a change intervention within the context of dementia and consider the impact of disseminating the research findings for implementation in practice and pedagogy.

Chapter 3: Evaluate the MOOC as a change intervention within the context of dementia and the impact of dissemination of research findings for implementation in practice and pedagogy

“One thing I absolutely adore about people with dementia is that they are never demanding the way someone without dementia would be. They would never come to you for help, as there they certainly don't have the capacity to ask for it …. As heavy as the workload may be, I have found my countenance and overall wellness has grown by dedicating my life to their needs. They are certainly, and adorably, useful to the world they are in and I would never try to change them.”

Bridging the Dementia Divide participant

Chapter introduction

This chapter will consider research and published works to address aim 2:

2. Evaluate the MOOC as a change intervention within the context of dementia and the impact of dissemination of research findings for implementation in practice and pedagogy.

This collection of works emerged around the same time as those included in chapter 2. Published works included in chapter 2 focused on conceptualising and implementing Bridging the Dementia Divide as well as using the MOOC itself to bring new insights. The collection of works in chapter 3 were developed to evaluate the MOOC and to disseminate findings from the programme of research for application in practice and pedagogy. These publications focused on sharing design, evaluation, and considered BTDD within the context of other interventions and programmes. These publications were highly influenced by findings from the research publications found in chapter 2.

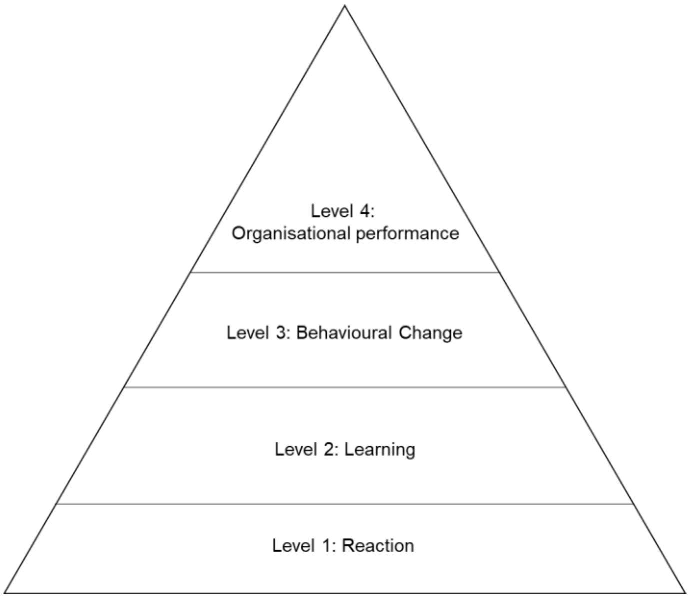
The published works relevant to this aim and chapter are:

- Published work 6: Robertshaw, D., Cross, A. (2016) MOOC as a platform for social learning, research, and social change in Dementia. In Khalil, M., Ebner, M,. Kopp, M., Lorenz, A., Kalz, M. (eds). Proceedings of the European Stakeholder Summit on experiences and best practices in and around MOOCs (EMOOCS 2016).
- Published work 7: Robertshaw, D., Kotera, Y. (2019) Changing Attitudes with a MOOC on Dementia. European Journal of Open, Distance and E-learning 22 (2), 27-39. Retrieved from http://www.eurodl.org/?p=current&sp=full&article=802
- Published work 8: Robertshaw D, Babicova I (2019) New perspectives on great questions: what can MOOCs tell us? EURODL
- Published work 9: TEDx Talk - https://www.youtube.com/watch?v=63lobffry6s https://www.eurodl.org/index.php?p=current&sp=brief&article=828

- Published work 10: Robertshaw D (2019) Technologisation of nursing education, in Dyson S E and McAllister M (Eds) (2019) Routledge International Handbook of Nurse Education

This chapter uses Kirkpatrick’s four-level evaluation model as a framework (Kirkpatrick and Kirkpatrick, 2016). The model identifies four levels: 1. Reaction, 2. Learning, 3. Behaviour and 4. Results. Each level of the model involves a deeper analysis of an intervention and evaluates the effectiveness and usefulness of the intervention (Smidt et al., 2009). A fifth level has been added to Kirkpatrick’s model, focussing on return on investment (Phillips, 2012). This model will be used to evaluate BTDD as a change intervention within the context of dementia as well as the impact of the dissemination of research findings for implementation in practice and pedagogy. It demonstrates how each publication relates to and informs each level of the evaluation model.

Figure 2: Kirkpatrick evaluation model adapted from Kirkpatrick, D. (1996). Great ideas revisited. Techniques for evaluating training programs. Revisiting Kirkpatrick’s four-level model. Training and Development, 50, 54–59



Published work 6: Robertshaw, D., Cross, A. (2016) MOOC as a platform for social learning, research and social change in Dementia. In Khalil, M., Ebner, M,. Kopp, M., Lorenz, A., Kalz, M. (eds). Proceedings of the European Stakeholder Summit on experiences and best practices in and around MOOCs (EMOOCS 2016).

This publication was the first to originate from the BTDD project and was written early on after the delivery of the first course in 2015/16. The publication appeared in the peer-reviewed proceedings of the eMOOCs European conference, accompanying an oral presentation. It aimed to outline the approach and content of the BTDD, as well as identify potential research applications. This publication was the first written published record of the MOOC, and it was influenced by published work 1. The paper focused on two aspects: disseminating feedback from BTDD users to share their qualitative feedback and suggesting areas for future research considering participants’ perspectives. The published work included information about the layout, content, and design of BTDD and positioned BTDD as a change intervention. This paper was an opportunity to share early ideas with colleagues and receive feedback on proposed future approaches. At that time, MOOCs were being used for educational research, but not as a platform to conduct research into broader questions like “what is your experience of dementia?”. This publication influenced later work which sought to answer these types of questions.

Part of this publication was to examine representative feedback from participants, which were used to evaluate BTDD as a change intervention within the context of dementia. Participants said:

- *“Well written authoritative textual content and an impressive array of found and newly developed videos often featuring excellent stories of practice from carers and practitioners on the dementia frontline.”*
- *“The course was well planned, easy to navigate with high quality content.”*
- *“The ease of use, the availability, the content. It was excellent!”*

Participants found the content to be scientific and academic, but at the same time accessible:

- *"The content of the course covers the whole topic of dementia from scientific until end of life. I love it."*
- *"The Course was really scientific with each tutor replying and engaging with us and our questions having studied them first. The most amazing Course I have ever attended and I have to say I will miss such an engagement with specialists like the ones from the University of Derby."*

This published work considered the future of BTDD and its wider impact. There was early evidence that the course had an external impact, with participants making comments like:

> *"I've already signed up to volunteer with a few dementia patients overseas. Having gained the pre-requisite knowledge, I'll be able to identify more easily signs of dementia in a client since I'm working at the community level, assist families and educate them about the condition as well as advocate for a national dementia policy in my country."*

The limitations of this publication were that it was short and narrative in style and reported participant feedback descriptively. However, it described BTDD in detail. Hudson et al. (2019) recognised BTDD by citing this publication in their paper on supporting urban change. They identified BTDD as an example of a MOOC aimed at affecting social change. In their paper, BTDD was discussed alongside a MOOC on citizen engagement developed by the World Bank and was one of only two examples given. In this publication, BTDD was positioned as a change intervention within the context of dementia. Questions asked in this publication increased the desire to investigate BTDD's impact further and to determine if there was any measurable change in attitudes and perceptions towards dementia. This was explored in the next published work (published work 7).

This research contributed to aim 2 and addressed research question 3. Relating this published work to Kirkpatrick's model (Kirkpatrick and Kirkpatrick, 2016) this publication examined user feedback which is relevant for the first level of evaluation: reaction. The feedback included in this published work demonstrated that participants enjoyed BTDD and found it useful.

Published work 7: Robertshaw, D., Kotera, Y. (2019) Changing Attitudes with a MOOC on Dementia. European Journal of Open, Distance and E-learning 22 (2), 27-39. Retrieved from http://www.eurodl.org/?p=current&sp=full&article=802

This published work aimed to examine if a MOOC on dementia can be used to make demonstrable changes to attitudes towards dementia and utilised a pre- and post-course survey approach. Previous publications dealt with the textual elements of BTDD’s data, inductively determining useful information. However, it was not yet clear whether BTDD made a measurable difference to attitudes or perceptions. At the time of undertaking this research, the effect of MOOCs on people had only been considered in a small number of cases, and not at scale (Watson et al., 2016a; Watson et al., 2016b; Watson, Kim, and Watson, 2016). MOOCs were being developed and delivered; however, it was unknown whether they were useful, had an impact, or if participants’ behaviour, attitudes, or perceptions were changed because of them. It is now known that participants engage in microlearning and may not complete all elements of a MOOC (Bothe et al., 2019) but at the time BTDD began it was expected that people would fully participate in the whole programme.

This research was influenced by published works 2, 3, and 4, and was designed to determine if studying BTDD had an impact on participants. The study utilised the Northern Ireland Life and Times survey on dementia: an un-validated survey examining attitudes towards dementia and capacity for independent living in Northern Ireland (Dowds et al., 2010). Although this survey was tested at scale, the un-validated nature of the survey is a limitation. Participants were invited to participate via a web page within BTDD to complete the survey before and after they studied the course. Participation in this survey was optional and learners could continue the course without completing the survey. Using opportunity sampling, a total of 956 participants agreed to participate of which 107 (16 males and 91 females; Age 41-50 years = 28, 51-60 years = 26, 21-30 years = 20, 31-40 years = 19, 61-70 years = 10, 16-20 and 71-80 years = 2 respectively) completed the questionnaire at both pre- and post-MOOC stages. Seventy-four per cent were British (n = 79), and the remaining 28% included nine people from Oceania, seven people from North America, six people from Europe, three people from Africa, two people from Asia, and one person from South America.

Sixty-one percent were healthcare workers (n = 65); 37% included managers, students, and researchers with no area specified, and retirees (n = 40); and 2% did not answer (n = 2).

This study was large in scale and used robust quantitative analysis with statistical software. The project had four hypotheses:

- Hypothesis 1: There would be a significant median difference between pre- and post-MOOC assessments for the attitudes towards dementia – this was partially accepted.
- Hypothesis 2: There would be a significant median difference in people’s attitudes towards someone who has been newly diagnosed with dementia and who has been living with dementia for a long time – this was accepted.
- Hypothesis 3: The change in the attitudes towards dementia between pre- and post-MOOC would be different between healthcare and non-healthcare workers – this was partially accepted.
- Hypothesis 4: The change in the attitudes towards dementia between pre- and post-MOOC and demographics would be related to each other – this was partially accepted.

Of the four hypotheses, one was accepted and three were partially accepted. The results suggested that BTDD was more effective in changing the attitudes of non-healthcare workers, older people, and UK-based participants. Generalising these findings indicated that change interventions aimed at perceptions of or attitudes towards dementia should keep independence, autonomy, and control at the centre of their content because providing awareness training about this aspect could change the overall attitudes of dementia. This type of intervention seemed to be useful and have some impact, therefore it might be useful to consider MOOCs for other health conditions requiring attitudinal change including diabetes, obesity, depression, heart disease, cancer, stroke, alcoholism, and smoking.

This study collected many survey responses; however, it was difficult to perform participant matching. Once this has been completed, the number of actual people who completed the pre- and post- survey was less than expected. This lower number was due to loss to follow up and non-completion of the course. Although completion for

BTDD was higher than other MOOCs, this resulted in the loss of participants. It was possible to perform an analysis comparing the whole pre- and post-groups, however, these results were not meaningful because many of the participants were different people. The size of the effect was not determinable and the sample size of people who completed the pre- and post-course surveys was small when compared with the overall number of participants. The Northern Ireland Life and Times Survey on Dementia (ARK, 2018) was used in this survey, and although this has been reliably deployed on a national scale in Ireland the survey has not been validated.

The results from the publication were interesting and stimulated further debate and discussion about the impact of MOOCs. The data indicated there may be an association between studying BTDD and changes in perceptions or attitudes. However, participants could have been exposed to other events during BTDD which could have affected their attitudes towards dementia. The sample size was also small, and therefore the study is probably underpowered to make strong conclusions: further research is needed on a larger scale to quantify the effect. This study assessed attitudes, and these are notoriously difficult to understand and measure due to their individuality (Myers, Abell and Sani, 2013). It is possible that any changes in attitudes or perceptions happened either because of taking the course or another extraneous uncontrolled variable.

Research is ongoing to determine the specific factors to improve attitudes and perceptions. Phillipson et al. (2014) surveyed Australian adults to examine the factors associated with attitudes towards dementia. They used a range of scales of identified four attitudinal factors: personal avoidance, fear of labelling, fear of discrimination, and person-centredness. They also examined the links between these and help-seeking intentions, finding an association between personal avoidance, fear of labelling, fear of discrimination and delaying or avoiding help-seeking (Phillipson et al. 2015). A randomised controlled trial is currently underway examining the effects of education versus ‘contact’. Kim et al., (2019) are currently investigating the differences between a group studying an online course about dementia only; a group who watch video clips reflecting life with dementia; a group who have both the course and video clips; and a control group who receive nothing. The study uses the attribution questionnaire by replacing the words ‘mental illness’ with ‘dementia’, and the dementia knowledge assessment scale (Annear et al., 2017). Surr and Gates’ (2017) systematic review, audit and case studies determined some of the success factors of dementia training and education. Their work found the importance of social learning and presenting the experience of living with dementia. Phillipson et al. (2016) reviewed knowledge transfer methods in dementia education for health professionals, identifying six principles: matching the education strategy to the learning goal and learner preferences, using integrated multimodal strategies, building relationships, using compelling messages relevant for the audience, providing incentives, and planning to change the environment, not just the person. These projects can be compared with Hattink et al.’s (2015) European Skills Training and Reskilling project, involving an eLearning tool on dementia. Their randomised controlled trial reported improvement in attitudes towards dementia and person-centred care, empathic concern, and awareness of distress. This study used the Usefulness, Satisfaction and Ease of Use (USE) questionnaire and the Alzheimer’s Disease Knowledge Scale (ADKS), and evaluated the usefulness, user-friendliness and effectiveness of the training. These studies demonstrate there is an ongoing interest to evaluate education programmes and determine the factors which succeed in making improvements for participants.

This research contributed to aim 2 and addressed research questions 2 and 3. Applying the Kirkpatrick model (Kirkpatrick and Kirkpatrick, 2016) to this published work, this research examined levels 2 and 3: learning and behavioural change. The research found that BTDD did make a difference in the attitudes towards and perceptions of dementia. This demonstrates BTDD’s use as a useful and meaningful change intervention within the context of dementia. These findings are significant for policy and practice, as well as pedagogy. Educators desire for their students to improve, develop and grow and this research identified some of the potential factors which promote this growth and change, focusing on specific areas of information and knowledge to elicit changes. This study allowed me to develop quantitative research skills and is a demonstration of the mixed-methods and pragmatic approaches of my work.

Published work 8: Robertshaw, D., Babicova, I. (2019) New perspectives on great questions: what can MOOCs tell us? EURODL <u>https://www.eurodl.org/index.php?p=current&sp=brief&article=828</u>

This publication aimed to consider the role of MOOCs as a source of rich natural language data to be mined and analysed. It also aimed to consider whether MOOCs could bring new perspectives and insights to questions, theories, or experiences in relation to health and healthcare. This publication was influenced by published works 2, 3, 4, and 7. The prior research findings led to further discussion and thought about the usefulness and purposes of MOOCs like BTDD, and their value as a change intervention within the context of dementia. Findings also needed dissemination for implementation in practice and pedagogy. Therefore, the following publications were aimed at disseminating the information and new knowledge obtained throughout these research projects.

This publication examined the philosophical aspects of MOOCs and BTDD, and narratively discussed whether using MOOCs like BTDD was a viable and useful one. Online research is a contentious area, and MOOCs have only recently been used for research in this way reference (Zhu et al., 2020). This publication was different from others, in that it was a narrative exploration of the use of MOOCs to answer ‘great’ questions. Aimed at stimulating debate and discussion, this publication also took a critical perspective of MOOCs as a research platform and whether there were any issues with this approach. A prior paper (Robertshaw and Babicova, 2020b), which used Twitter as an alternative source of data to analyse dementia, also raised many of these questions. Therefore, this paper considered the contentious aspects of using these types of platforms for research. The participant metadata in both MOOCs and Twitter is a source of rich natural language data which can be mined and analysed to bring new insights, yet ethical and moral questions arose throughout this thesis about using the data in this way.

This publication contributed to aim 2 and addressed research question 3. This publication intended to challenge previous work and consider whether researchers should be undertaking research with a MOOC: continuing a pragmatist approach to scrutinise and re-examine prior findings and conclusions. It also considered the value of research originating from within MOOCs. This paper took the position that using participant metadata is a controversial methodology and there are many complex issues surrounding its use. This published work situated BTDD within the wider context of MOOCs and pedagogy and made the judgement that even though this area is fraught with ethical, legal, and moral challenges, the research findings were still beneficial and applicable. Despite these challenges, this publication judged that BTDD's contribution was worthwhile and valid. This publication can be reviewed under the fourth level of Kirkpatrick's model because it discussed some of the organisational, theoretical, ethical, and moral implications of BTDD as an intervention. This work offered reassurance that BTDD was an ethical and moral intervention for change and confirmed that earlier conclusions were applicable.

Published work 9: Robertshaw, D. (2016) *Online learning as a vehicle for social change. TEDx Derby.* Available at https://www.youtube.com/watch?v=63lobffry6s

The final two publications included within this thesis were also aimed at the dissemination of research findings for implementation in practice and pedagogy. This published work, a TEDx talk, is a recorded presentation given at the TEDxDerby event in 2016. This work aimed to situate MOOC within the wider context of online learning, and consider how this could be used for social change. It intended to share early findings from the research programme. TEDx events are organised by the community and are guided by TED's mission to "research and discover ideas worth spreading". The events are designed to identify new ideas, share the latest thinking, and research, and start conversations about what the future may be like (TED, 2020). This published work is 11-minutes long and was one of the earliest disseminations of this project. It was influenced by published works 1 and 2, and included findings from the initial analysis, positioning BTDD within the wider context of online learning as a vehicle for social change. The talk gives a narrative account of the use and abuse of technology and sets out a case for how our use of technology will change in the coming years. This video considered the idea that online learning gives people access to higher education that would never have. BTDD was a central concept of this TEDx talk and this work analysed the contribution of BTDD, situating its development within the wider body of evidence and society. It considered some of the challenges and issues in relation to increased technologization.

This published work contributed to aim 2 and addressed research question 3. It is relevant for evaluation at the fourth level of Kirkpatrick’s model (Kirkpatrick and Kirkpatrick, 2016). This level is concerned with the impact of an intervention including moral, financial, or ethical impacts (Smidt et al., 2009). Although the video is short, this work is important and had an impact because TEDx talks are a useful component of a dissemination strategy and help to inform wider audiences about research and scholarly work (di Carlo, 2015; Rankin, 2020). It is highly likely that this video has had a broader impact than the other published works included in this thesis, because it has been viewed more than 1,800 times on YouTube, and its intended audience is those who work in practice or education settings. This work allowed me to bring my research to a wider audience and taught me about the importance of engaging with the public on research findings. This published work demonstrated the impact of BTDD, and the research undertaken throughout this thesis.

Published work 10: Robertshaw, D. (2019) Technologisation of nursing education, in Dyson, S.E., McAllister. M. (Eds) (2019) Routledge International Handbook of Nurse Education

Following the other research projects and publications, this chapter on the technologization of nursing education featured as part of a wider textbook on nursing education. This chapter aimed to consider the use of technology in nursing education and explored MOOCs (including BTDD) alongside a range of other technologies. This publication drew together the findings and implications from the whole body of work included in this thesis. BTDD featured in this chapter heavily, and MOOCs were discussed as part of a wider toolkit of resources. This chapter echoed the TEDx talk in that its aim was public dissemination and it was intended to stimulate discussion and debate. This chapter, which appeared in a textbook on nursing education, brought together most of the research work in this critical appraisal with the specific purpose of implementation into practice and pedagogy. This published intended to disseminate the research to a broader professional and practitioner audience.

The chapter focused on the technologization of nursing education, and explored various technologies including virtual reality, augmented reality, online learning, MOOCs, applications, barriers, and enablers of the use of technology and the future development of technology in nursing education. This chapter was situated in a wider text about nursing education and discussed the use and application of technology in pedagogy. This chapter discussed MOOCs and BTDD in particular, as an opportunity for nursing and healthcare, and research. It argued that MOOCs have changed the way universities and higher education engages with the world, making education accessible to all (Sanchez-Gordon and Lujan-Mora, 2016). BTDD was considered as part of a range of pedagogical approaches used in nursing and healthcare studies generally. It demonstrated the use of BTDD as an example and gave information and advice to educators about how they can use MOOCs like BTDD for a positive effect.

The chapter covered a range of topics related to the use of technology in nursing education; the strength of this work is that it was able to review the main theories and applications, and then make a judgement about whether each technology was useful or not. The chapter also considered how the future may look for technology-enabled learning in nursing.

This publication contributed to aim 2 and addressed research question 3. Phillips (2012) added a fifth level to Kirkpatrick’s model (Kirkpatrick and Kirkpatrick, 2016), “return on investment”. This level was concerned with the wider implications and return of investment or an intervention or training and is particularly important to consider the impact of BTDD within the context of this publication. Considering BTDD and this publication from the perspective of level 5, this published work drew together the knowledge, understanding and application of the research conducted as part of this thesis and became BTDD’s legacy, returning the investment to practice and pedagogical applications. This publication also demonstrated to me that BTDD had a legacy and confirmed the wider impact of findings conducted as part of this programme of research.

Chapter summary

Using Kirkpatrick’s model (Kirkpatrick and Kirkpatrick, 2016) and Phillips’ (2012) ‘fifth level’ this chapter has used published works included in this thesis to evaluate BTDD as a change intervention within the context of dementia and the impact of dissemination of research findings for implementation in practice and pedagogy. Reflecting on these works, they demonstrate a wider practitioner and researcher journey. The publications identified impact and outcomes as well as disseminating findings from earlier work. The works contained in this chapter highlighted to me the importance of engaging with a broader audience than just those who read academic journals. The video and book chapter may have a larger audience than the works published in academic journals included in this thesis. These publications have demonstrated, in combination with the Kirkpatrick model, that BTDD was a useful change intervention within the context of dementia. The body of work has also demonstrated impact from its research findings, and these are beginning to be implemented in practice and pedagogy. The next chapter will consider these impacts and the next steps in greater detail.

Chapter 4: Impact and next steps

“It is sad and fatiguing for families who have to look after their loved ones and can also become frustrating, especially when the only thing left for them to do is to wish them a quick recovery and feeling hopeless at the same time knowing it is impossible since there is no cure. I believe the only chance, is to provide the best care for these folks, and maintain their dignity, and quality of life to the best of one's ability.”

Bridging the Dementia Divide participant

Impact of the published works

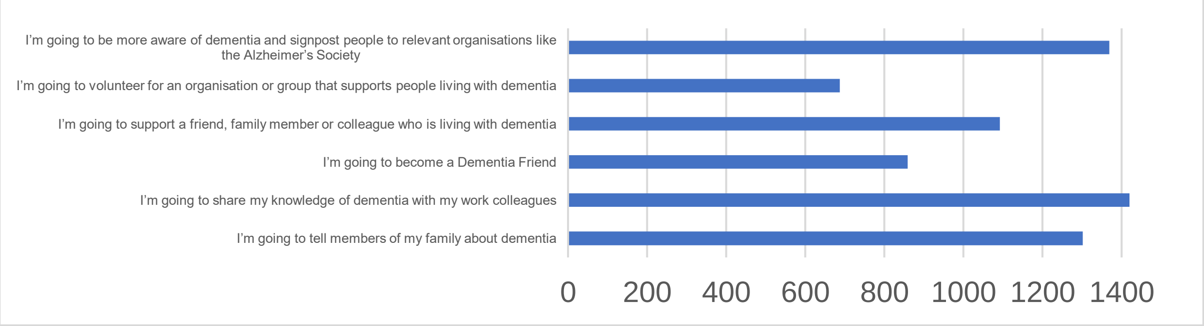
The published works included in this thesis have included a range of different methodologies. These projects and publications have characterised dementia from MOOC-user perspectives, characterised dementia from Twitter user perspectives, discovered new knowledge about integrated care for dementia, examined whether BTDD had any impact on perceptions and attitudes towards dementia, disseminated practice about the technologisation of nursing education, and considered the use of social media and forum data to bring new insights. This body of work has demonstrated that further research is needed on understanding dementia and related diseases (Robertshaw and Cross 2019a, Robertshaw and Cross 2019b, Robertshaw and Kotera 2019). It has shown that dementia is still poorly understood (Robertshaw and Kotera, 2019). There remains a lack of awareness of each type of dementia and there are many misconceptions. The body of work has shown that these misconceptions can be changed however: a person’s attitudes towards dementia are not fixed, they can and do change (Robertshaw and Kotera, 2019). The research has shown that there are positive and negative perspectives of dementia (Robertshaw and Babicova, 2020). It is not all ‘doom and gloom’: people are living well with dementia and people are thinking positively about it. The published works have found the whole range of healthcare professionals are valued in dementia care (Robertshaw and Cross, 2019b), and families are important as well as keeping the person at the centre of their care (Robertshaw and Cross, 2019a). Communication has been found to be one of the most important aspects of dementia care, and participants consistently valued this. Participants felt that care coordination and care navigation are important aspects of this, but they are not yet fully embedded processes (Robertshaw and Cross, 2019a). Future areas of work concerning integrated dementia care should identify the ‘levers’ to make integrated dementia care happen, to consider the factors and activities that make it successful. Training and education on dementia are important: and the research has identified that interventions should keep independence, autonomy, and control at the centre of their content (Robertshaw and Kotera, 2019).

This research has shown that MOOCs are a useful resource for their users (Robertshaw and Cross, 2016; Robertshaw and Cross, 2019a; Robertshaw and Cross, 2019b; Robertshaw and Babicova, 2019; Robertshaw and Babicova, 2020a;

Robertshaw, 2019). It has shown that MOOCs can be used as platforms for testing ideas and asking questions (Robertshaw and Cross, 2016). Online fora, in general, are useful sources of data and can be used as platforms for research: the information and insights available from participant metadata are valuable, if analysed correctly (Robertshaw and Cross, 2019a; Robertshaw and Cross, 2019b; Robertshaw and Babicova, 2020a, Robertshaw and Babicova, 2020b). Using MOOC meta-data is a surface-level method, however, and generates further deeper questions to be tested with more rigorous research. The findings suggested that this MOOC could change attitudes of specific groups of people and the same approach could be used for other diseases (Robertshaw and Kotera, 2019). MOOCs, although they have limitations, have proven to be a useful method of conducting social research in health and social care by “crowd-sourcing” solutions, ideas, and insights (Robertshaw and Babicova, 2019).

The published works included in this thesis have impacted the development of MOOCs, dementia, pedagogy, the University of Derby, as well as having a personal and professional impact. BTDD had an impact on the learners themselves, and hopefully the communities they live in. A key part of BTDD was that it was designed to be a national and international ‘call to action’ to encourage participants to commit to doing something in relation to dementia. All responses were collated and related to six different commitments (figure 3).

Figure 3: The commitments



Participants were also invited to submit an open-text comment regarding their contribution. A representative sample of responses are included below (table 4), which were chosen to reflect the themes of the direct commitments participants’ made following the thematic analysis of responses. The course did not exist solely for information, it was designed to be a tool to implement change and collect research data. Participants from all over the world completed this, demonstrating international impact.

Table 4: Commitments from BTDD participants

"Advocate for the communication needs of people with dementia, regardless of their native language, through my work with patients in the acute hospital."	"To request my local member of parliament to propose to parliament to have a national dementia strategy before the end of the current parliament."	"To create public awareness on dementia by organising rallies, road walks, market place, churches, mosques, and other public areas."
"To become a dementia friend and advocate. Attend training in dementia. Spread dementia awareness to other people. Support client with dementia as well as families and friends to make their lives easier"	"To speak at our infant primary school in the village about dementia, so that the children understand a bit more, if any of their family members have dementia."	"I am going to share knowledge of dementia with my work colleagues and reflect own practice of care for patient with dementia so that me and other care workers will not be burn out and to improve health care services for the patients with dementia."
"To visit local businesses to get them to sign up to become dementia aware to get them to sign up to become dementia aware, by taking out the Purple Angel documentation. Businesses will be those who deal directly with the public. I will visit four a month."	"I will speak to schools and universities to start a small private summer school for teenagers of my local community to learn about Dementia and assist those family members who are living with a Dementia patient"	"I have downloaded the application forms for becoming a volunteer with the Alzheimer's Society Research Network. I have already discussed this with my relative who is in the very early stage of FTD and we feel he has a lot to offer."

BTDD had a wider impact, and participants demonstrated they had learned and changed their feelings and perceptions towards dementia:

- *“I have a better understanding of Dementia and I can apply the learning around communication to my working practice.”* - participant.
- *“I will like to join or form a dementia support group ask for assistant from individuals, corporate bodies, religious organisation and government. The course has a positive impact on my future career.”* – participant.
- *“I feel better prepared to encounter dementia in my personal and public life and I will want to learn more.”* – participant.
- *“Definitely to make a difference for those affected by the grief when a loved one has dementia and for my patients to focus even more on their needs”* – participant.
- *“I am 69, so I do not expect to use my new knowledge in employed work, however I hope to use it in a voluntary capacity and also to help me as my role as my husband's carer becomes more difficult as his FTD progresses.”* - participant
- *“I will look at them more as a person with feelings, fears and wanting to have a purpose with the rest of their days. Then just look at them as the person down the hall with dementia and leave them be.”* – participant.
- *“I have been able to learn new ideas and ways of teaching and dealing with different situations. It impacts on my professional and private life as we are all touched by dementia”* – participant.

The course assessments were also impactful, and there were many inspiring examples of work that participants had undertaken as part of the MOOC. A sample can be found in appendix 28. Participants from around the world took their learning seriously and created a range of high-quality artefacts which could be disseminated and shared. These artefacts were so good, they were included in repeat runs of the course in an area called “Bridging the Dementia Divide+” which incorporated community-generated content – a novel idea at a time when MOOCs were becoming highly-produced and highly-controlled media.

BTDD involved a gamification element, enabling participants to gain open badges. This encouraged participation but also meant that participants shared their participation with others further increasing awareness of the course. These badges (figure 4) were designed by a designer, using the titles of the individual units. When a participant completed a unit, they received the badge. Thousands of badges were awarded, which demonstrating that people who participated in the course have learned skills and knowledge relevant to dementia care. Badges have now been implemented successfully across the University of Derby for a range of short courses, MOOCs, and mandatory staff training.

Figure 4: Badges

More than 100,000 learners from around the world have now studied MOOCs and short courses at the University of Derby (University of Derby, 2020) which were based on BTDD's model. BTDD was the first MOOC to be developed by a member of staff at the University of Derby, and this involved developing a quality assurance framework for MOOCs (Robertshaw, Owen and Hadi, 2015). This quality assurance framework was eventually adapted for short courses. BTDD was the first course to help the University gain OpenUpEd approval, a marker of quality and a high standard to attain (University of Derby, 2017). The course was included in mandatory training for all staff at the University and counted as equality, diversity, and inclusion training. Therefore, many staff at the University have studied BTDD and have been impacted by participating.

During the 2020 COVID-19 pandemic, many of the lessons learned during the delivery of MOOCs (including BTDD) by the University were able to be applied across the institution. There are still ongoing conversations about MOOCs, short courses and microlearning which have been informed by BTDD’s development and delivery. BTDD impacted pedagogic approaches to online learning and open educational resources at the University of Derby.

Since its development, BTDD has impacted upon the development, validation and approval of 16 degree programmes and short courses at the University of Derby as well as 28 other degree programmes and short courses (see appendix 26). These programmes were significantly informed and influenced by BTDD, as at least 23 of these were online courses or programmes. BTDD provided the opportunity to test assessments or activities and then bring the successful ones to the curricula being developed.

Reflecting on earlier work (Robertshaw, 2016; Robertshaw and Cross, 2016), the analytical techniques and findings were presented simply. The TEDx talk presented some analysis of a pre-course and post-course survey examining the perceptions of dementia. This first analysis of the results looked at groups, rather than matching individual participants. The findings from this first analysis were not contradictory to the final papers, but they were not in detail and not as robust as research performed later in this thesis. There was, therefore, methodological development and each project impacted upon the next. This work helped to process the dissemination of the research undertaken and recognise the importance of international public engagement in research. There was public and international interest in this research, therefore there was a professional responsibility to present the information correctly and coherently. The audience was different to an academic audience, yet arguably this video may have had a more professional and practitioner impact. This video supplemented the videos already created as part of the MOOC which to date have been watched more than 76,000 times.

Later research and published works have begun to have a wider national and international impact. Robertshaw and Cross (2019a) have been cited by several authors in the field including McInerney et al. (2018) who cited this paper, referencing it as an example of using participant metadata to bring new insights and findings. Backhouse (2017) cited the work in her PhD thesis, referencing this work to demonstrate that effective collaborative and integrated services have consistently been a priority. Ojo, Brooke and Cronin (2019) cited the work in their paper on cultural beliefs in dementia, using the publication as an example of Framework Analysis. Parsons and Gamble (2019) identified this paper in their review of caregivers’ perspectives and experiences of withdrawing acetylcholinesterase inhibitors and memantine in advanced dementia, specifically because this study focused on using online fora as a data collection tool. They identified the publication as an example where “naturally occurring data” has been analysed. Jacobsohn et al. (2019) also cited this paper in their study on emergency care services in people living with dementia, saying that although there is growing evidence about individual and caregiver needs only a small number of studies have included the needs of healthcare providers. This paper was one of the examples. Martin-Valero et al (2019) highlighted BTDD as an example in their work also, including information about BTDD’s content and design. They identified BTDD’s purpose of changing attitudes and perceptions of dementia.

Robertshaw and Cross (2019b) have been cited by authors mapping post-diagnostic dementia care in England (Frost et al., 2020), using a key finding of the work that electronic systems are key to supporting interprofessional communication. Ylitalo-Katajisto’s (2019) study on health and social care integration in Finland cited Robertshaw and Cross (2019) to demonstrate how slow progress had been towards multi-professional cooperation. The research is beginning to have an impact on other MOOCs and publications relating to policy, resulting in citations by others.

These published works have used a variety of methodologies and approaches. This is a strength of the work; however, each paper has its limitations which are acknowledged in the publications themselves. Earlier work was briefer, and was more surface-level, focusing on the MOOC’s content and structure and how BTDD could contribute to dementia care. However, this stimulated debate and acted as an introduction to the field. Later work grew in-depth and focused on answering important questions about dementia, as well as dissemination for implementation in practice and pedagogy.

Throughout these research projects and published works, it has been more effective to collaborate with other authors. This has been a great strength of the work; the discussion and debate arising from collaboration has made each project and study better than it could be. This has resulted in research and scholarship networks with researchers across the University and in other institutions. It has been a delight to lead, develop and deliver BTDD. This work has demonstrated a professional, practitioner and researcher journey.

BTDD opened new doors, and this work was recognised at a national level. The Member of Parliament for Mid-Derbyshire noticed BTDD and its impact. This resulted in being invited to speak at the Palace of Westminster (Robertshaw, 2015). Following an oral presentation at the Higher Education Academy (HEA) National Conference (Robertshaw, 2016a), the HEA invited me to host a development day aimed at practitioners working in Universities throughout the United Kingdom. The development day included workshops on the strategic context of MOOCs (Robertshaw, 2016b) as well as how to design MOOCs for impact (Robertshaw, 2016b). The course continues to this day and has increased in popularity during the COVID-19 pandemic when MOOCs have proved their worth to disseminate information to large populations quickly.

This body of work has been broad and has involved a range of research methodologies, publication types, audiences, and outlets. There has been a range of original contributions. Table 5 identifies the original contributions originating from this thesis and demonstrates how these are mapped to the aims and research questions.

Table 5: Original contribution originating from this thesis

Original contribution originating from this thesis	Relevant aim	Relevant research question
The design and build of the MOOC itself, and the impact it had on the people who studied it. It took an innovative approach to change peoples' minds about dementia. This demonstrated a proof of concept.	A1	RQ1, RQ2, RQ3
Demonstrated the use of MOOCs and Twitter as a data source that can be analysed (mined) to bring new insights/knowledge.	A2	RQ1, RQ2, RQ3

Characterised experiences of integrated care for dementia and the roles and responsibilities people play in integrated care for dementia from the perspective of MOOC participants.	A1	RQ1, RQ2
Characterised experiences of dementia from the perspective of MOOC participants.	A1	RQ1, RQ2
Discovered what people were saying and how people talking about dementia on Twitter. Themes and concepts were explored in this dataset.	A1	RQ1, RQ2, RQ3
Performed pre- and post-MOOC analysis to determine what changed as a result of studying the MOOC. This type of comparison to look at this change in this context has not been performed before. It demonstrated that the MOOC may make a change in some areas.	A2	RQ2, RQ3
Considered the usefulness of and applicability of data originating from MOOCs, and discussed the ethical/moral issues related to this.	A2	RQ2, RQ3
The TEDx talk disseminated early findings from the research.	A1, A2	RQ2, RQ3
The chapter contributed to nursing education and practice, identifying a range of useful technological tools and techniques which can be used. One of these was the MOOC, and so this work referenced other publications in this body of work.	A2	RQ3
The MOOC itself has contributed to the actions of MOOC participants and the people they care for or work with.	A1, A2	RQ2
This MOOC was the first at the University of Derby and was an early MOOC. This body of work overall has contributed to University and teaching/learning policy and practice, influencing other programmes and developments (e.g. during COVID-19).	A1, A2	RQ3

The thesis resulted in a conceptual model of a MOOC aimed at promoting social change, which is an original contribution and will be prepared for publication.	A1, A2	RQ3

Next steps and future work

Future work will be aimed at a larger scale and ongoing analysis of perceptions and attitudes of dementia as a sort of ‘litmus test’ to see how these change over time. This thesis has used big data to bring new insights and knowledge about dementia. Big data is an approach involving the storage and computational analysis of an extremely large and complex volume of data using a variety of methods and techniques (Ward and Barker, 2013). Big data is characterised by high volume, velocity, and variety, and is focused on applying specific technological and analytical methods to transform these into value (De Mauro, Greco, and Grimaldi, (2016). Big data analysis, where large datasets are computationally analysed, has great potential for dementia. It was identified as an opportunity as early as 2014 (OECD, 2014). Big data is useful because this approach can be used for monitoring and detecting patterns and concepts in large datasets which would not or could not be seen otherwise (Moore et al, 2013; Moore et al 2013; Ienca, Vayena, and Blasimme, 2018; Gendelman et al., 2018). Some examples of big data projects in the field of dementia include the European Prevention of Alzheimer Disease (EPAD) study (Solomon et al., 2019) and the PREVENT research programme (Ritchie and Ritchie, 2012). Big data has been widely used for many applications in high-income countries (Doubal et al., 2017) however because big data is highly cost-effective and efficient when compared with other methods, this approach particularly presents opportunities for low- to middle-income countries (Danso et al., 2019).

There are ethical and legal challenges in Big data research, particularly around consent, data privacy, and respect for human rights. New branches of ethics are forming to cater for this (data ethics) (Floridi and Taddeo, 2016). Ultimately, this data must be ethically and legally obtained as well as being scalable. This requires sustainable governance procedures and policies which specifically cater for data relating to people living with dementia (Milne and Brayne, 2020). The DEEP-Ethics

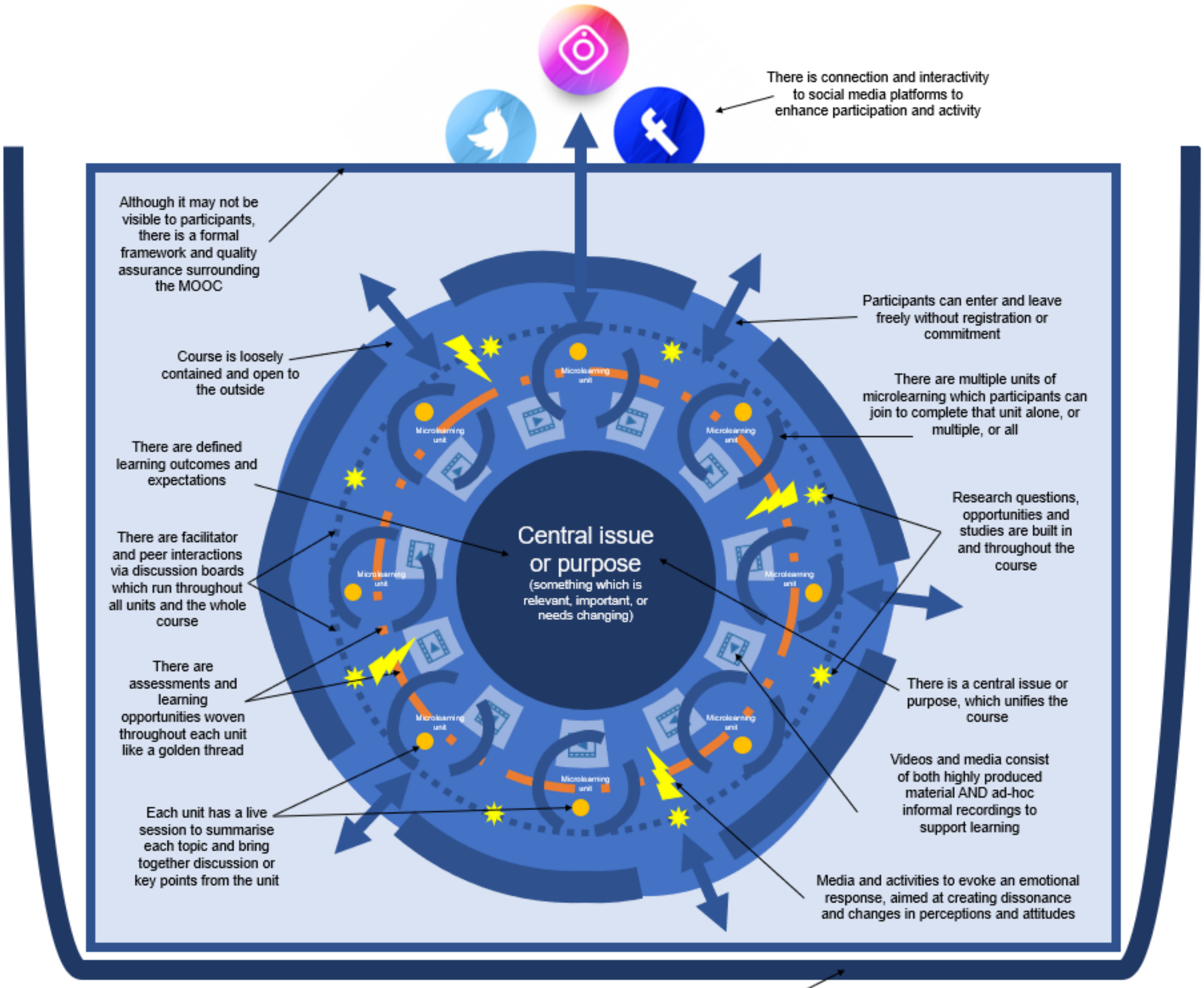
Gold Standards for Dementia Research (Innovations in Dementia, 2020) tackles some of these challenges. These principles ensure that research involving people living with dementia is fair, transparent, and safe. It should also acknowledge and respect individuals, have robust informed consent and capacity processes, and confidentiality and anonymity must be maintained.

This thesis has used participant metadata, a type of big data. The works included in this thesis have demonstrated that this type of research can be useful and bring meaningful insights. Although this research took place before the publication of the DEEP Ethics Gold Standards for Dementia Research (Innovations in Dementia, 2020), the methodological design was highly cognizant of the needs and wishes of people living with dementia. Future projects will continue to be cognizant of these needs and wishes, will fully adopt the DEEP Ethics Gold Standards, and will involve larger elements of big data research, datasets, and computational analysis.

Further research will be conducted on the application of MOOCs in this area but also for other diseases. It would also be interesting to identify the impact of MOOCs on other courses and programmes, and to determine the longitudinal impact on learning, professional practice, and patient care to see if MOOCs make a positive or negative change. COVID-19 has demonstrated the widespread use of MOOCs, and it would be interesting to evaluate their impact on professional practice during this time using some of the methods demonstrated during this thesis.

The research conducted as part of this doctoral work has suggested there are useful elements to implement when designing a MOOC aimed at promoting social change. BTDD featured a centrally important issue and purpose of its existence. It also included art, poetry, videos, interactivities, and learning opportunities aimed at causing dissonance to evoke emotional responses. These elements can be conceptualised in a model (figure 5) for a MOOC aimed at instigating change in attitudes and perceptions. This conceptual model demonstrates that MOOCs should have a central purpose or issue which should be emotionally important or an issue worth changing (Robertshaw and Cross, 2016). The units can be studied in any order, and the MOOC is open without the need to register (although users can register for the MOOC). There are assessments running throughout each unit although these are optional and involve peer assessment. The MOOC should target social change by focusing on emotion and personalising the issue or problem (Robertshaw and Kotera, 2019). There should be research and scholarship opportunities identified throughout the MOOC to answer important questions (Robertshaw and Babicova, 2019). Open activities where participants respond with text could also undergo content analysis (Robertshaw and Cross, 2019a; Robertshaw and Cross, 2019b; Robertshaw and Babicova, 2020). Learners should be invited to be creative and there should be media and video content to enhance participation. Social media interaction can also be helpful to encourage participation. Sharing of user content as happened in BTDD can also be a powerful way to involve users in their learning experiences.

Figure 5: a conceptual model of a MOOC aimed at promoting social change (from Robertshaw, D (2021) Designing a MOOC for change and social impact, *working paper*)



There is connection and interactivity to social media platforms to enhance participation and activity

Although it may not be visible to participants, there is a formal framework and quality assurance surrounding the MOOC

Course is loosely contained and open to the outside

There are defined learning outcomes and expectations

There are facilitator and peer interactions via discussion boards which run throughout all units and the whole course

There are assessments and learning opportunities woven throughout each unit like a golden thread

Each unit has a live session to summarise each topic and bring together discussion or key points from the unit

Participants can enter and leave freely without registration or commitment

There are multiple units of microlearning which participants can join to complete that unit alone, or multiple, or all

Research questions, opportunities and studies are built in and throughout the course

There is a central issue or purpose, which unifies the course

Videos and media consist of both highly produced material AND ad-hoc informal recordings to support learning

Media and activities to evoke an emotional response, aimed at creating dissonance and changes in perceptions and attitudes

There is a container for the MOOC, for example a virtual learning environment or social media platform

Chapter summary

This chapter has considered the impact of research and publications within this body of work. This evaluation has demonstrated that BTDD and its resulting research have had an impact and its findings are now being implemented in practice and pedagogy. This chapter also considered some of the next steps as well as suggesting a conceptual model of a MOOC aimed at promoting social change, which was designed based upon the research findings within this body of work. The next chapter will consider recommendations arising from the research as well as conclude this critical appraisal.

Chapter 5: Recommendations and conclusion

I am Sally, or I used to be. Until dementia got hold of me.
My head became fuzzy, my memories lost. The disease took hold at quite a cost.
My family despaired and could not see. What this awful disease was doing to me.
Do not shout, please treat me well. I cannot stand this living hell.
“It’s me, it’s me”, I want to shout. When people start to shut me out.
Please hold my hand and say you care. Don’t leave me here in my despair.
Sometimes I’m lost, sometimes I’m found. Don’t run off please stay around.
As time goes on my functions fade. Someone comes round, who you have paid.
They wash me, dress me, treat me nice. But all this comes at quite a price.
The world out there has taken note, and put it to a government vote.
Money for research, they put aside. This increasing disease they cannot hide.
The word is out and all combine. To try and make my world seem fine.
The days drag on, my breath grows shallow. My face becomes a sunken hollow.
They understand my time is near. I rest my head nothing to fear.
One last breath, I slip away. “That was Sally” I hear them say.

- *Bridging the Dementia Divide participant*

Recommendations

The published works in this critical appraisal resulted in a range of recommendations. They are graded according to the Harbour and Miller (2001) classification of evidence by comparing the methodological approach to the types of evidence in each classification (table 6). Evidence grades are generally low because of the type of studies and the small number of studies informing the recommendation.

Table 6s: Recommendations

Recommendation	Relevant aim and RQ	Source	Level of evidence	Strength of recomm.	Commentary
MOOCs should be investigated for the opportunities they provide for social change through their potential for internet-mediated research.	A1, A2, RQ2, RQ3	Robertshaw, D., Cross, A. (2016)	3	D	This was a recommendation of the 2016 work, and since that time this opportunity has been explored further by the research in this thesis, and by other authors (Lorizzo, Watson and Watson, 2018; Hudson et al., 2019; Watson et al., 2016). There is still potential for greater implementation and examination of this recommendation.
Dementia care should utilise the whole community of professionals and family	A1, RQ1	Robertshaw, D., Cross, A. (2019a)	2+	D	Work has continued in this area in a range of research projects (Hutchinson, 2018; Hutchinson et al., 2020; Webb and Dening, 2016; Brown, Oliver and Dening, 2020). This recommendation advocated a holistic approach, which is supported by a range of authors (Jackson et al., 2020; Aldridge et al., 2019; Wood et al., 2020; Lillekroken, 2020) however challenges in working with a whole community of professionals and family members still remain (Moore and Crawley, 2020; Jackson et al., 2020).
Dementia care should keep the person at the centre of care.	A1, RQ1	Robertshaw, D., Cross, A. (2019a)	2+	D	This was a recommendation of Kitwood’s work (Mitchell and Agnelli, 2015; Dewing, 2008; Brooker, 2004) and this has been implemented widely

					across care. There are examples of innovative and good practice (O’Rourke et al., 2020; Blake, Berry and Brown, 2020; Backman et al., 2020) yet many challenges remain and person-centred care is probably still not being implemented effectively (McKenzie and Brown, 2020; Scerri et al., 2020a).
During dementia care there should be clear lines of communication.	A1, RQ1	Robertshaw, D., Cross, A. (2019a)	2+	D	Communication is still vitally important and is still part of the research agenda (Alsawy et al., 2020; Savundranayagam, Basque and Johnson, 2020).
There should be an integration of health and social care systems.	A1, RQ1	Robertshaw, D., Cross, A. (2019a)	2+	D	Integrated care and transformation are a key part of sustainability and transformation plans (Alderwick et al., 2016), and there is still a focus on integrated dementia care, although this is still not fully embedded with some areas still piloting interventions (Oostra et al., 2020). Work is gathering pace internationally (Ritchie et al., 2020), as well as focusing on improvement and enhancement of existing integrated care systems for dementia (Sampson et al., 2020; Frost et al., 2020; Barman and Paulson, 2020).
Undertake further research to characterise the experiences of integrated care for people living with dementia and their carers	A1, RQ1	Robertshaw, D., Cross, A. (2019a)	2+	D	There has been continued research in this area, focusing on the experiences of dementia care in European countries (Lillo-Crespo et al., 2018), caregivers in integrated primary care models (Kovaleva et al., 2019) and research is now seeking to visualise solutions to day to day challenges (Chase et al., 2020).
All organisations should consider developing care navigation and co-ordinator roles and functions and develop interoperable IT	A1, RQ1	Robertshaw, D., Cross, A. (2019b)	2+	D	Care navigators as a role are still being used and reviewed positively, although their implementation could be broader. Several studies have reviewed the functions of care navigators, coordinators and interoperable IT systems (Bernstein et al., 2020; Frost et al., 2020; MacInnes, 2020).

systems with electronic records.					
All staff involved in dementia care should access education and training to promote skills and knowledge development.	A1, RQ1, RQ2, RQ3	Robertshaw, D., Cross, A. (2019b)	2+	D	Research has been ongoing in this area; Surr et al., (2020a) have identified the importance of dementia education and training and considered the barriers and facilitators of implementing education and training. There have also been innovative approaches to dementia education using YouTube (Lam and Woo, 2020) and Facebook (Chan and Leung, 2020) with success.
Knowledge and understanding of the roles and responsibilities of people and organisations need to be embedded into future professional programmes to give professionals of the future an awareness of their potential.	A1, RQ1, RQ3	Robertshaw, D., Cross, A. (2019b)	2+	D	This recommendation was identified during the research in 2016/2017. Subsequently, the optimal contents of dementia training and education were identified in Surr's (2017) 'What works' study and have been identified again in a recent study (Surr et al., 2020b).
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.	A1, RQ2, RQ3	Robertshaw, D., Cross, A. (2019b)	2+	D	Research has been conducted in this area concerning urgent care (Dooley et al., 2020), personalised care and quality of life (Hamiduzzaman et al., 2020), and quality of care (Werner, 2019). This area would benefit from a systematic review; one has been undertaken for Parkinson's disease (Rajan et al., 2020) and there has been some work on dementia care frameworks (Koumakis et al., 2019).
Change interventions aimed at perceptions of dementia should keep independence, autonomy, and control at the centre of their content because providing awareness training	A2, RQ2, RQ3	Robertshaw and Kotera (2019)	2++	C	There is still ongoing work to understand how attitudes and perceptions can be changed. Further work has been undertaken to consider the impact of change interventions (Cowan, 2019), and understand the attitudes of specific groups (Griffiths et

about this particular aspect could change the overall attitudes of dementia.					al., 2020; Scerri, Innes and Scerri, 2020b). The impacts of interventions are also now being analysed in randomised controlled trials, which is a positive step (Bjørge, Kvaal, and Ulstein, 2019).
Consider how MOOCs could be employed as public health interventions with potential large-scale impacts on society	A2, RQ2, RQ3	Robertshaw and Kotera (2019); Robertshaw and Cross (2019a), Robertshaw and Cross (2019b), Robertshaw and Babicova (2020a)	2++	C	This is still an area of interest and research but has not yet been explored fully. Fremont et al. (2020) explored this idea with concussion and Van den Broeck et al (2020) have recently examined the use of MOOCs to affect change in engineering.

Conclusion

This body of work began with the purpose of informing people about dementia and making a difference to the lives of people living with dementia and their carers. The resulting research had two aims. Firstly, to conceptualise and implement a MOOC on dementia: generating new knowledge pertaining to attitudes and perceptions and the lived experience of dementia within online fora. Secondly, to evaluate the MOOC as a change intervention within the context of dementia and the impact of dissemination of research findings for implementation in practice and pedagogy. BTDD has been studied more than 10,000 times and therefore has contributed to the education and experience of many people. BTDD has demonstrated that MOOCs can be used as a platform for research and social change (Robertshaw and Cross, 2016; Robertshaw and Cross, 2019a; Robertshaw and Cross, 2019b; Robertshaw and Babicova, 2020; Robertshaw and Kotera; 2019), and MOOCs like BTDD can be used to understand answers to important questions (Robertshaw and Cross, 2016; Robertshaw and Cross, 2019a). This work took a pragmatist perspective and has been focused on action, values, active communication, and change.

Research within BTDD identified that the experiences of integrated care from the perspectives of carers and families with dementia can be described in three themes: achieving person-centred holistic care, roles and the diffusion of responsibility, challenges for integrated care (Robertshaw and Cross, 2019a). It also found that care navigation is a useful function for people living with dementia, however, the care navigator role is not fully embedded (Robertshaw and Cross, 2019b). The research found that shared care records are felt to be important (Robertshaw and Cross, 2019b), but there is still a need to identify the activities which “work” to promote integrated dementia care (Robertshaw and Cross, 2019b). There still needs to be a greater understanding of the roles and responsibilities people and organisations play in relation to dementia care (Robertshaw and Cross, 2019b). Four conceptual themes were found to be central to the experience of dementia: “the condition”, “caring,” “perception”, and “control” (Robertshaw and Babicova, 2020). The research has also found that dementia is frequently discussed on Twitter, with tweets focused on the diseases, family members and friends, risk, and the emotions associated with dementia. (Robertshaw and Babicova, 2020).

BTDD did make a difference to participants’ attitudes towards dementia, finding a difference between pre- and post-MOOC assessments for attitudes towards dementia, a significant median difference in people’s attitudes concerning the time after diagnosis, and changes in attitudes between healthcare and non-healthcare workers.

BTDD’s design influenced the quality assurance framework, design, and approach of a range of other MOOCs and short courses at the University of Derby which have been studied more than 100,000 times. BTDD was able to help the University gain the OpenUpEd quality label (Rosewell and Jansen, 2014), and was implemented as one of the mandatory training options for equality, diversity, and inclusion training at the University. Many of the lessons learned during the development of BTDD and MOOCs generally were able to be applied during the 2020 COVID-19 pandemic, when teaching and learning experiences were delivered online. many of the lessons learned during the delivery of MOOCs by the University were able to be applied across the institution. BTDD has also impacted at least 44 degree programmes and short courses at the University of Derby. A book chapter (Robertshaw, 2019) situated BTDD within a wider handbook of nursing education which will be widely read and used by many nursing educators who may implement some of the technologies discussed.

This research on BTDD is having a wider impact and has influenced several research projects and publications. For example, how palliative care is considered in the context of dementia (McInerney et al., 2018), factors influencing emergency care by persons with dementia (Jacobsohn et al., 2019), caregivers perspectives and experiences of withdrawing medicines in advanced dementia (Parsons and Gamble, 2019), developing complex interventions to coordinate care for people with dementia (Backhouse, 2017), developing an analytical framework to explore student nurses cultural beliefs of dementia (Ojo, Brooke and Cronin, 2020) and creating audio-visual content in a MOOC about postural and technological adaptations in paediatrics (Martin-Valero et al., 2019).

This critical appraisal has the demonstrated new knowledge originating from research in, with and around BTDD as well as its use as a change intervention, and its subsequent impact on practice and pedagogy. It has brought together a range of works concerning these aims and demonstrated a coherent body of work. The body of research has shown that BTDD has had a measurable effect on dementia care and pedagogy (Robertshaw and Kotera, 2019; Robertshaw and Cross, 2019a; Robertshaw and Cross, 2019b; Robertshaw and Babicova 2019; Robertshaw and Babicova, 2020a; Robertshaw and Babicova, 2020b) however further research is needed in this area. MOOCs may offer a great opportunity for dementia and other health problems: they can raise awareness (Robertshaw, 2016), they may change attitudes (Robertshaw and Kotera, 2019), and they can help us to understand these problems in a more detailed way (Robertshaw and Cross, 2019a; Robertshaw and Cross, 2019b; Robertshaw and Babicova, 2020; Robertshaw and Babicova 2019).

BTDD provided rich data ready for analysis, and participants wrote about and shared their thoughts on dementia (Robertshaw and Cross, 2019a; Robertshaw and Cross, 2019b). Participants were clear about the roles they played and the responsibilities they held (Robertshaw and Cross, 2019b) (this was the focus on research question 1). BTDD did have some impact on perceptions and attitudes (Robertshaw and Kotera, 2019) (this was the focus of research question 2). BTDD did have key lessons for MOOCs and open educational resources, and its model informed and influenced MOOCs and short courses which would eventually support more than 100,000 learners (this was the focus of research question 3).

Preventative measures and treatments may eventually mean that diseases causing dementia do not exist. This will, ultimately, mean this work is not required or needed. However, if people are living with dementia, it is important to understand their experience. Now, dementia is a life-changing set of diseases. Researchers should be finding as many ways as possible to support people living with dementia, their families, their caregivers, and their healthcare professionals. This research has shown that it is not all ‘doom and gloom’. Having dementia can be a positive and a negative experience, although much of the literature focuses on the negative experience yet it does not need to.

Dementia is one of the most important issues of our time, and there are ongoing physical, psychological, social, and economic issues relating to dementia (Wimo et al., 2013). The care and support that people living with dementia receive have been unacceptable: they have been denied basic rights and freedoms, and the ability to make their own choices (Kelly and Innes, 2013; Boyle, 2010; Cahill, 2018). The “dementia divide” is the difference between how we expect to be treated, and the reality of people living with dementia. Bridging the Dementia Divide was designed to literally *bridge* this divide. However, BTDD is only one small part of the solution: national governments and international organisations as well as the members of society at large need to come together at scale and with resources to bridge the divide once and for all, for everyone.

It has been a privilege and an honour to undertake this work over the last six years; to have been the creator and custodian of a course that has taken on its own life. The research brought greater understanding and knowledge of dementia, allowed new approaches to be taken with MOOC research, and had a broader impact on practice and pedagogy. BTDD has made a significant contribution to pedagogy at the University of Derby and in universities nationally, by challenging previous notions of education and asking what could be, given a blank canvas.

Eventually, people and society will cross the ‘dementia divide’ and eradicate stigma and negative attitudes towards dementia. This critical appraisal concludes that BTDD has made a unique and valuable contribution to this movement.

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Appendix 1: MOOC Structure

Unit	Unit title, theme and indicative content	Unit learning outcomes (visible to learners)	Indicative activities may include
1	**Introduction to dementia** What is dementia and why is it important? Indicative content: • Types of dementia • History of dementia care • How the brain changes with ageing • How the brain changes with ageing	1. Learners will demonstrate a critical understanding of dementia, challenging its myths and stereotypes.	1. In the discussion boards, introduce yourself. 2. Outline your reasons for undertaking this course; do you have personal experience of dementia? 3. Write a short reflection on the challenges facing society in meeting the health and social needs of people with dementia. Remember to be reflective in your thoughts; use an example to illustrate how this directly applies to your situation. Formative Quiz
2	**Communication and Compassion** Why is effective communication important and how can you show compassion? Indicative content: • Compassion as a concept	1. Learners will evaluate the main theoretical perspectives applicable to the study of 'compassion' in care. 2. Learners will demonstrate a critical awareness of enhanced communication skills to enable	1. Share a website related to communication or compassion, which could be a government organisation or charity, from your own context. 2. Create a mindmap [support and definition will be given] of techniques you could use to help carers of people with dementia to communicate their needs. Share your mindmap on the discussion board. You could create your

	- Models and principles of compassion - Compassion in dementia care - Communication techniques	them to better communicate with people with dementia.	mindmap digitally or draw it on a piece of paper and then photograph the image with your smart phone or scan it. Formative Quiz
3	**Independence, control and quality of life** How can you help the person living with dementia to maintain independence, control and a good quality of life Indicative content: - Self-determination and the maintenance of independence - Ethical and legal challenges to enabling and respecting self-determination - Ethical theories - Consent and capacity	1. Learners will discuss techniques to defend independence, control and quality of life within the context of dementia, evaluating relevant ethical and legal frameworks.	1. What ethics and values apply to you? Are ethical principles universal? Share your thoughts on the discussion board. 2. Review Jacques’ comments on paternalism and consider whether paternalism in some form or another is inevitable in dementia care. Discuss this in the discussion board. 3. Reflect on the views expressed regarding euthanasia, particularly as applied to those with dementia. Share your thoughts as a group about the implications for those in need of ongoing care for dementia. [Optional activity] Formative Quiz

4	**Dementia as a Global health priority** Are Governments and organisations meeting the needs of people living with dementia? Indicative content: • Current UK Government approaches to dementia • European, USA and International responses to dementia • National Dementia Strategies	1. Learners will discuss and challenge global policies as related to dementia, considering what could be learnt from other societies.	1. Read the Executive summary of Dementia: A public health priority (WHO). 2. This document is internationally focused and examines dementia as a global public health priority. Pull out three points and explain their relevance and importance to your specific context (where you live or work). Share these on the discussion boards. Formative Quiz
5	**Integrating care** Is 'integrative' care able to support people living with dementia? Indicative content: • Definition and logic of integrated care • Implementing models of integrated care	1. Learners will appraise the concept of integrative care and consider why it is important in care generally, as well as in Dementia.	1. Consider the definition, strengths and limitations of integrated care as applied to Dementia, discuss these with your fellow learners in the forum. 2. Identify an area in your health and social care system that you consider to be 'fragmented' and may benefit from an integrated model of care. Share this and discuss with others. [Optional activity] Formative Quiz

	- Levels of integration in integrated care programmes - Effects and outcomes of integrated care		
6	**End of life care** The end: how can you support people living with dementia and their families during the final phase of life? Indicative content: - Loss of personhood - Key concepts of stigma and burden of care - Suffering - End of life care concepts	1. Learners will evaluate current approaches to the end of life care of people with dementia, maintaining personhood and quality of life.	1. Select two photographs that create a visual representation of living with dementia, or what it might be like to lose a close relative or friend to Dementia. These pictures may be of items, objects or places but please don't include pictures of people, even if they give their permission. 2. Post these photographs to the discussion board and share why you have chosen them and what they mean to you. Review other photographs and share your comments. Formative Quiz

Appendix 2: Summary of ethics applications

Application title	Date of approval	Reference number	Related publications
'MOOC' as a platform for social learning, research and social change in dementia	09/02/16	UDOL-02DR-AC-2015-16	Robertshaw D, Cross A (2016) 'MOOC as a platform for social learning, research and social change in Dementia'; Published in conference proceedings eMOOCs conference Robertshaw, D., Cross, A. (2019). Experiences of integrated care for dementia from family and carer perspectives: a framework analysis of massive open online course discussion board posts. Dementia, 18(4), 1492-1506 Robertshaw, D., Cross, A. (2019). Roles and responsibilities in Integrated Care for dementia. Journal of Integrated Care, 27(2), 131-140. https://doi.org/10.1108/JICA-05-2018-0037 Robertshaw D, Babicova, I (2019) discovering the memory thief: MOOC participants' personal experiences of dementia. Nurse Education in Practice
Can massive open social learning change perception of dementia?	04/03/16	UDOL-07DR-2015-16	Robertshaw, D. & Kotera, Y. (2019) Changing Attitudes with a MOOC on Dementia. European Journal of Open, Distance and E-learning 22 (2), 27-39. Retrieved from http://www.eurodl.org/?p=current&sp=full&article=802
Tweeting on dementia: a snapshot of the content and sentiment of tweets associated with dementia	28/06/19 Minor amendment 09/07/19	-	Robertshaw D, Babicova I (2019) Tweeting on dementia: a snapshot of the content and sentiment of tweets associated with dementia. First Monday [in press]

Appendix 3: Ethics application form for experiences of integrated care, roles and responsibilities in integrated care for dementia, personal experiences of dementia

Request for ethical approval for research undertaken by staff, post-graduate research and post-graduate professional students

Please submit your completed form to the chair of your college research ethics committee (CREC)

Your Name	David Robertshaw, Dr Ainslea Cross
College	UDOL
College Research Ethics Committee	UDOL
Staff ID	782814, 783835
Student ID	-
Unimail address	D.Robertshaw@Derby.ac.uk / A.Cross1@derby.ac.uk
Programme name / code	-
Name of supervisor(s)	-

Title of proposed research study
‘MOOC’ as a platform for social learning, research and social change in dementia

Background information	
Has this research been funded by an external organisation (e.g. a research council or public sector body) or internally (such as the RLTF fund)? If yes, please provide details.	No
Have you submitted previous requests for ethical approval to the Committee that relate to this research project? If yes please provide details.	No
Are other research partners involved in the proposed research? If yes please provide details.	No

Signatures

The information supplied is, to the best of my knowledge and belief, accurate. I clearly understand my obligations and the rights of the participants. I agree to act at all times in accordance with University of Derby Policy and Code of Practice on Research Ethics: http://www.derby.ac.uk/research/uod/ethics/

Signature of applicant	
Date of submission by applicant	
Signature of supervisor (if applicable)	
Date of signature by supervisor (if applicable)	

For Committee Use Reference Number (Subject area initials/year/ID number) ………………….

Date received …………………………….. Date considered …………………………………….

Committee decision …………………………………………………….. Signed ………………………

1. What is the aim of your study? What are the objectives for your study?

This research project will address two aims:

1. ***to explore the personal Experiences of Dementia*** from the perspective of participants in a Massive Open Online Course on dementia

The objectives are to focus on exploring the variation in clinical experiences of treating and managing dementia, as well as considering wider health care and resourcing influences. It will also consider personal accounts of dementia, looking at carer experiences and the role of social support.

2. to better understand dementia MOOC participants' understanding of the strengths and limitations of Integrated Care for dementia

The objectives will be to explore participants' perceptions of the strengths and limitations of integrated care. Crowd-sourcing ideas in this fashion could present some unique insights into integrated care as a concept.

2. Explain the rationale for this study (refer to relevant research literature in your response).

Dementia is a complex syndrome which affects brain function. It relates to an irreversible loss of cognitive ability and memory with a significant decline in behaviour, social and emotional capacity (Kitwood 1997; De Bellis et al. 2009; World Health Organisation (WHO) 2012). Although often seen as such, Dementia is not a normal part of ageing and many people who have a diagnosis are able to continue a positive quality of life, live in the community and maintain their independence. Dementia is a progressive disease and can reduce a person's ability to undertake normal daily activities which can lead to dependence on family memebrs and carers. Dementia is becoming a significant public health issue, and there are associted demands on health and social care systems (De Bellis et al. 2009).

The World Health Organisations estimates that number of new cases of dementia each year worldwide is nearly 8 million, meaning as many as one new case every four seconds. The number of people with dementia is expected to nearly double every 20 years, to 65.7 million in 2030 and 115.4 million in 2050.

During 2015, we ran a massive open online course (MOOC) on Dementia entitled ‚Bridging the Dementia Divide' which attracted 3,070 learners from a wide variety of professions, backgrounds and locations. We chose to run our course on dementia due to its importance in culture, society and its effects on the future of civilisation with the hope that the course might become a vehicle for social change and stimulate dialogue around the subject.

3. Provide an outline of your study design and methods.

In order to address the research question, aims and objectives of this study, over the coming months we intend to download MOOC discussion board posts on XXX and enter the data into Excel. The data will be used as a transcript and analysed using a Framework Analysis approach (Richie and Lewis, 2003):

1) transcript, consisting of MOOC posts on a) integrated care b) experience of dementia

2) familiarization with the MOOC posts (transcript)

3) Coding

4) Developing a working analytical framework

5) Applying the analytical framework

6) Charting data into the framework matrix

The analytical processes described above will be carried out by two researchers from different professional backgrounds to reduce bias. Any differences in interpretation and themes will be discussed and agreement sought. Where agreement cannot be reached, a third opinion from a colleague independent to the project will be sought.

4. If appropriate, please provide a detailed description of the study sample, covering selection, sample profile, recruitment and inclusion and exclusion criteria.

5. Are payments or rewards/incentives going to be made to the participants? Yes ☐ No ☐
If so, please give details.

6. Please indicate how you intend to address each of the following ethical considerations in your study. If you consider that they do not relate to your study please say so.

Guidance to completing this section of the form is provided at the end of the document.

The study has been designed in accordance with the British Psychological Society's (2014) code for internet mediated research, which outlines best ethical practice.

a. **Consent**

Email all MOOC participants (wording as an attachment) advising them of the study aims and proposed research, giving them the option to withdraw their data (and by when).

b. **Deception**

None

c. **Debriefing**

A summary of the research findings will be emailed to all MOOC participants once the data analysis has been finished, along with details of publications/outputs.

d. **Withdrawal from the investigation**

In the email outlining the purpose of the study, participants will receive instructions on how they can withdraw their data and responses from the study.

e. **Confidentiality**

Participant identities will only be known to the research team; discussion boards will be closed and hidden so that other participants cannot identify people from their responses. Each participant will be given a pseudonym to ensure anonymity and any references to organisations, places or people will be removed from quotes.

f. **Protection of participants**

see above

g. **Observation research**

n/a

h. **Giving advice**

No advice will be given to participants

i. **Research undertaken in public places**

j. **Data protection**

Research will be conducted in accordance with Data Protection Act principles; no personal or sensitive data will be collected for the purposes of this study. Only the two researchers will have access to the data, which will be password protected and kept for 6 years.

k. Animal Rights

n/a

l. Environmental protection

n/a

Are there other ethical implications that are additional to this list? Yes ☐ No x

7. Have / do you intend to request ethical approval from any other body/organisation? Yes ☐ No x

If 'Yes' – please give details

8. Do you intend to publish your research? Yes x No ☐.
If 'Yes', what are your publication plans?
Academic journals i.e. Dementia, Journal of Dementia Care etc. Academic conferences.

9. Have you secured access and permissions to use any resources that you may require? (e.g. psychometric scales, equipment, software, laboratory space).
Yes (we have a memorandum of understanding with Canvas, the VLE provider, that any data created as part of the MOOC belongs to the MOOC creator and owner which is us.) No ☐.

If Yes, please provide details.

10. Have the activities associated with this research project been risk-assessed? Yes ☐ No x

Which of the following have you appended to this application?

- ☐ Focus group questions
- ☐ Self-completion questionnaire
- ☐ Other debriefing material
- x Information sheet about your research study
- ☐ Location consent form
- ☐ Psychometric scales
- x Interview questions
- x Covering letter for participants
- x Informed consent forms for participants
- ☐ Other (please describe)

PLEASE SUBMIT THIS APPLICATION WITH ALL APPROPRIATE DOCUMENTATION

Advice on completing the ethical considerations aspects of a programme of research

Consent

Informed consent must be obtained for all participants before they take part in your project. The form should clearly state what they will be doing, drawing attention to anything they could conceivably object to subsequently. It should be in language that the person signing it will understand. It should also state that they can withdraw from the study at any time and the measures you are taking to ensure the confidentiality of data. If children are recruited from schools you will require the permission, depending on the school, of the head teacher, and of parents. Children over 14 years should also sign an individual consent form themselves. If conducting research with children or vulnerable adults you will normally also require Disclosure and Barring Service (DBS) clearance. Research to be carried out in any institution (prison, hospital, etc.) will require permission from the appropriate authority.

Covert or Deceptive Research

Research involving any form of deception can be particularly problematical, and you should provide a full explanation of why a covert or deceptive approach is necessary, why there are no acceptable alternative approaches not involving deception, and the scientific justification for deception.

Debriefing

Debriefing is a process of reflection once the research intervention is complete, for example at the end of an interview session. How will participants be debriefed (written or spoken feedback)? If they will not be debriefed, give reasons. Please attach the written debrief or transcript for the oral debrief. This can be particularly important if covert or deceptive research methods are used.

Withdrawal from investigation

Participants should be told explicitly that they are free to leave the study at any time without jeopardy. It is important that you clarify exactly how and when this will be explained to participants. Participants also have the right to withdraw their data in retrospect, after you have received it. You will need to clarify how they will do this and at what point they will not be able to withdraw (i.e. after the data has been analysed and disseminated).

Protection of participants

Are the participants at risk of physical, psychological or emotional harm greater than encountered ordinary life? If yes, describe the nature of the risk and steps taken to minimise it.

Observational research

If observational research is to be conducted without prior consent, please describe the situations in which observations will take place and say how local cultural values and privacy of individuals and/or institutions will be taken into account.

Giving advice

Students should not put themselves in a position of authority from which to provide advice and should in all cases refer participants to suitably qualified and appropriate professionals.

Research in public places

You should pay particular attention to the implications of research undertaken in public places. The impact on the social environment will be a key issue. You must observe the laws of obscenity and public decency. You should also have due regard to religious and cultural sensitivities.

Confidentiality/Data Protection

You must comply with the Data Protection Act and the University's Good Scientific Practice http://www.derby.ac.uk/research/policy-and-strategy This means:

- It is very important that the Participant Information Sheet includes information on what the research is for, who will conduct the research, how the personal information will be used, who will have access to the information and how long the information will be kept for. This is known as a 'fair processing statement.'
- You must not do anything with the personal information you collect over and above that for which you have consent.
- You can only make audio or visual recordings of participants with their consent (this should be stated on the Participant Information sheet)
- Identifiable personal information should only be conveyed to others within the framework of the act and with the participant's permission.
- You must store data securely. Consent forms and data should be stored separately and securely.
- You should only collect data that is relevant to the study being undertaken.
- Data may be kept indefinitely providing its sole use is for research purposes and meets the following conditions:
- The data is not being used to take decisions in respect of any living individual.
- The data is not being used in any which is, or is likely to, cause damage and/or distress to any living individual.
- You should always protect a participant's anonymity unless they have given their permission to be identified (if they do so, this should be stated on the Informed Consent Form).
- All data should be returned to participants or destroyed if consent is not given after the fact, or if a participant withdraws.

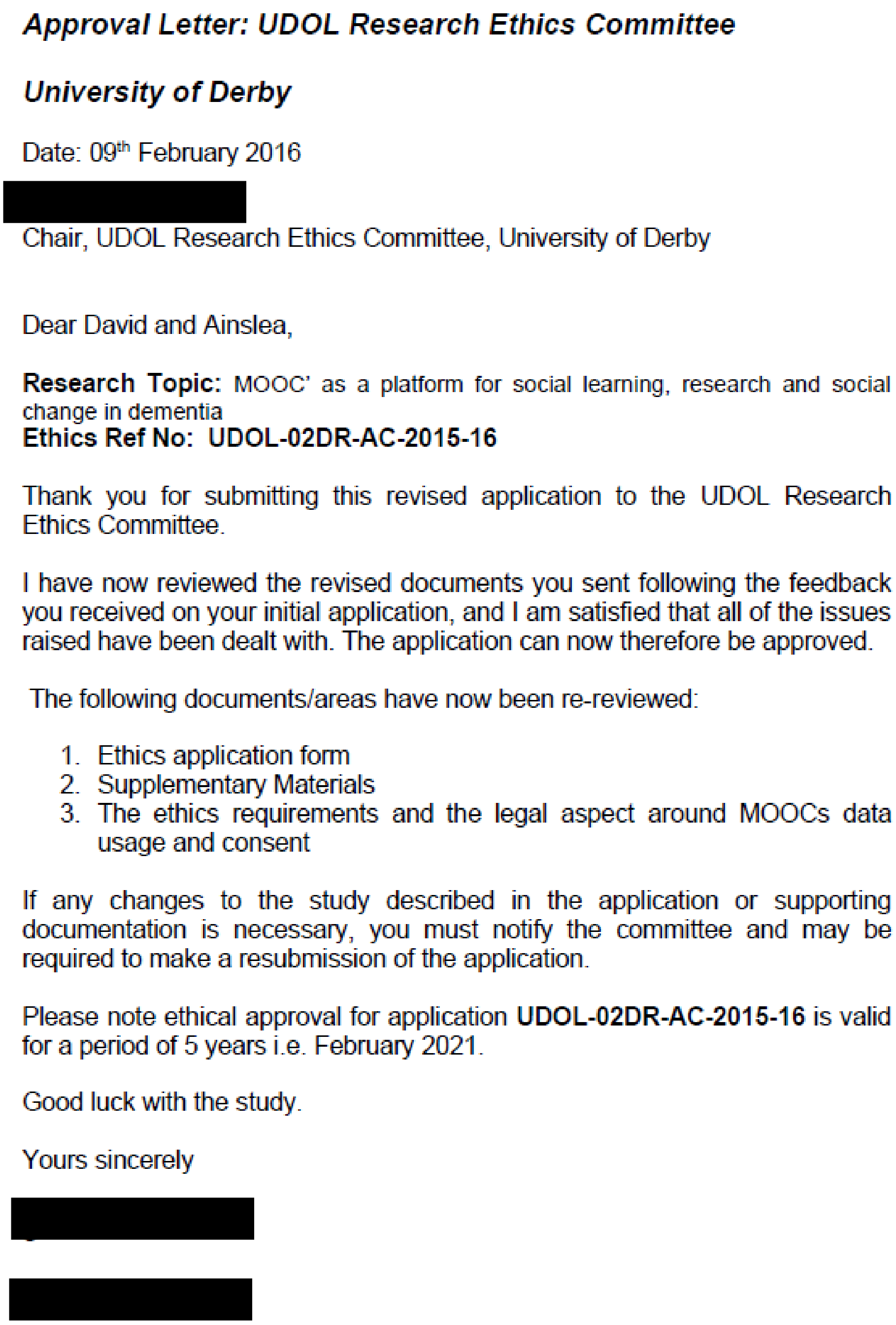
Animal rights.

Research which might involve the study of animals at the University is not likely to involve intrusive or invasive procedures. However, you should avoid animal suffering of any kind and should ensure that proper animal husbandry practices are followed. You should show respect for animals as fellow sentient beings.

Environmental protection

The negative impacts of your research on the natural environment and animal welfare, must be minimised and must be compliant to current legislation. Your research should appropriately weigh longer-term research benefit against short-term environmental harm needed to achieve research goals.

Appendix 4: Ethics application approval for experiences of integrated care, roles and responsibilities in integrated care for dementia, personal experiences of dementia



Approval Letter: UDOL Research Ethics Committee

University of Derby

Date: 09th February 2016

[redacted]
Chair, UDOL Research Ethics Committee, University of Derby

Dear David and Ainslea,

Research Topic: MOOC' as a platform for social learning, research and social change in dementia
Ethics Ref No: UDOL-02DR-AC-2015-16

Thank you for submitting this revised application to the UDOL Research Ethics Committee.

I have now reviewed the revised documents you sent following the feedback you received on your initial application, and I am satisfied that all of the issues raised have been dealt with. The application can now therefore be approved.

The following documents/areas have now been re-reviewed:

1. Ethics application form
2. Supplementary Materials
3. The ethics requirements and the legal aspect around MOOCs data usage and consent

If any changes to the study described in the application or supporting documentation is necessary, you must notify the committee and may be required to make a resubmission of the application.

Please note ethical approval for application **UDOL-02DR-AC-2015-16** is valid for a period of 5 years i.e. February 2021.

Good luck with the study.

Yours sincerely

[redacted]

[redacted]

Appendix 5: Robertshaw, D., Cross, A. (2016) ‘MOOC as a platform for social learning, research and social change in Dementia’; Published in conference proceedings eMOOCs conference

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Appendix 6: Robertshaw, D., Cross, A. (2019). Experiences of integrated care for dementia from family and carer perspectives: a framework analysis of massive open online course discussion board posts. Dementia, 18(4), 1492-1506.

Content removed for copyright reasons

Appendix 7: Robertshaw, D., Cross, A. (2019). Roles and responsibilities in Integrated Care for dementia. Journal of Integrated Care, 27(2), 131-140. https://doi.org/10.1108/JICA-05-2018-0037

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Appendix 8: Robertshaw. D., Babicova, I. (2019) discovering the memory thief: MOOC participants' personal experiences of dementia. Nurse Education in Practice 41 102693

Content removed for copyright reasons

Appendix 9: Ethics application for changing attitudes with a MOOC on dementia

Request for ethical approval for research undertaken by staff, post-graduate research and post-graduate professional students

Please submit your completed form to the chair of your college research ethics committee (CREC)

Your Name	David Robertshaw [redacted]
College	UDOL
College Research Ethics Committee	UDOL
Staff ID	[redacted]
Student ID	-
Unimail address	D.Robertshaw@Derby.ac.uk
Programme name / code	-
Name of supervisor(s)	-

Title of proposed research study

Can massive open social learning change perception of dementia?

Background information

Has this research been funded by an external organisation (e.g. a research council or public sector body) or internally (such as the RLTF fund)? If yes, please provide details.	No

Have you submitted previous requests for ethical approval to the Committee that relate to this research project? If yes please provide details.	UDOL-02DR-AC-2015-16
Are other research partners involved in the proposed research? If yes please provide details.	No

Signatures

The information supplied is, to the best of my knowledge and belief, accurate. I clearly understand my obligations and the rights of the participants. I agree to act at all times in accordance with University of Derby Policy and Code of Practice on Research Ethics: http://www.derby.ac.uk/research/uod/ethics/

Signature of applicant	
Date of submission by applicant	
Signature of supervisor (if applicable)	
Date of signature by supervisor (if applicable)	

For Committee Use Reference Number (Subject area initials/year/ID number) ………………….

Date received …………………………….. Date considered …………………………………….

Committee decision …………………………………………………….. Signed ………………………

1. What is the aim of your study? What are the objectives for your study?

The key aims of this study are threefold:

1. To identify the various factors that define the perception of dementia among the participants.
2. To examine whether demographics play a critical role in shaping the perception of dementia.
3. Whether studying a MOOC on dementia has a contributory effect in changing perceptions to dementia.

2. Explain the rationale for this study (refer to relevant research literature in your response).

Dementia is a complex syndrome which affects brain function. It relates to an irreversible loss of cognitive ability and memory with a significant decline in behaviour, social and emotional capacity (Kitwood 1997; De Bellis et al. 2009; World Health Organisation (WHO) 2012). Although often seen as such, Dementia is not a normal part of ageing and many people who have a diagnosis are able to continue a positive quality of life, live in the community and maintain their independence. Dementia is a progressive disease and can reduce a person’s ability to undertake normal daily activities which can lead to dependence on family memebrs and carers. Dementia is becoming a significant public health issue, and there are associted demands on health and social care systems (De Bellis et al. 2009). The World Health Organisations estimates that number of new cases of dementia each year worldwide is nearly 8 million, meaning as many as one new case every four seconds. The number of people with dementia is expected to nearly double every 20 years, to 65.7 million in 2030 and 115.4 million in 2050.

During 2015, we ran a massive open online course (MOOC) on Dementia entitled ‚Bridging the Dementia Divide‘ which attracted 3,070 learners from a wide variety of professions, backgrounds and locations. We chose to run our course on dementia due to its importance in culture, society and its effects on the future of civilisation with the hope that the course might become a vehicle for social change and stimulate dialogue around the subject. During March 2016, this course will be run again. Early data from the first MOOC is suggestive that open learning at scale can change the attitudes and perception of participants; this research project seeks to characterise that change through the use of a survey before the course, after the course, and at 3 months post-course.

3. Provide an outline of your study design and methods.

In this study we will gather user data from surveys specifically embedded in the MOOC. The study will use the Dementia knowledge and attitudes scale from the Northern Ireland Life and Time Survey (Dowds, McParland, Devine and Gray, 2010), see appendix 1. The scale will be administered before the launch of the MOOC, at the end of the MOOC (6 weeks), and again three and six months after the MOOC. The scale will assess individuals' knowledge of dementia, perceptions of people with dementia, attitudes towards people with dementia and perceptions of capacity for independent living.

We will use ANOVA and t-test to identify whether the various factors have any significant impact on the perception of dementia. We will employ formative path analysis (Structural Equation Modelling) to analyse the cause and interactive impact of the various factors that shape the overall perceptions.

Reference

Gayle, V, McParland, P, Devine, P & Innes, A (2012), 'Dementia knowledge and attitudes of the general public in Northern Ireland: an analysis of national survey data' International Psychogeriatrics, vol 24, pp. 1600-1613., 10.1017/S1041610212000658

4. If appropriate, please provide a detailed description of the study sample, covering selection, sample profile, recruitment and inclusion and exclusion criteria.

All participants who sign up for the MOOC will be presented with the survey and asked to complete it, however this will not be a compulsory activity.

5. Are payments or rewards/incentives going to be made to the participants? Yes ☐ No ☐
If so, please give details.

No.

6. Please indicate how you intend to address each of the following ethical considerations in your study. If you consider that they do not relate to your study please say so.

Guidance to completing this section of the form is provided at the end of the document.

m. Consent

Full informed consent will be sought by inviting participants to take part in the study and providing them with a Participant Information Sheet outlining the aims and purpose of the study, which states that participation is voluntary. Participants will give consent by ticking the consent form in Qualtrics, after which they will be able to proceed with the baseline survey. Participants will receive a link to the survey after the MOOC and at three and six month follow up via email. Participants can withdraw at any time by closing the page, or by not responding to the invitation to take part in the follow up surveys.

n. Deception

None

o. Debriefing

A summary of the research findings will be emailed to all MOOC participants once the data analysis has been finished, along with details of publications/outputs. A debriefing will be presented after completion of the survey.

p. Withdrawal from the investigation

In the information about the study, participants will receive instructions on how they can withdraw their data and responses from the study. This information includes how they can withdraw from the study. Participants are able to withdraw their data up to two weeks after the final survey.

q. Confidentiality

Participant identities will only be known to the research team; survey responses will not be made public so that other participants cannot identify people from their responses. Participants will be required to generate a unique ID code (comprising the last three digits of their phone number and the last two digits of their data of birth). Personal data will not be collected.

r. Protection of participants

Please see above.

s. Observation research

n/a

t. Giving advice

No advice will be given to participants.

u. Research undertaken in public places

A MOOC is not a public place, as learners are required to sign up to join a closed community, therefore this section does not apply.

v. Data protection

Research will be conducted in accordance with Data Protection Act principles; no personal or sensitive data will be collected for the purposes of this study. Only the research team will have access to the data, which will be password protected and kept for 6 years.

w. Animal Rights

n/a

x. Environmental protection

n/a

Are there other ethical implications that are additional to this list? Yes ☐ No x

7. Have / do you intend to request ethical approval from any other body/organisation? Yes ☐ No x

If 'Yes' – please give details

8. Do you intend to publish your research? Yes x No ☐.
If 'Yes', what are your publication plans?

Academic journals i.e. Dementia, Journal of Dementia Care etc. Academic conferences.

9. Have you secured access and permissions to use any resources that you may require? (e.g. psychometric scales, equipment, software, laboratory space).

A previous ethics approval dealt with this question in relation to MOOCs.

No ☐.

If Yes, please provide details.

10. Have the activities associated with this research project been risk-assessed? Yes ☐ No x

Which of the following have you appended to this application?

☐ Focus group questions
x Self-completion questionnaire
☐ Psychometric scales
☐ Interview questions

q Other debriefing material

x Information sheet about your research study

☐ Location consent form

x Covering letter for participants

x Informed consent forms for participants

☐ Other (please describe)

PLEASE SUBMIT THIS APPLICATION WITH ALL APPROPRIATE DOCUMENTATION

Advice on completing the ethical considerations aspects of a programme of research

Consent

Informed consent must be obtained for all participants before they take part in your project. The form should clearly state what they will be doing, drawing attention to anything they could conceivably object to subsequently. It should be in language that the person signing it will understand. It should also state that they can withdraw from the study at any time and the measures you are taking to ensure the confidentiality of data. If children are recruited from schools you will require the permission, depending on the school, of the head teacher, and of parents. Children over 14 years should also sign an individual consent form themselves. If conducting research with children or vulnerable adults you will normally also require Disclosure and Barring Service (DBS) clearance. Research to be carried out in any institution (prison, hospital, etc.) will require permission from the appropriate authority.

Covert or Deceptive Research

Research involving any form of deception can be particularly problematical, and you should provide a full explanation of why a covert or deceptive approach is necessary, why there are no acceptable alternative approaches not involving deception, and the scientific justification for deception.

Debriefing

Debriefing is a process of reflection once the research intervention is complete, for example at the end of an interview session. How will participants be debriefed (written or spoken feedback)? If they will not be debriefed, give reasons. Please attach the written debrief or transcript for the oral debrief. This can be particularly important if covert or deceptive research methods are used.

Withdrawal from investigation

Participants should be told explicitly that they are free to leave the study at any time without jeopardy. It is important that you clarify exactly how and when this will be explained to participants. Participants also have the right to withdraw their data in retrospect, after you have received it. You will need to clarify how they will do this and at what point they will not be able to withdraw (i.e. after the data has been analysed and disseminated).

Protection of participants

Are the participants at risk of physical, psychological or emotional harm greater than encountered ordinary life? If yes, describe the nature of the risk and steps taken to minimise it.

Observational research

If observational research is to be conducted without prior consent, please describe the situations in which observations will take place and say how local cultural values and privacy of individuals and/or institutions will be taken into account.

Giving advice

Students should not put themselves in a position of authority from which to provide advice and should in all cases refer participants to suitably qualified and appropriate professionals.

Research in public places

You should pay particular attention to the implications of research undertaken in public places. The impact on the social environment will be a key issue. You must observe the laws of obscenity and public decency. You should also have due regard to religious and cultural sensitivities.

Confidentiality/Data Protection

You must comply with the Data Protection Act and the University's Good Scientific Practice http://www.derby.ac.uk/research/policy-and-strategy This means:

- It is very important that the Participant Information Sheet includes information on what the research is for, who will conduct the research, how the personal information will be used, who will have access to the information and how long the information will be kept for. This is known as a 'fair processing statement.'
- You must not do anything with the personal information you collect over and above that for which you have consent.
- You can only make audio or visual recordings of participants with their consent (this should be stated on the Participant Information sheet)
- Identifiable personal information should only be conveyed to others within the framework of the act and with the participant's permission.
- You must store data securely. Consent forms and data should be stored separately and securely.
- You should only collect data that is relevant to the study being undertaken.
- Data may be kept indefinitely providing its sole use is for research purposes and meets the following conditions:
- The data is not being used to take decisions in respect of any living individual.
- The data is not being used in any which is, or is likely to, cause damage and/or distress to any living individual.
- You should always protect a participant's anonymity unless they have given their permission to be identified (if they do so, this should be stated on the Informed Consent Form).
- All data should be returned to participants or destroyed if consent is not given after the fact, or if a participant withdraws.

Animal rights.

Research which might involve the study of animals at the University is not likely to involve intrusive or invasive procedures. However, you should avoid animal suffering of any kind and should ensure that proper animal husbandry practices are followed. You should show respect for animals as fellow sentient beings.

Environmental protection

The negative impacts of your research on the natural environment and animal welfare, must be minimised and must be compliant to current legislation. Your research should appropriately weigh longer-term research benefit against short-term environmental harm needed to achieve research goals.

Appendix

This survey is designed to capture your perceptions of dementia at the beginning of this course and at the end to see if your thoughts on dementia have changed or remain the same. These questions were originally used by The Northern Ireland Life and Times (NILT) Survey which was launched in the autumn of 1998 with the aim of monitoring how attitudes and behaviours change over time related to specific issues.

Please give your honest answer which reflects your thinking at his current time.

Age range	13-20	21-30	31-40	41-50	51-60	61-70	71-80	80+
Gender	Male	Female		Prefer not to say				
Country where are living	Free text box							
Occupation	Free text box							

There comes a time when all you can do for someone with dementia is to keep them clean, healthy and safe.	Strongly disagree, disagree, neither agree nor disagree, agree, strongly agree
Other people take over making decisions for people with dementia far too much.	Strongly disagree, disagree, neither agree nor disagree, agree, strongly agree
Once they have dementia the person you knew eventually disappears.	Strongly disagree, disagree, neither agree nor disagree, agree, strongly agree
As soon as someone is diagnosed with dementia they are not treated like a thinking human being any more.	Strongly disagree, disagree, neither agree nor disagree, agree, strongly agree
For people with really bad dementia I don’t think life is worth living.	Strongly disagree, disagree, neither agree nor disagree, agree, strongly agree
People with dementia are like children and need cared for as you would a child.	Strongly disagree, disagree, neither agree nor disagree, agree, strongly agree
People with dementia should be involved in activities in the community	Strongly disagree, disagree, neither agree nor disagree, agree, strongly agree
It is better for people with dementia and their families if they are cared for in a residential unit or a nursing home	Strongly disagree, disagree, neither agree nor disagree, agree, strongly agree
There is little or no benefit to be gained from telling someone they have dementia	Strongly disagree, disagree, neither agree nor disagree, agree, strongly agree
People who have just been diagnosed with dementia are unable to make decisions about their own care	Strongly disagree, disagree, neither agree nor disagree, agree, strongly agree

There is no point in trying to talk to people with dementia as they won't be able to understand	Strongly disagree, disagree, neither agree nor disagree, agree, strongly agree
Should someone newly diagnosed with dementia…	
Continue to live alone	Strongly disagree, disagree, neither agree nor disagree, agree, strongly agree
Continue to manage their own medication	Strongly disagree, disagree, neither agree nor disagree, agree, strongly agree
Continue to drive	Strongly disagree, disagree, neither agree nor disagree, agree, strongly agree
Have an electronic device fitted so they can be located if they wander	Strongly disagree, disagree, neither agree nor disagree, agree, strongly agree
Should someone who has been living with dementia for a long time…	
Continue to live alone	Strongly disagree, disagree, neither agree nor disagree, agree, strongly agree
Continue to manage their own medication	Strongly disagree, disagree, neither agree nor disagree, agree, strongly agree
Continue to drive	Strongly disagree, disagree, neither agree nor disagree, agree, strongly agree
Have an electronic device fitted so they can be located if they wander	Strongly disagree, disagree, neither agree nor disagree, agree, strongly agree

Appendix 10: Author attribution form for Robertshaw, D., Cross, A. (2019). Experiences of integrated care for dementia from family and carer perspectives: a framework analysis of massive open online course discussion board posts. Dementia, 18(4), 1492-1506.

Publication title	Robertshaw, D., & Cross, A. (2019). Experiences of integrated care for dementia from family and carer perspectives: a framework analysis of massive open online course discussion board posts. Dementia, 18(4), 1492-1506. https://doi.org/10.1177/1471301217719991
Author(s)	David Robertshaw Ainslea Cross

Area of activity	**DR**	**AC**
Formulation of objectives (%)	30	70
Contribution to the conception and design of methodology (%)	30	70
Literature review (%)	50	50
Acquisition/collection of data (%)	80	20
Analysis of data (%)	50	50
Interpretation of data (%)	50	50
Drafting the manuscript (%)	50	50
Revising the manuscript (%)	75	25
Final approval of the manuscript (%)	50	50
Accountability for all aspects of the work (%)	50	50
Corresponding author (✓)	✓	-
Responsibility for submissions (%)	100	0
Responsibility for revision and re-submissions (%)	100	0
Signed	[redacted]	[redacted] 1/10/2020

Criteria for author attribution:

- Substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work; AND
- Drafting the work or revising it critically for important intellectual content; AND
- Final approval of the version to be published; AND
- Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Appendix 11: Author attribution form for Robertshaw, D., Cross, A. (2019). Roles and responsibilities in Integrated Care for dementia. Journal of Integrated Care, 27(2), 131- 140. https://doi.org/10.1108/JICA-05-2018-0037

Publication title	Robertshaw, D., & Cross, A. (2019). Roles and responsibilities in Integrated Care for dementia. Journal of Integrated Care, 27(2), 131-140. https://doi.org/10.1108/JICA-05-2018-0037
Author(s)	David Robertshaw Ainslea Cross

Area of activity	**DR**	**AC**
Formulation of objectives (%)	50	50
Contribution to the conception and design of methodology (%)	50	50
Literature review (%)	50	50
Acquisition/collection of data (%)	80	20
Analysis of data (%)	50	50
Interpretation of data (%)	50	50
Drafting the manuscript (%)	50	50
Revising the manuscript (%)	75	25
Final approval of the manuscript (%)	50	50
Accountability for all aspects of the work (%)	50	50
Corresponding author (✓)	✓	-
Responsibility for submissions (%)	100	0
Responsibility for revision and re-submissions (%)	100	0
Signed	[redacted]	[redacted] 1/10/2020

Criteria for author attribution:

- Substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work; AND

- Drafting the work or revising it critically for important intellectual content; AND
- Final approval of the version to be published; AND
- Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Appendix 12: Author attribution form for Robertshaw, D., Cross, A. (2016) ‘MOOC as a platform for social learning, research and social change in Dementia’; Published in conference proceedings eMOOCs conference

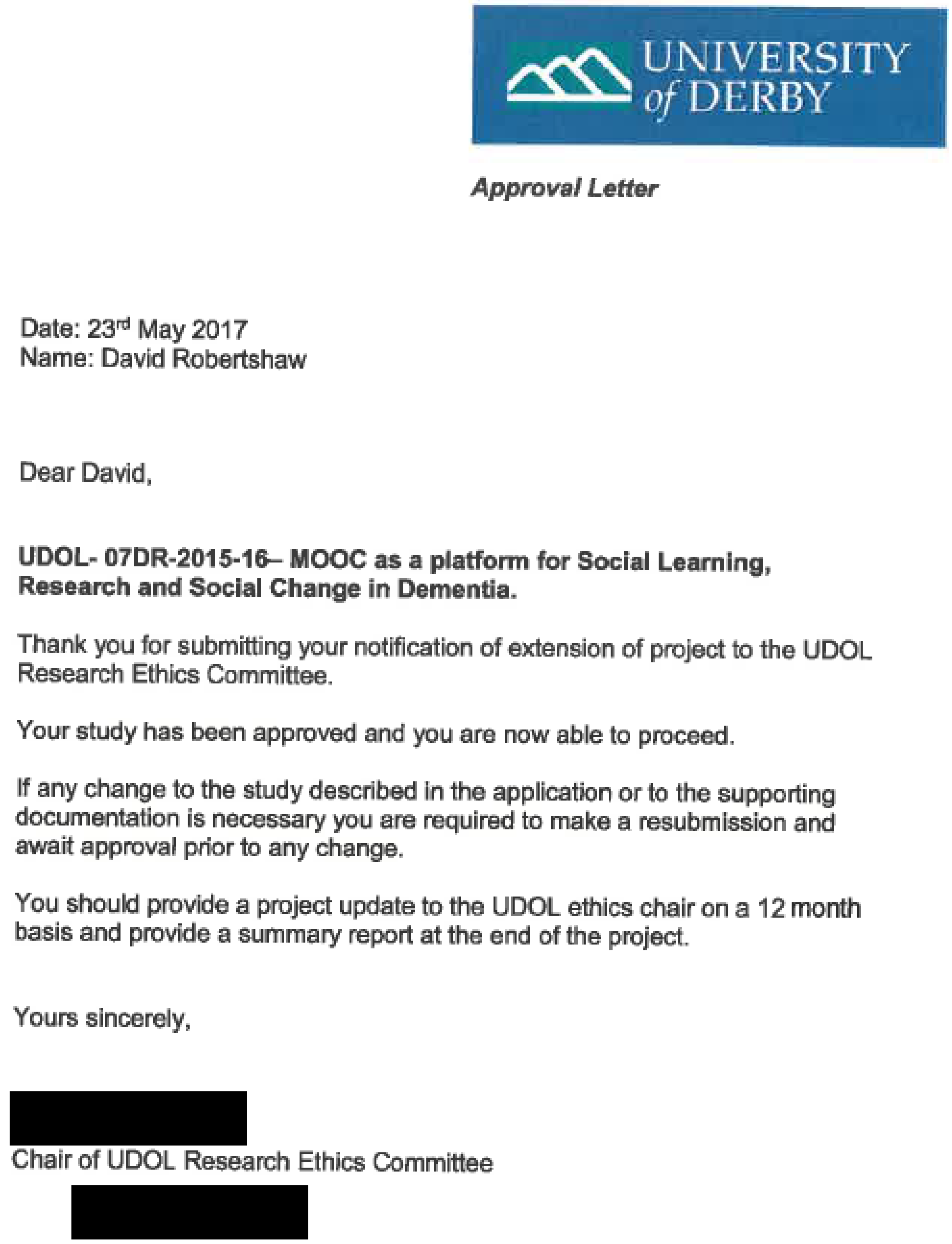
Publication title	ROBERTSHAW D, CROSS A (2016) ‘MOOC as a platform for social learning, research and social change in Dementia’; Published in conference proceedings eMOOCs conference
Author(s)	David Robertshaw Ainslea Cross

Area of activity	**DR**	**AC**
Formulation of objectives (%)	75	25
Contribution to the conception and design of methodology (%)	50	50
Literature review (%)	75	25
Acquisition/collection of data (%)	75	25
Analysis of data (%)	75	25
Interpretation of data (%)	75	25
Drafting the manuscript (%)	75	25
Revising the manuscript (%)	75	25
Final approval of the manuscript (%)	50	50
Accountability for all aspects of the work (%)	50	50
Corresponding author (✓)	✓	-
Responsibility for submissions (%)	100	0
Responsibility for revision and re-submissions (%)	100	0
Signed	[redacted]	[redacted] 1/10/2020

Criteria for author attribution:

- Substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work; AND
- Drafting the work or revising it critically for important intellectual content; AND
- Final approval of the version to be published; AND
- Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Appendix 13: Ethics application approval for changing attitudes with a MOOC on dementia



UNIVERSITY
of DERBY

Approval Letter

Date: 23rd May 2017
Name: David Robertshaw

Dear David,

UDOL- 07DR-2015-16– MOOC as a platform for Social Learning, Research and Social Change in Dementia.

Thank you for submitting your notification of extension of project to the UDOL Research Ethics Committee.

Your study has been approved and you are now able to proceed.

If any change to the study described in the application or to the supporting documentation is necessary you are required to make a resubmission and await approval prior to any change.

You should provide a project update to the UDOL ethics chair on a 12 month basis and provide a summary report at the end of the project.

Yours sincerely,

[redacted]
Chair of UDOL Research Ethics Committee
[redacted]

Appendix 14: Robertshaw, D., Kotera, Y. (2019) Changing Attitudes with a MOOC on Dementia. European Journal of Open, Distance and E-learning 22 (2), 27-39. Retrieved from http://www.eurodl.org/?p=current&sp=full&article=802

Content removed for copyright reasons

Appendix 15: Ethics application for tweeting on dementia

Request for ethical approval for research undertaken by staff, post-graduate research and post-graduate professional students

Please submit your completed form to the chair of your college research ethics committee (CREC)

Your Name	**David Robertshaw/Ivana Babicova**
College	**Health and Social Care**
College Research Ethics Committee	**UDOL**
Staff ID	[redacted]
Student ID	[redacted]
Unimail address	**d.robertshaw@derby.ac.uk/i.babicova@derby.ac.uk**
Programme name / code	
Name of supervisor(s)	**-**

Title of proposed research study
Tweeting on dementia: a snapshot of the content and sentiment of tweets associated with dementia
Background information

Has this research been funded by an external organisation (e.g. a research council or public sector body) or internally (such as the RLTF fund)? If yes, please provide details.	No
Have you submitted previous requests for ethical approval to the Committee that relate to this research project? If yes please provide details.	No
Are other research partners involved in the proposed research? If yes please provide details.	No

Signatures
The information supplied is, to the best of my knowledge and belief, accurate. I clearly understand my obligations and the rights of the participants. I agree to act at all times in accordance with University of Derby Policy and Code of Practice on Research Ethics: http://www.derby.ac.uk/research/uod/ethics/

Signature of applicant	[redacted]

Date of submission by applicant	12/02/2019
Signature of supervisor (if applicable)	
Date of signature by supervisor (if applicable)	

<u>For Committee Use</u> Reference Number (Subject area initials/year/ID number) ………………….

Date received …………………………….. Date considered …………………………………….

Committee decision …………………………………………………….. Signed ………………………

1. What is the aim of your study? What are the objectives for your study?

This study aims to discover the nature, context and terminology used by Twitter users when talking about dementia and dementia-related terms. Discovery of this terminology may lead to increased understanding of their attitudes towards dementia, and whether dementia is viewed positively or negatively.

The objective of this study is to provide a snapshot of the content and sentiment of tweets associated with dementia and dementia related terms

2. Explain the rationale for this study (refer to relevant research literature in your response).

Dementia is one of the most important social issues of our time. Over 850,000 people in the UK are diagnosed with dementia or a dementia-related condition and this number is expected to increase. Dementia is an umbrella term consisting of over 60 different syndromes and diseases. It is now the leading cause of death in the United Kingdom. Public perception and awareness of dementia has increased in recent years through a range of initiatives including dementia awareness weeks and dementia friends. Dementia is having an increasing impact on everyday people, and it is now rare for someone to have not met someone with dementia. Although initiatives are aimed at changing and improving the perceptions of dementia and dementia-related conditions, we do not have a full characterisation of these perceptions. Studies have been conducted to investigate this, however these have generally taken place in closed fora such as classrooms, private surveys (NILT) or MOOCs (Robertshaw and Babicova, 2019).

Health is generally regarded as one of the central priorities of our lives. Phenomenological studies have characterised experiences of health conditions, but there is little data examining how the public at large perceives health conditions. Small scale studies have been conducted manually to analyse a small number of tweets (Cheng, Liu and Woo, 2018; Robillard et al., 2013;) . There has been some small-scale investigation of Alzheimer's disease on Twitter (Oscar et al, 2017). Twitter and, more broadly, online social media offers some of the largest and richest datasets currently available. Twitter is an online microblogging platform where users can post statuses of up to 280 characters. Twitter has over 326 million users per month who 'tweet' up to 500 million times per day (https://blog.hootsuite.com/twitter-statistics/). Each tweet consists of up to 280 characters. The amount of text produced each day is therefore up to 140,000,000,000 characters. A big data source, social media natural language data is vast with great variety (Ignatow and Mihalcea, 2017). This information can be investigated allowing discovery of new insights into problems which present challenges unsolvable with manual analysis or to answer questions not yet asked (Tattersall, 2016). Social media data is reasonably obtainable by using commercially available products or software packages designed by academics for academic purposes. This paper interrogates Twitter using dementia and dementia-related terms with a range of software packages available to academics. These software packages have been used previously for academic inquiry and they are validated for this purpose.

This study therefore uses Twitter-derived natural language data, processed through academic software, to provide a snapshot of the content and sentiment of tweets related to dementia. This study proposes to use a big data-approach to analyse and interrogate the perceptions and attitudes of the public towards dementia.

We believe we do not require ethical approval for this study, because Tweets analysed as part of this study are in the public domain. Twitter users expressly give their consent through acceptance of terms of service that their data will be made available to third parties for their analysis including academic research. Twitter users must accept the terms of service to be able to use Twitter (Williams, 2018). They maymake their tweets 'private' which prevents them from being used in analysis. However, we wish to seek ethical approval for completeness and assurance.

3. Provide an outline of your study design and methods.

This study involves two steps:

1. Collection of twitter data;

This phase uses Twitter Archiving Google Sheet (TAGS), which is a free Google Sheet template allowing automatic collection of tweets based on a search term. TAGS collects tweets through the Twitter Application Programme Interface (API). The Twitter API is governed by a developer agreement and policy, which expressly permits extraction and analysis of data. Data can only be obtained from the preceding 7 days with this method, so data from a longer duration is collected using automatic hourly collections preventing data gaps. Data will be collected for one month.

In this phase, key words are chosen carefully dependent upon the topic being sought. A search string is then constructed with Boolean operators. Private tweets are not collected through this method.

We conducted a trial-run with Tweetcatcher (a software tool which captures a snapshot of tweets over the preceding 7 days) to test feasibility of this collection between 5th February 2019 and 12th February 2019 and identified the following number of tweets:

- Dementia [search term: dementia] 61,581
- Alzheimer [search terms: Alzheimer OR alzheimers] 25,568
- Vascular Dementia [search term: vascular dementia] 428
- Lewy Bodies [search term: lewy body or lewy bodies] 61
- Frontotemporal [search term: frontotemporal] 704

These tweets were identified but not stored and were not analysed.

2. Visual analysis of twitter data and identification of key words and tags, and analysis of word frequency/thematic analysis;

This phase uses Microsoft Excel to clean the data and produce graphs showing frequency of tweets. Data is then exported from Excel to NVivo and then analysed using NVivo's word frequency function at specialization level. This analysis is performed with NVivo using the built-in algorithm. Additional graphs and data visualisations are available from within TAGS using the dashboard and summary pages.

Tweets are also exported from Excel into .txt format for analysis by SentiStrength, an algorithm widely used in academic research using Twitter data (Brooker, Barnett and Cribbin, 2016; Thelwall, 2010). SentiStrength provides a positive sentiment and negative sentiment for each Tweet.

Results recording

For each dementia-related term we will record the number of tweets, the top 10 words based on frequency, the top 10 hashtags based on frequency, the average positive sentiment, the average negative sentiment, the overall average sentiment, and the top 10 word count based on specializations. Stop words such as 'http' or any twitter usernames will be excluded from analysis.

Data will be presented in a table which allows direct comparison between dementia types.

Search term	Top 10 words based on frequency	Top 10 hashtags	Average positive sentiment	Average negative sentiment	Overall average sentiment	Top 10 word count based on specializations
Dementia						
Alzheimer						
Vascular dementia						
Lewy bodies						
Frontotemporal						

Methodological approach

This is a netnographic study, examining people's interactions and contributions in the online environment (Kozinets, 2009). Netnography, sometimes known as digital ethnography, is a methodological approach which provides limited access to true participant identity and demographic information, but Kozinets (2002) sees this as a necessary and acceptable shift from traditional ethnographic approaches. This study uses an inductive logic approach, where we begin by analysing the data then allowing conclusions to emerge organically from the analysis (Ignatow and Mihalcea, 2017).

This study uses Tweets as a data source to explore the attitudes (sentiment) and themes associated with the most common types of dementia as outlined by Alzheimer's Research UK (Alzheimer's Research UK, 2019):

1. Dementia
2. Alzheimer’s disease
3. Vascular dementia
4. Dementia with Lewy Bodies
5. Frontotemporal dementia

Dementia is the leading cause of death in the UK and is responsible for more than one in eight of all deaths (ONS, 2018). To obtain a fully rounded understanding of differences in attitudes (sentiments) towards types of dementia, the most common types of dementia are selected.

4. If appropriate, please provide a detailed description of the study sample, covering selection, sample profile, recruitment and inclusion and exclusion criteria.

There are greater ethical concerns with using social media data in textual analysis, because participants are not able to directly consent to participating in the study. Yet there is an expectation of public exposure by users (Sveningsson, 2003).

This paper uses the approach posited by Sudweeks and Rafaeli (1996) that social media data is in the public domain and is therefore accessible for research purposes. Twitter’s privacy policy (Twitter, 2018a), developer agreement and developer policy (Twitter, 2018b) adopt a similar approach, expressly permitting the use of its data for analysis through its application programming interface (API). This study was fully cognizant of the British Psychological Society’s Code for Internet-Mediated Research (BPS, 2017).

Inclusion criteria

Any tweet within the specified timeframe containing the search terms Dementia, Alzheimer OR Alzheimers, Vascular dementia, Lewy bodies OR Lewy Body, or Frontotemporal. All natural language data in the tweet will be analysed with the exception of stop words such as ‘https’ or @usernames. The words ‘RT’ and ‘https’ will be excluded from analysis because they are not relevant to the aims or objectives and are considered ‘stop’ words.

Exclusion criteria

Private tweets will be excluded from analysis and these are not collected. Only tweet natural language will be processed, and usernames and other metadata will be excluded from analysis.

5. Are payments or rewards/incentives going to be made to the participants? Yes ☐ No x

If so, please give details.

6. Please indicate how you intend to address each of the following ethical considerations in your study. If you consider that they do not relate to your study please say so.

Guidance to completing this section of the form is provided at the end of the document.

We recognise the ethics committee may have some concerns regarding the ethical nature of this study. To offer reassurance, studies of this type have been performed previously (Cheng et al, Robillard et al, Reavley et al), and have not required express consent to participate. Reavley and Pilkington (2014), in their published peer-reviewed report, did not seek any sort of ethical approval, as their study (like this one) uses publicly available information for content analysis.

y. Consent

Consent is not obtainable from Twitter users but we suggest that we are not required to obtain this. This study uses the approach posited by Sudweeks and Rafaeli (1996) that social media data is in the public domain and is therefore accessible for research purposes. This approach has also been replicated more recently in studies conducted by Scanfeld, Scanfeld and Larson (2010), Reavley and Pilkington (2014), where both studies use Twitter as the main platform to obtain data. Twitter's privacy policy (Twitter, 2018a), developer agreement and developer policy (Twitter, 2018b) adopt a similar approach, expressly permitting the use of its data for analysis through its application programming interface (API). Twitter's privacy policy says: "Twitter is public and Tweets are immediately viewable and searchable by anyone around the world." (Twitter, 2018a). This study will be fully cognizant of and complaint with the British Psychological Society's Code for Internet-Mediated Research (BPS, 2017). We will provide a web page for users to be directed to, outlining frequently answered questions and the purposes of the study. The created web page will also be tweeted and shared on Twitter by the researchers, to increase visibility and awareness of the ongoing study. This will include information such as:

- What are you trying to find out?
  - Thank you for your interest in this study. This study is looking at how twitter users talk about dementia and diseases related to dementia. Dementia is a common health condition and it is important that we understand how it is talked about. We also hope that by undertaking this study, we discover some new ideas about dementia.
- Why are you searching for my tweets?
  - Tweets are a really good source of written information. We can use this written information to look for patterns and ideas which we might not have been able to see otherwise. Other researchers have done smaller projects where they have looked at tweets, but they have done this manually. We are going to use computers to help us look at the information.
- Which tweets can you use?
  - Our computers are able to use any tweets which have been posted in the previous week. We also have a tool which allows us to collect and store tweets over a longer period of time, and we are going to use this to collect tweets over a period of a month. This will help us to see longer-term patterns. Essentially, we can access anything which is public on twitter. The information shared in public spaces on twitter is just like sharing information in real life in public places: anyone can access it.
- Which tweets can you not use?

    - We aren’t able to use any tweets which you mark as private, or if your account is set to private. We will not use them because you have chosen to keep them private, and just for you and your followers. We can’t access these with our computer so we won’t be able to see anything you write that is private.
- What if I don’t want you to use my tweets?
    - If you don’t want us to use your tweets please change your settings to make your account private. That way we won’t be able to collect your tweets. The search strategy which we are using to collect tweets can only access tweets which are publicly available, therefore if your profile or individual tweets are private, we will not have access to them. Once the data (tweets) are collected, they will be mass analysed. We will never indicate your name (real or twitter ID) to identify you or other twitter members. All data collected will be analysed as a whole rather than individually, and to do this we will be using an analytical software to get a result.
- What will you use my tweets for?
    - We will be looking at only the status updates. We won’t be looking at your username or any personal information you have shared with twitter. We won’t be including anything about you or your account in our study, other than your status updates. These statuses will be collected into our computer and we will be looking at graphs and counting how often words occur. This information will help us to find answers to the study’s objectives.
- How are you conducting the study, what’s your approach?
    - This study is a digital ethnographic study. Ethnography is the study of people, things or places and is a very old way of studying social environments. We are using an updated and modified way of doing this which looks at the digital environment as a social world.
- How will you protect my personal information?
    - Your personal information will not be used in this study. As part of the collection process we do receive some information about your username and your user description but this information will be deleted when we process the information files before analysis takes place.
- Who are you as researchers?
    - This study is being undertaken by David Robertshaw, who is a Registered Nurse and educator working at the University of Derby, and by Ivana Babicova who is a psychologist and researcher working at the University of Derby.
- Where can I read about your study?
    - We haven’t published our study yet but if you would like to know some early findings or receive a link to the paper when it is published please contact d.robertshaw@derby.ac.uk
- What are the main findings of your study?
    - We haven’t published our study yet but if you would like to know some early findings or receive a link to the paper when it is published please contact d.robertshaw@derby.ac.uk

Responsibility is held by Twitter users regarding the public nature of their tweets, and Twitter makes it clear to their users how these tweets can be used. We will not quote usernames, or include pictures, or make direct references/quotes, or include personal or sensitive information. These tweets will not be used for commercial purposes.

z. Deception

This study is non-interventional, therefore we will not deceive or coerce participants in any way.

aa. Debriefing

No debriefing is available, nor is required in this case. Debriefing is contextually available in the web pages as identified above.

bb. Withdrawal from the investigation

Contributors may not withdraw their data from the study. They may withdraw their tweets by deleting them from Twitter prior to collection. However, we see this as acceptable within this context. This is comparable to walking in the street and someone taking a picture of you: this is not illegal and they are not required to gain your consent because you are in a public space. Sudweeks and Rafaeli (1996) argued that researchers should treat “public discourse on computer-mediated communication as that: public”, and that “such study is more akin to the study of tombstone epitaphs, graffiti or letters to the editor”.

cc. Confidentiality

We will not include any personal data, usernames or user descriptions as part of analysis. These will not be reported in the final paper. We will also not include any descriptions or quotes from Tweets. Twitter’s developer policy and agreement expressly forbids the sharing of twitter datasets therefore we are not able to include indicative tweets even if we wished to do so, which we do not.

dd. Protection of participants

We will not quote usernames, or include pictures, or make direct references/quotes, or include personal or sensitive information. These tweets will be held securely on a system only the researchers can access. Twitter’s developer policy and agreement expressly forbids the sharing of twitter datasets therefore we are not able to include user details even if we wished to do so, which we do not. Participants are not at risk of physical, psychological or emotional harm greater than encountered ordinary life.

ee. Observation research

By its nature, this project is observation research. This study will adopt an ethnographic approach, and ‘observations’ (or, records of Tweets) will be conducted using recognised software designed for academic research purposes. This observation and collection will be guided by and cognizant of the British Psychological Society’s Code for Internet-Mediated Research (BPS, 2017).

ff. Giving advice

This study will not give or offer advice.

gg. Research undertaken in public places

We hold Twitter, as a social world, to be a public place. The study will abide by its laws and regulations, as well as those of the University and the United Kingdom.

hh. Data protection

Twitter’s developer policy and agreement expressly forbids the sharing of twitter datasets. Participants data will be held securely and will only be accessible by the researchers.

ii. Animal Rights

Not applicable

jj. Environmental protection

Not applicable

Are there other ethical implications that are additional to this list? Yes ☐ No X

7. Have / do you intend to request ethical approval from any other body/organisation?

No

8. Do you intend to publish your research? Yes
If ‘Yes’, what are your publication plans?

We intend to publish this research upon completion of the project.

9. Have you secured access and permissions to use any resources that you may require? (e.g. psychometric scales, equipment, software, laboratory space).

Yes

We have secured access to the academic software required, and to the Twitter application programme interface.

10. Have the activities associated with this research project been risk-assessed? Yes

Which of the following have you appended to this application?

- ☐ Focus group questions
- ☐ Self-completion questionnaire
- ☐ Other debriefing material
- ☐ Information sheet about your research study
- ☐ Location consent form
- ☐ Psychometric scales
- ☐ Interview questions
- ☐ Covering letter for participants
- ☐ Informed consent forms for participants
- ☐ Other (please describe)

PLEASE SUBMIT THIS APPLICATION WITH ALL APPROPRIATE DOCUMENTATION

Advice on completing the ethical considerations aspects of a programme of research

Consent

Informed consent must be obtained for all participants before they take part in your project. The form should clearly state what they will be doing, drawing attention to anything they could conceivably object to subsequently. It should be in language that the person signing it will understand. It should also state that they can withdraw from the study at any time and the measures you are taking to ensure the confidentiality of data. If children are recruited from schools you will require the permission, depending on the school, of the head teacher, and of parents. Children over 14 years should also sign an individual consent form themselves. If conducting research with children or vulnerable adults you will normally also require Disclosure and Barring Service (DBS) clearance. Research to be carried out in any institution (prison, hospital, etc.) will require permission from the appropriate authority.

Covert or Deceptive Research

Research involving any form of deception can be particularly problematical, and you should provide a full explanation of why a covert or deceptive approach is necessary, why there are no acceptable alternative approaches not involving deception, and the scientific justification for deception.

Debriefing

Debriefing is a process of reflection once the research intervention is complete, for example at the end of an interview session. How will participants be debriefed (written or spoken feedback)? If they will not be debriefed, give reasons. Please attach the written debrief or transcript for the oral debrief. This can be particularly important if covert or deceptive research methods are used.

Withdrawal from investigation

Participants should be told explicitly that they are free to leave the study at any time without jeopardy. It is important that you clarify exactly how and when this will be explained to participants. Participants also have the right to withdraw their data in retrospect, after you have received it. You will need to clarify how they will do this and at what point they will not be able to withdraw (i.e. after the data has been analysed and disseminated).

Protection of participants

Are the participants at risk of physical, psychological or emotional harm greater than encountered ordinary life? If yes, describe the nature of the risk and steps taken to minimise it.

Observational research

If observational research is to be conducted without prior consent, please describe the situations in which observations will take place and say how local cultural values and privacy of individuals and/or institutions will be taken into account.

Giving advice

Students should not put themselves in a position of authority from which to provide advice and should in all cases refer participants to suitably qualified and appropriate professionals.

Research in public places

You should pay particular attention to the implications of research undertaken in public places. The impact on the social environment will be a key issue. You must observe the laws of obscenity and public decency. You should also have due regard to religious and cultural sensitivities.

Confidentiality/Data Protection

You must comply with the Data Protection Act and the University's Good Scientific Practice http://www.derby.ac.uk/research/policy-and-strategy This means:

- It is very important that the Participant Information Sheet includes information on what the research is for, who will conduct the research, how the personal information will be used, who will have access to the information and how long the information will be kept for. This is known as a 'fair processing statement.'
- You must not do anything with the personal information you collect over and above that for which you have consent.
- You can only make audio or visual recordings of participants with their consent (this should be stated on the Participant Information sheet)
- Identifiable personal information should only be conveyed to others within the framework of the act and with the participant's permission.
- You must store data securely. Consent forms and data should be stored separately and securely.
- You should only collect data that is relevant to the study being undertaken.

- Data may be kept indefinitely providing its sole use is for research purposes and meets the following conditions:
- The data is not being used to take decisions in respect of any living individual.
- The data is not being used in any which is, or is likely to, cause damage and/or distress to any living individual.
- You should always protect a participant's anonymity unless they have given their permission to be identified (if they do so, this should be stated on the Informed Consent Form).
- All data should be returned to participants or destroyed if consent is not given after the fact, or if a participant withdraws.

Animal rights.

Research which might involve the study of animals at the University is not likely to involve intrusive or invasive procedures. However, you should avoid animal suffering of any kind and should ensure that proper animal husbandry practices are followed. You should show respect for animals as fellow sentient beings.

Environmental protection

The negative impacts of your research on the natural environment and animal welfare, must be minimised and must be compliant to current legislation. Your research should appropriately weigh longer-term research benefit against short-term environmental harm needed to achieve research goals.

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Cheng, T. Y. M., Liu, L., & Woo, B. K. (2018). Analyzing Twitter as a Platform for Alzheimer-Related Dementia Awareness: Thematic Analyses of Tweets. *JMIR Aging*, *1*(2), e11542.

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Scanfeld, D., Scanfeld, V., & Larson, E. L. (2010). Dissemination of health information through social networks: Twitter and antibiotics. *American journal of infection control, 38*(3), 182-188.

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Twitter (2018a) Privacy Policy. Online at https://twitter.com/en/privacy

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Ignatow, G., Mihalcea, R. (2017). Text mining: a guidebook for the social sciences. Los Angeles: SAGE

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ONS (2018) Deaths registered in England and Wales (series DR): 2017. Online at https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsregisteredinenglandandwalesseriesdr/2017

Oscar, N., Fox, P. A., Croucher, R., Wernick, R., Keune, J., & Hooker, K. (2017). Machine learning, sentiment analysis, and tweets: an examination of Alzheimer's disease stigma on Twitter. *Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, *72*(5), 742-751.

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Williams, M.L., (2018). *Data journalism and the ethics of publishing Twitter data*. Retrieved from: http://datadrivenjournalism.net/news_and_analysis/data_journalism_and_the_ethics_of_publishing_twitter_data

Appendix 16: Ethics application modification for tweeting on dementia

AMENDMENT TO STUDY METHODOLOGY

University of Derby Kedleston Road Derby DE22 1GB

D.Robertshaw@derby.ac.uk

29th June 2019

Dear Dr Dainty

Thank you for the confirmation of ethical clearance. I am writing to you to confirm some amendments to our study ‘Tweeting on Dementia: a snapshot of the content and sentiment of tweets associated with dementia’.

These amendments are due to changes in the approach to analysis however philosophically the approach remains the same and data will be treated the same.

Our original proposal indicated that we would use software to collect Tweets (tweetcatcher), and then other software to analyse them (nvivo). Since our initial application it has since become apparent that these software tools are not powerful enough for the volume of data collected. We are therefore changing our data collection and analysis approach. We still intend to use software to collect tweets (TAGS), and other software to analyse them (LIWC, AntWordProfiler).

More detailed information regarding the analysis is outlined below.

Step 1. Collection of Twitter data;

This phase uses Twitter Archiving Google Sheet (TAGS), which is a tool allowing automatic collection of tweets based on a search term. TAGS collects tweets through the Twitter Application Programme Interface (API) (Hawskey, 2019). The Twitter API is governed by a developer agreement and policy which expressly permits extraction and analysis of data (Twitter 2018a; Twitter, 2018b). Data can only be obtained from the preceding 7 days with this method, so data from a longer duration is collected using automatic hourly collections over six weeks preventing data gaps. In this step, keywords were chosen carefully and based on the frequency of condition associated with dementia:

- Dementia
- Alzheimer’s disease
- Vascular dementia
- Dementia with Lewy Bodies
- Frontotemporal dementia

A search string was then constructed with Boolean operators. Private tweets are not collected through this method.

Step 2a. Analysis with LIWC Sensitivity: Internal

Tweets will be extracted into a Microsoft Excel spreadsheet with personal data removed and deleted. Tweets will then be processed with Linguistic Inquiry and Word Count (LIWC) software. LIWC is a text analysis program which determines the percentage of words reflecting varied emotions, perceptions and social issues (Tausczik & Pennebaker, 2010). This software allows the research team to compare the emotional tone of voice, sentiment, strength of writing, and the analytical nature of the tweets.

Step 2b. Analysis with AntWordProfiler

The same data will then be analysed using AntWordProfiler (Anthony, 2009). This software analyses a corpus using defined word lists: an analogy of this is using a pair of glasses to look at an object, with the varying lenses representing different word lists. General service lists are included with the software and include the first and second most common 1000 words in the English language. The first list, of the first 1000 most common words, are generally shorter and less purposeful words like “I”, “It”, “She”. The second list is more purposeful and meaningful words and was therefore used within this project. Finally, the output results of these two software packages will be built into tables which are presented in the results section of this paper.

I wondered if you would be willing to consider this as a chair’s action, given the minor nature of the change. If you would like any further information please do not hesitate to contact me directly.

Thank you for your consideration.

Yours sincerely,

David Robertshaw

Head of Pre-Qualification Healthcare College of Health and Social Care

Appendix 17: Ethical approval for tweeting on dementia

UNIVERSITY OF
DERBY
Health and Social Care
Research Ethics Committee

Applicant: David Robertshaw and Ivana Babicova

Study title: Tweeting on dementia: a snapshot of the content and sentiment of tweets associated with dementia

Outcome: Minor amendment approved

Date: 9th July 2019

Dear David

Thank you for submitting an application for a minor amendment to the College of Health and Social Care Research Ethics Committee detailed within your letter dated 29th June 2019.

The minor amendments relating to data collection/analysis software has been approved by the committee and you are now able to proceed. Once the study commences if any changes to the study described in the application or to the supporting documentation are necessary, you are required to make a resubmission to the committee.

We will also require an annual review of the progress of the study and notification of completion of the study for our records.

The committee wishes you the best for the future of your project.

Yours Sincerely,

[redacted]

Chair - Health and Social Care Research Ethics Committee

Committee Secretary: **j.mo@derby.ac.uk**
Committee Vice Chair: **a.kerr@derby.ac.uk**
Committee Chair: **a.dainty@derby.ac.uk**

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Appendix 18: Robertshaw, D., Babicova, I. (2020b) Tweeting on dementia: a snapshot of the content and sentiment of tweets associated with dementia. First Monday [In press]

Content removed for copyright reasons

Appendix 19: Robertshaw, D., Babicova, I. (2020) New perspectives on great questions: what can MOOCs tell us? EURODL https://www.eurodl.org/?p=current&sp=brief&article=828

Content removed for copyright reasons

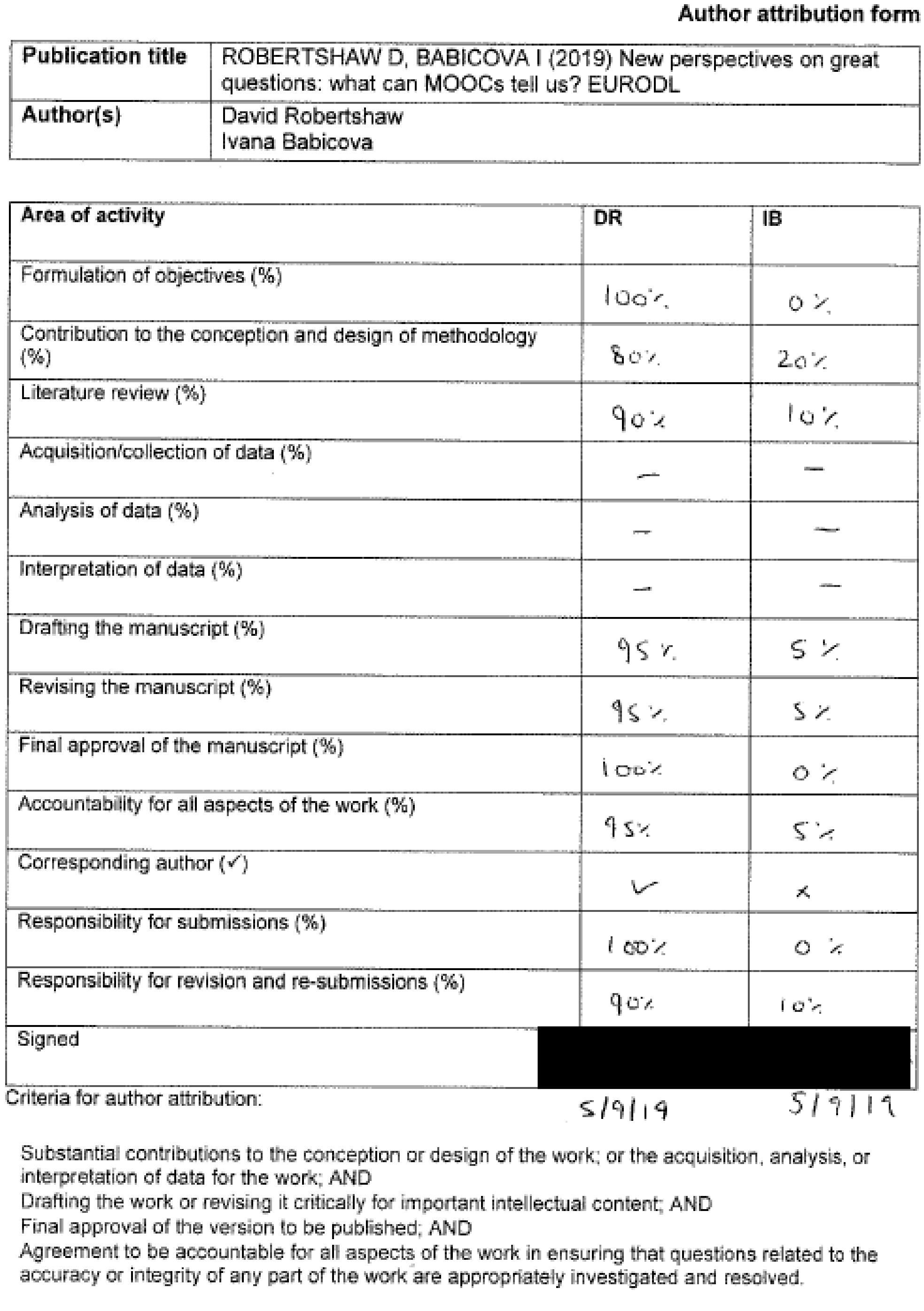
Appendix 20: Robertshaw, D. (2019) Technologisation of Nurse Education. In Dyson, S., Mcallister, M. (Eds). Routledge International Handbook of Nurse Education. Abingdon: Routledge

Content removed for copyright reasons

Appendix 21: Author attribution form for Robertshaw, D., Kotera, Y. (2019) Life with Dementia is worth living: changing perceptions of dementia through massive open social learning. EURODL

Content removed for copyright reasons

Appendix 22: Author contribution form for Robertshaw, D., Babicova, I. (2019) New perspectives on great questions: what can MOOCs tell us? EURODL



Author attribution form

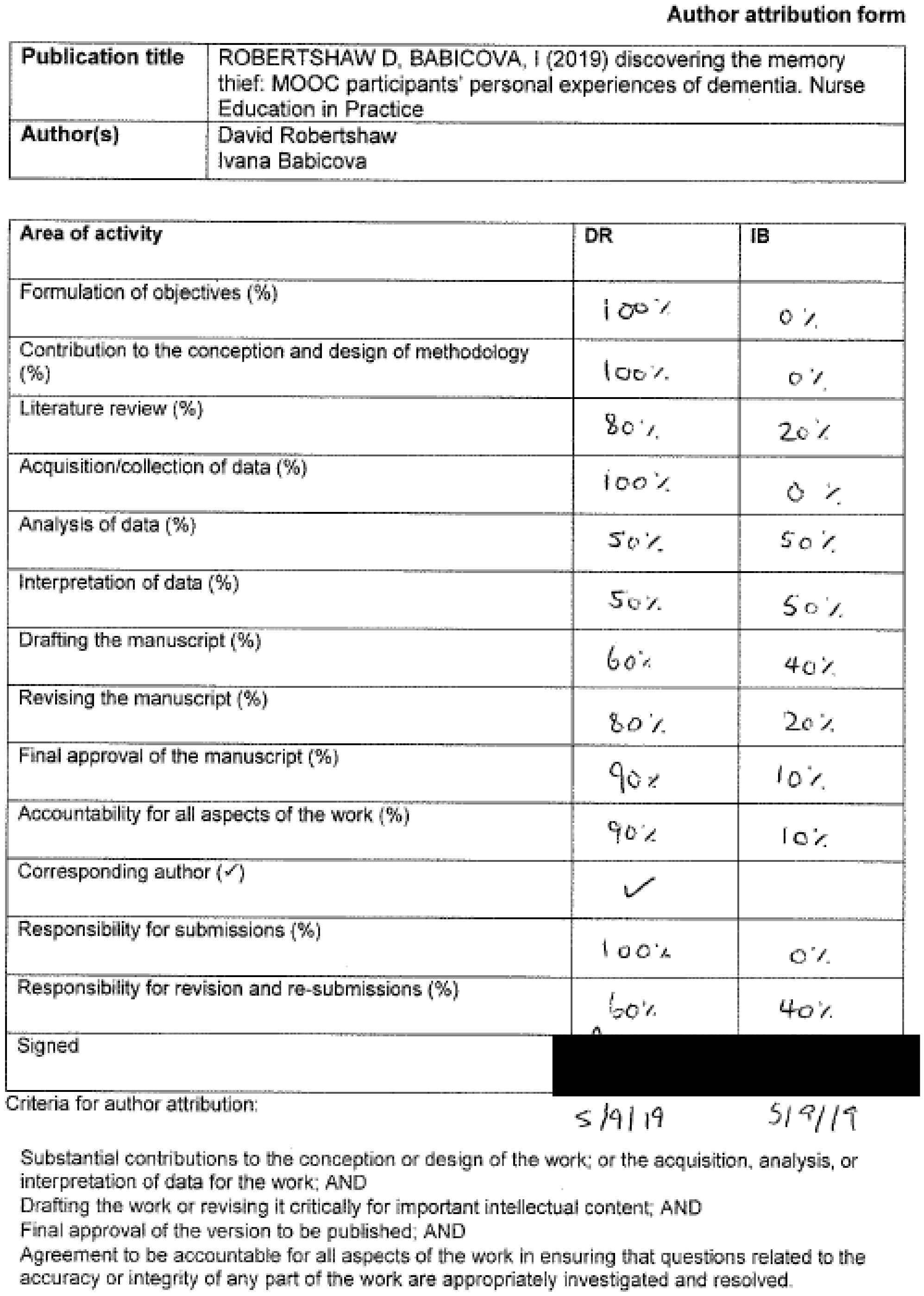
Publication title	ROBERTSHAW D, BABICOVA I (2019) New perspectives on great questions: what can MOOCs tell us? EURODL
Author(s)	David Robertshaw Ivana Babicova

Area of activity	**DR**	**IB**
Formulation of objectives (%)	100%	0%
Contribution to the conception and design of methodology (%)	80%	20%
Literature review (%)	90%	10%
Acquisition/collection of data (%)	–	–
Analysis of data (%)	–	–
Interpretation of data (%)	–	–
Drafting the manuscript (%)	95%	5%
Revising the manuscript (%)	95%	5%
Final approval of the manuscript (%)	100%	0%
Accountability for all aspects of the work (%)	95%	5%
Corresponding author (✓)	✓	×
Responsibility for submissions (%)	100%	0%
Responsibility for revision and re-submissions (%)	90%	10%
Signed	[redacted]	[redacted]
	5/9/19	5/9/19

Criteria for author attribution:

- Substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work; AND
- Drafting the work or revising it critically for important intellectual content; AND
- Final approval of the version to be published; AND
- Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Appendix 23: Author contribution form for Robertshaw, D., Babicova, I. (2019) discovering the memory thief: MOOC participants’ personal experiences of dementia. Nurse Education in Practice 41 102693



Author attribution form

Publication title	ROBERTSHAW D, BABICOVA, I (2019) discovering the memory thief: MOOC participants' personal experiences of dementia. Nurse Education in Practice
Author(s)	David Robertshaw Ivana Babicova

Area of activity	**DR**	**IB**
Formulation of objectives (%)	100%	0%
Contribution to the conception and design of methodology (%)	100%	0%
Literature review (%)	80%	20%
Acquisition/collection of data (%)	100%	0%
Analysis of data (%)	50%	50%
Interpretation of data (%)	50%	50%
Drafting the manuscript (%)	60%	40%
Revising the manuscript (%)	80%	20%
Final approval of the manuscript (%)	90%	10%
Accountability for all aspects of the work (%)	90%	10%
Corresponding author (✓)	✓	
Responsibility for submissions (%)	100%	0%
Responsibility for revision and re-submissions (%)	60%	40%
Signed	[redacted]	[redacted]

Criteria for author attribution: 5/9/19 5/9/19

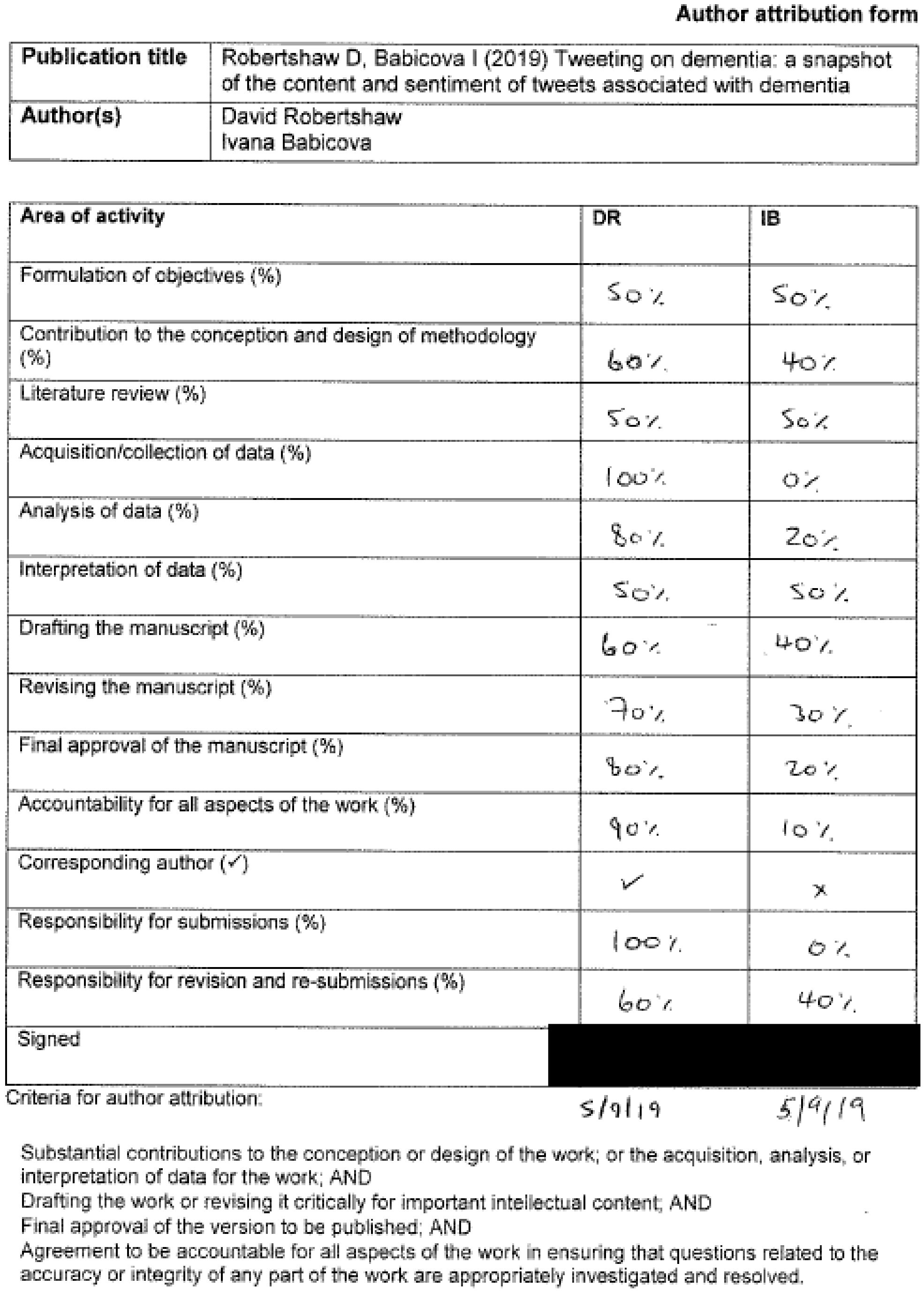
Substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work; AND

Drafting the work or revising it critically for important intellectual content; AND

Final approval of the version to be published; AND

Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Appendix 24: Author attribution form for Robertshaw, D., Babicova, I. (2019) Tweeting on dementia: a snapshot of the content and sentiment of tweets associated with dementia. First Monday [In press]



Author attribution form

Publication title	Robertshaw D, Babicova I (2019) Tweeting on dementia: a snapshot of the content and sentiment of tweets associated with dementia
Author(s)	David Robertshaw Ivana Babicova

Area of activity	**DR**	**IB**
Formulation of objectives (%)	50%	50%
Contribution to the conception and design of methodology (%)	60%	40%
Literature review (%)	50%	50%
Acquisition/collection of data (%)	100%	0%
Analysis of data (%)	80%	20%
Interpretation of data (%)	50%	50%
Drafting the manuscript (%)	60%	40%
Revising the manuscript (%)	70%	30%
Final approval of the manuscript (%)	80%	20%
Accountability for all aspects of the work (%)	90%	10%
Corresponding author (✓)	✓	x
Responsibility for submissions (%)	100%	0%
Responsibility for revision and re-submissions (%)	60%	40%
Signed	[redacted]	[redacted]

Criteria for author attribution: 5/9/19 5/9/19

Substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work; AND
Drafting the work or revising it critically for important intellectual content; AND
Final approval of the version to be published; AND
Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Appendix 25: MOOC Content

0: Get Started

[7933] Course Information

Welcome to your course on **Bridging the Dementia Divide: Supporting People Living with Dementia**. Get started by watching this video on why this course matters to you.

https://www.youtube.com/watch?v=wXqg7CfJuwQ

Transcript - Bridging the Dementia Divide

Bridging the Dementia Divide: Supporting people living with dementia

Unit 1: Introduction to Dementia

David Robertshaw

Academic Lead for Health and Social Care

There are 35.6 million people living worldwide with dementia. This number will double by 2030 and triple by 2050. Many people think that almost all people with dementia are living in isolation, in hospital or the end of their life. The reality of living with dementia is quite different. Most people lead a full and independent life and are very far from death. In this course, we'll discover more about dementia, considering how you can be compassionate and also help people to maintain their independence. We'll ask what the world is doing in response to dementia and question how we can integrate health and social care services to improve collaborative care. We'll also talk about the end of life, with the understanding that this is just the end of a long journey. We'll hear from experts at the University of Derby, clinicians in practice and carers of people living with dementia, who are helping to challenge the myths, stereotypes and stigma associated with this life-changing condition.

University of Derby

Produced by Learning Enhancement

www.derby.ac.uk (Links to an external site.)Links to an external site.

University of Derby Online Learning

www.derby.ac.uk/online (Links to an external site.)

Welcome to the course!

This massive open online course is suitable for anybody who is interested in dementia and its effects on society, culture and economics. The course also examines the pathophysiology of dementia in an accessible way, promoting a person-centred and holistic approach to care. Person-centred care promotes a partnership approach, placing the patient, service-user or client at the centre of care, ensuring their dignity (Kitwood, 1997). One of the seven principles contained within the Department of Health's *"A vision for adult social care: Capable communities and active citizens"*, 2010, calls for partnership working to ensure care and support delivered in a partnership between individuals, communities, the voluntary and private sectors, the NHS and councils.

Kitwood's person-centred principles assert and promote:

the human value of people with dementia, regardless of age or cognitive impairment, and those who care for them

the individuality of people with dementia, with their unique personality and life experiences among the influences on their response to the dementia

the importance of the perspective of the person with dementia

the importance of relationships and interactions with others to the person with dementia, and their potential for promoting well-being.

(NICE, 2006).

This course provides an open platform for all individuals, regardless of education, training, perspective, or location to reflect on the challenges facing society in their context in meeting the health and social care needs of people living with dementia. Using the best available evidence, learners will also examine dementia in the global context and consider the importance of communication and compassion, independence, control and quality of life, care integration and provide a platform for discussion about the end of life care of people with dementia. The course challenges the medicalisation of care, promoting a holistic approach that is reflective encouraging learners to consider their own context and how they might improve the care for people with dementia where they are. The course gives people with dementia a voice, and expresses their views and opinions as partners in care.

How does the course work?

This massive open online course (MOOC) uses online learning and the virtual learning environment as tools for you to read, watch, study and engage with material on dementia. That material is supported by discussion forums. Each week has one or two learning outcomes, which indicate the content, depth and breadth of learning during that week. The whole course's content is available throughout the entire course; however, we'll be covering the topics week by week. This means that if you want to continue on ahead then you can do, but we may not be able to respond to your discussion forum posts until the unit comes around. Each week you'll participate in activities that will involve your interaction with other students. There's at least one activity each week; if you complete that, you'll receive a digital badge to show your participation. Once you have earned all six badges, you will be awarded with a completion certificate.

There is also an optional assessment at the end, which will involve you creating an artefact to demonstrate your learning. This could be an oral history of a person with dementia, or a video about how to support a person with dementia, for example. It could be a reflective essay or a teaching package for people who work with dementia, but the emphasis is on you being creative and approaching the assessment from your own perspective. Your submitted work will be reviewed by other students, but more information on that will follow later. As well as your badges and certificate, if you complete the final assessment, you’ll be awarded a 'Super Badge', showing that you have demonstrated your knowledge of dementia gained through studying the course.

Objectives

Course Learning Objectives

This massively open online course is at level 6 on the Framework for Higher Education Qualifications (FHEQ).

Knowledge and Understanding

Demonstrate a conceptual understanding of dementia, its context and wider perspectives.

Intellectual Skills

Deploy techniques for high-quality integrated person-centred care interventions.

Practical / Subject-Specific Skills

Analyse situations, identify issues and propose recommendations to enhance care for people with dementia.

Transferable Skills

Demonstrate effective information and communication technology skills to advance care provision.

Activities

Course Activities Required for Successful Completion of the Course

The course is designed to be supportive of learners who are interested in only parts of the course and would like their micro learning to be recognised by us. We have split the course into **Six Units**. Successfully completing each of the units will grant you a digital badge. The digital badge will be associated with your Canvas profile.

Once you earn all six badges, the Canvas system will give you access to your digital certificate of completion for this course. You can print the paper certificate at this stage.

The criteria for earning each badge are listed below.

Unit 1: Introduction to dementia

View all pages, take part in the discussion forum, and complete the unit quiz.

Unit 2: Communication and compassion

View all pages, complete the activities, take part in the discussion forum and complete the unit quiz.

Unit 3: Independence, control and quality of life

View all pages, and take part in the discussion forum.

Unit 4: Dementia as a global health priority

View all pages, take part in the discussion forum and complete the activities.

Unit 5: Integrating care

View all pages, take part in the discussion forum and complete the unit quiz.

Unit 6: End-of-life care

View all pages, and take part in the discussion forum.

Note: You can see your progress against these criteria in the Modules page.

References

Kitwood, T. (1997) *Dementia Reconsidered: the Person Comes First*. Buckingham: Open University Press.

NICE (2006) Dementia: supporting people with dementia and their carers in health and social care. https://www.nice.org.uk/guidance/cg42/resources/dementia-supporting-people-with-dementia-and-their-carers-in-health-and-social-care-975443665093 accessed on 17.12.2015

[7934] What Can You Expect?

Select the tabbed headings to find out what you can expect from your course on Bridging the Dementia Divide.

Cost

Time Commitment

Prerequisites

Open Education Licence

Support

Instructors and The Team

Communication

Forum Rules

Data Protection

Welcome Survey

This course is free.

More free courses are available here: Free Courses (Links to an external site.).

You are expected to invest an average of two hours per week in the course. The course runs for six weeks. Participate at your leisure.

There are no prerequisites for the course but a reasonable level of understanding of English is expected to study and collaborate on this course as the course is delivered in the English (UK) Language.

Unless explicitly stated, all content released is under the Creative Commons Attribution-NonCommercial-ShareAlike 4.0 International License. For more details, please see the University of Derby MOOCs Intellectual property rights and Open Licensing policy.

The University of Derby has developed a MOOC Learner Charter (Links to an external site.), which lays down in detail the level of support that is available for our MOOC Learners and the responsibilities we expect from our learners. If you have any questions regarding the use of the Canvas platform features, we invite you to review the Canvas Guides. If you are unable to find your answer, please refer to the Help Forum within the course Discussions area. The University of Derby MOOCs project team and your fellow peer learners will be able to assist you with your queries.

The University of Derby team consists of:

The lead academic: David Robertshaw

Moderators:

Daniel Kelly

Amber Danks

The University of Derby MOOCs project team actively monitors the Discussion Forums and communicates via course Announcements. You are expected to adhere to the following policies

University of Derby MOOC Learner Charter (Links to an external site.)

Canvas Network Code of Conduct

Canvas Terms of Use (Links to an external site.)

Canvas Privacy (Links to an external site.)

Any behaviour that infringes upon the above policies, rules or guidelines; causes distress to individuals; or causes disruption or disturbance in the learning or social environments of the MOOC is unacceptable, and the individual(s) may be subject to disciplinary procedures.

The disciplinary procedure can result in you being taken off the course by the Lead Academic or your Canvas account being disabled by the Instructure team without prior notice.

When you participate in the discussion forums, you must abide by the forum rules.

We collect some data about you during your participation in the MOOC. This data is managed according to well established data protection policies. We may also contact you to inform you about upcoming MOOCs and courses on offer from University of Derby. You can see details of these policies on our web site. ITS Policies.

Before you continue, please complete the Welcome Survey.

[7935] About Us

This course has been developed by the University of Derby. The University has campuses in Derby and across the English county of Derbyshire.

The University of Derby Online Learning is the thriving distance learning division of the University of Derby.

Since 2001, the University of Derby has offered online distance learning to students who require more-flexible study options. As demand for these popular online distance learning courses increased, we learned to tailor course content specifically for online delivery. In 2011, based on the increasing success of our distance learning courses, we launched *University of Derby Online Learning* (UDOL).

Academic rigour, pioneering techniques

Today, our online distance learning degrees continue to match the high academic standards you would expect on campus in any British university. And we continue to exploit the latest research into online study to refine course delivery and increase the success of our online distance learning students.

Be part of a cutting edge team

As the University of Derby Online Learning continues to grow, so does our need to recruit the best staff to support students. If you are interested in joining a team at the cutting edge of online study, find out what opportunities are available.

Valued by industry

Our vocational online distance learning courses are particularly suited to busy, working professionals. Many of our degree courses are accredited by a professional body, so you can be sure that course content is relevant, and your qualification will be recognised and valued by your industry.

So if you need a university degree or professional qualification to progress in your chosen career, but don't want to commit to full time or on-campus study, we're ready to help you achieve your goals.

Developed by

The development of this course involved the collaboration of three departments at the university:

Academic Innovation Hub,

University of Derby Online Learning,

College of Health and Social Care.

[7936] Frequently Asked Questions (FAQs)

Any questions that are frequently asked by learners, we will share here. We have grouped our FAQs into the following categories. Select the category that your question is related to. If you cannot find the answer to your question, then post your question in the Help Discussion Forum.

Select the tabbed headings to view each category.

Content Licence

Help

Modules and Units

Badges

Certificate

Can I resuse the content?

The content may be reused provided you follow the terms and conditions stated in our Open Education Licence. However, you should recognise that material posted in the discussion forums is posted by others and so it is recommended that you do not share the content of discussion forums.

Where do I find help?

See the Help page.

What is the difference between a module, a unit and a week?

A module is a collection of web pages in this Canvas learning environment. Typically, a Canvas module contains a unit, but some modules contain other things like badges and certificates. A unit refers to a set of learning resources and activities that cover a specific topic. Typically, a unit corresponds to one week of study; however, if you wish to do so, you can study at your own pace. You may study a unit in less than one week or take longer than one week. However, please note that the lead academic and the moderators will progress from unit to unit one week at a time. So if you wish to benefit from this support you should study one unit per week. Note that the Home page indicates which unit is the current unit, and this will change week by week.

The Canvas guide explains how to view modules (Links to an external site.).

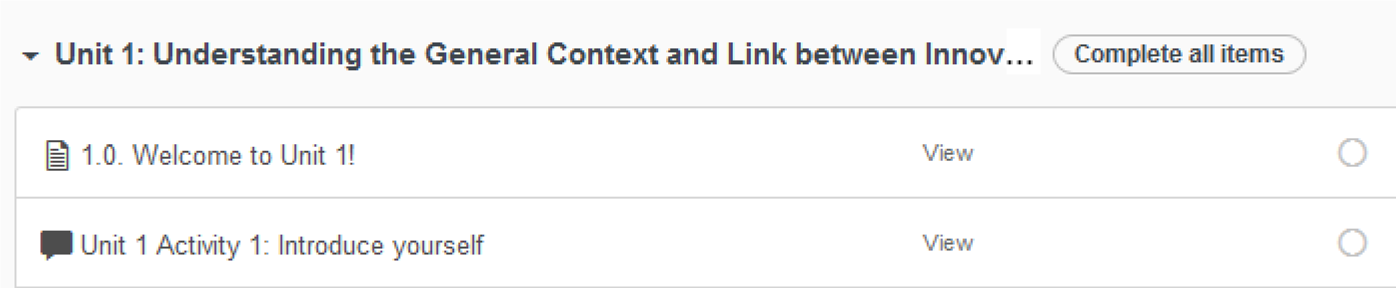
How do I view the units in this course?

The easiest way to view the units in this course is to go the home page. This can be reached from any page by clicking Home in the top left of the page.

How do I view my progress?

You can view your progress by viewing your modules, as shown within the guide above. Pages and activities that you have completed will have a tick beside their title. For the pages listed that don't display ticks, there will be a brief description of what you need to do within that page in order for it to show as completed.

Before you start a unit it will look similar to the image shown below:

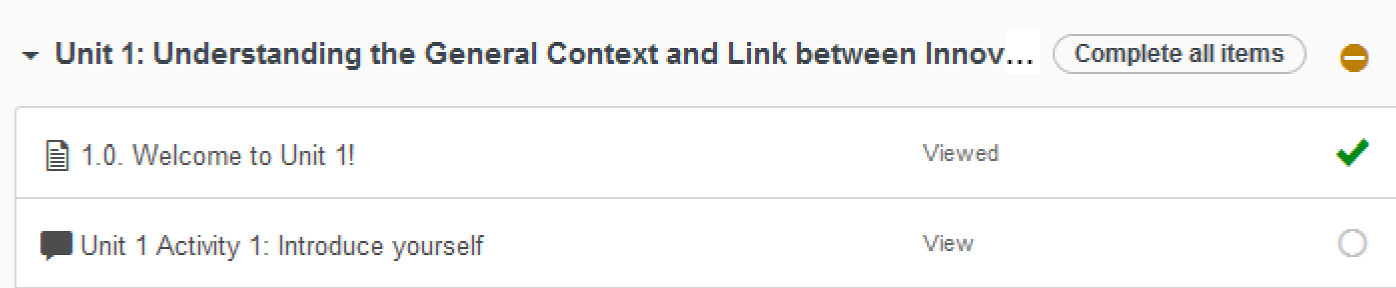


Unit 1: Understanding the General Context and Link between Innov…

1.0. Welcome to Unit 1! View ○

Unit 1 Activity 1: Introduce yourself View ○

When the unit has been started, but not competed, yiou will see a red circle on the title line, and some ticks:

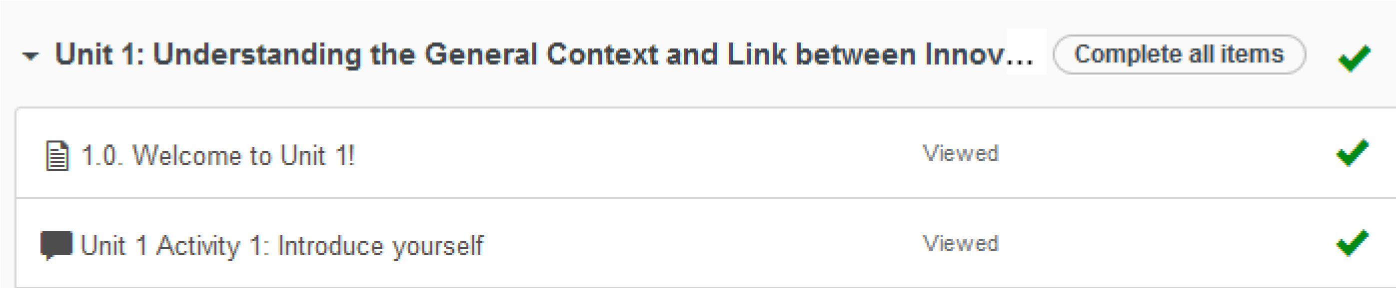


Unit 1: Understanding the General Context and Link between Innov…

1.0. Welcome to Unit 1! Viewed ✓

Unit 1 Activity 1: Introduce yourself View ○

Once the unit has been completed, then all required items will be ticked, and there will also be a tick on the title line (top-left):



Unit 1: Understanding the General Context and Link between Innov… ✓

1.0. Welcome to Unit 1! Viewed ✓

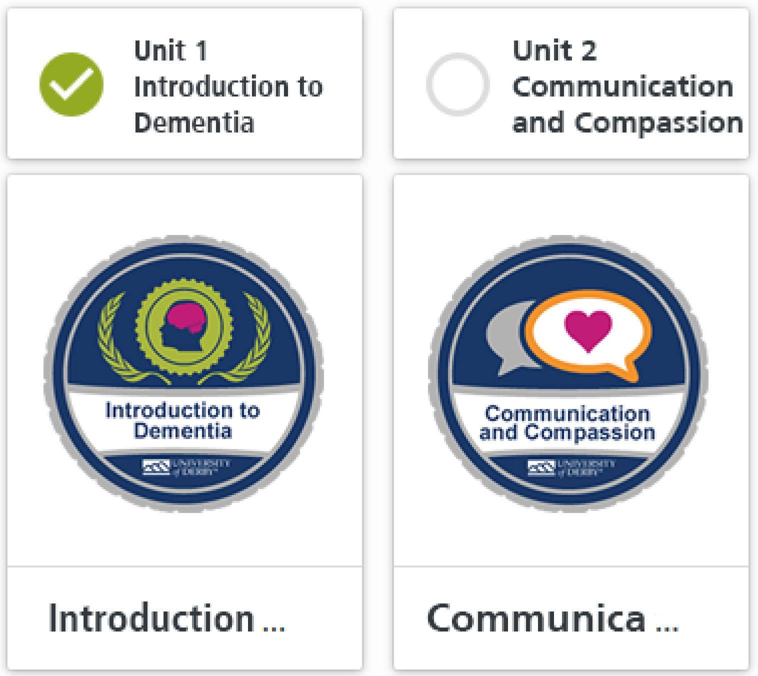
Unit 1 Activity 1: Introduce yourself Viewed ✓

How do I get a badge?

There is a badge available for each unit in the course. To access your badge **it is recommended that you use Chrome or Firefox**, otherwise you may see an error message. To get the badge for a unit you have to complete the activities in that unit. See the Course Activities for more details.

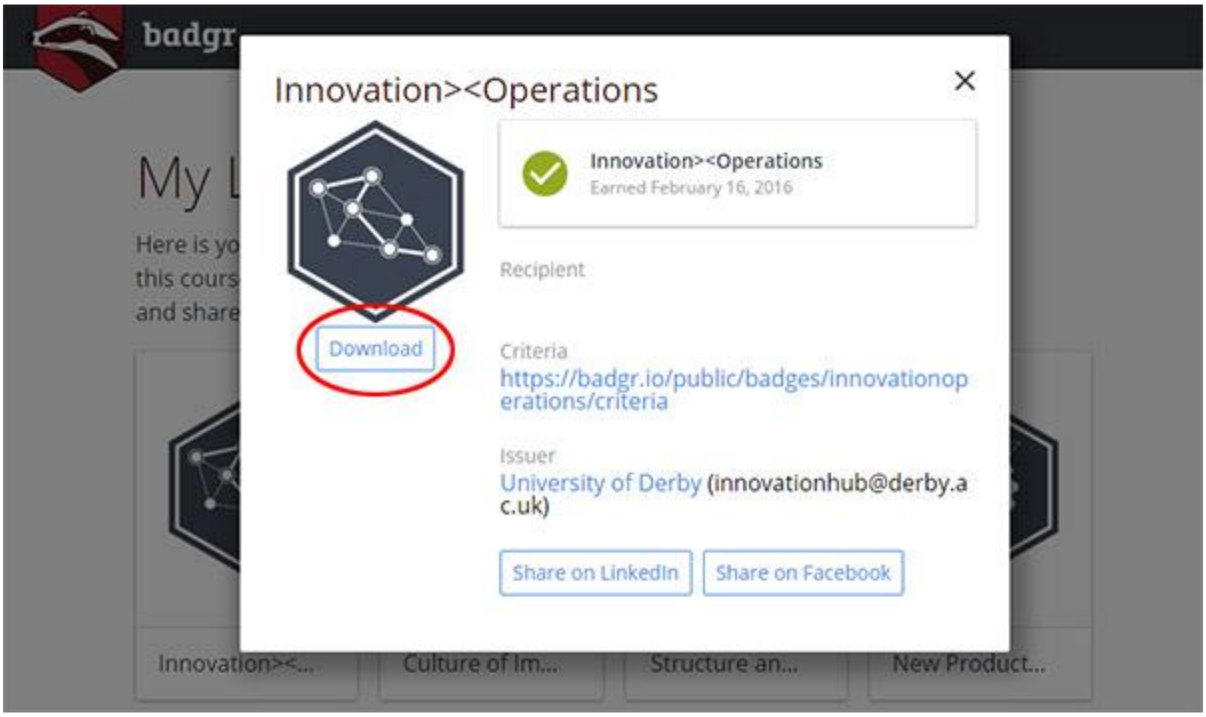
You can track your progress by clicking on the Modules link in the menu on the left. If you find the unit that you want to get a badge for, you should be able to see which parts you have completed (look for ticks). Anywhere you see the word *must* is something that still needs to be done.

Once you have completed all of the requirements for a unit you will need to visit a badge page. There is one at the end of each unit. Once that page loads you will see all of the available badges displayed. Badges that have a tick (shown on the left below) have been achieved. Those that do not display a tick (shown on the right below) have not yet been achieved.



How Do I Save My Badges?

The badge interface now allows you to download your badges directly to your computer. When you visit one of the pages that displays the badges (either the last page of each unit, or the <u>course Badges page</u>), you can click on a badge that you have earnt to view its details. You will then see a download button (as shown in the image below):



Innovation><Operations

Innovation><Operations
Earned February 16, 2016

Recipient

Criteria
https://badgr.io/public/badges/innovationoperations/criteria

Issuer
University of Derby (innovationhub@derby.ac.uk)

These files are not only images, they also contain information that specifically ties the badge to you, as well as providing a link back to the description of how you earnt it.

Why can't I claim my badge?

The last page of each unit (named Digital Badges) shows which badges you have achieved, and which you have not. Some people have had issues when trying to view this page when using certain web browsers. **Please try using the latest version of Firefox or Chrome**. All other pages in the course will work with any browser.

You can try to solve the issue of not being able to see the badge page by enabling third-party cookies (you can disable them again afterwards). The badges are awarded through a separate company's website (the third-party), and information needs to be stored on your computer (a cookie) to make it work.

Internet Explorer

Click on the small cog icon in the top right to access *Tools* (or press Alt + x)

Select *Internet Options* from the menu

Select the *Privacy* tab

Press the *Advanced* button

Choose the *Accept* option for third-party cookies (if it is greyed out then tick the box to override automatic settings first).

Safari

From the *Safari* drop-down menu, choose *Preferences* (or press cmd,)

Select the *Privacy* tab

Under *Cookies and website data* choose *Always allow*

How do I get a completion certificate?

You can only access your completion certificate once you have completed the course, earning all six badges. On completion of the course, the summary module will become unlocked and you will be able to claim your certificate. The certificates are in PDF format, so you will need software such as the Adobe Acrobat Reader to view them.

To get the certificate, you have to complete the activities in every unit, and gain every badge. See the Course Activities for more details.

[7937] Help Discussion Forum

[7938] Canvas User Orientation

Get Started with Canvas Network

Update Your Profile All new Canvas users should read this information. Click on your name at the top right corner to view your profile at any time!

Update Your Notification Preferences Canvas can send you Notifications about course activities to your email, and your cell phone. Read the information found by clicking the link, then go to Settings in the top right corner to customize your Notification preferences.

Search Canvas Guides Find helpful information! Canvas Guides provide you with all the information you need to use Canvas.

Read the Canvas Network Code of Conduct Find out how you can promote a safe learning environment.

Getting Started in Canvas Network (EN) from Canvas LMS on Vimeo.

Additional Tutorials

Communicate With Your Instructor Canvas has a messaging system you can use to send messages to your instructor.

Collapse and Expand Modules Learn how to manage the modules in your course; simplify your view of modules.

Manage Your Personal Files Canvas users get a small amount of storage to store files such as assignment drafts and readings.

How do I drop the course? If you want to drop this course, read this lesson to find out when and how you can do that.

Logging in to Canvas Network

The login URL for this course is learn.canvas.net. Be sure to bookmark that link for quick reference later.

If you use an iPad or other tablet or phone with a mobile app, be sure to login in at **learn.canvas.net**.

Supported Browsers and Mobile Apps

Supported Browsers Find out what browsers work best for this course (Chrome, Firefox, Safari, Internet Explorer).

Apps: The Canvas UI was optimized for desktop displays but can be used on mobile browsers and we do provide free apps for some mobile devices. Try the iOS and Android free Mobile Apps!

Guide to Download the Canvas by Instructure Android App

How do I use the Canvas App on my Android Device?

Guide to Download Canvas by Instructure iOS App

How do I use the Canvas app on my IOS device?

When using the mobile app, be sure to login in at **learn.canvas.net**.

Depending on your device, not all Canvas features may be available on the app at this time. View Canvas mobile features by version and device.

Accessibility Statement

Canvas provides a user experience that is easy, simple, and intuitive. Special attention has been paid to making Canvas screen-readable. The Rich Content Editor encourages users to create accessible content pages (i.e. text formatting is accomplished using styles). Canvas is designed to allow limited customization of colors and schemes to be accessible for all users. The National Federation of the Blind granted Canvas the Gold Level Web Certification in 2010. Find more information by visiting the Canvas Accessibility information page on our website.

[7939] Welcome Survey

1: Unit 1: Introduction to Dementia

[7941] Unit 1: Introduction to Dementia

If you have not viewed the course information then please visit it now before starting the course: **Course Information**.

Let’s get started!

During the week it will take to complete this unit, you will use the opportunity to identify key concepts in relation to the clinical aspects of dementia.

The learning outcome for this unit is:

Learners will demonstrate a critical understanding of dementia, challenging its myths and stereotypes.

Dementia is a complex umbrella condition consisting of a number of diseases. To start this journey, the aim this week is to provide you with background information about dementia. We’ll consider what it is and isn’t, and we'll discuss the biomedical aspects of dementia in terms of the types, causes, stages and treatment options. We’ll also outline some of the associated myths and stereotypes around dementia. The resources used and recommended by us throughout this week aim to afford you a deeper understanding of the complexity of dementia.

Adapted from Flickr

Badge

You will earn the Introduction to Dementia badge for this unit, which recognises that you have "**demonstrated a basic understanding of dementia, challenging its myths and stereotypes**".

To earn the badge you have to successfully complete the following criteria

Read all of the Unit pages

Take part in the discussion forum

Successfully complete the Unit Quiz

The badge will appear on the page that comes after completing the unit. If you do not see a badge then you still have some tasks left to complete. Don’t worry. Look at the list on that page, complete the necessary tasks, and then return to get your badge.

For more information on how you can track your progress, look at the FAQ entry for How do I get a badge.

Activity

Let's start the activities for this course by introducing yourselves to your fellow learners. Find out more on the next page.

This is an optional activity (it is not required to get the badge for this unit).

[7942] Unit 1 Activity: Introduce yourself

[7943] Invitation to take part in a research study

Invitation to take part in a research study

During this course we will ask you to reflect upon your learning, but also your perception of dementia. We’d like to invite you to take part in some research on this, through completion of a survey now before you begin the course, which will be repeated at the end and after three months. As you may know, dementia is one of the greatest social issues of our time and undertaking research is one of the ways we can seek to understand the condition and its impact. This link will take you to the survey and includes further information about the study we are undertaking including how you can take part.

Participate in the research study

Thank you for considering participating in this study.

It’s entirely optional and you can still study the course without participating.

Best wishes

David Robertshaw on behalf of The Course Team

[7944] Unit 1: Dementia is a complex syndrome

€œDementia affects the whole person: not just the brain and the memory but also a host of important aspects of daily living€•

Hughes 2011, p.14.

Dementia is a complex syndrome affecting brain functioning, relating to the irreversible loss of cognitive capacity and memory, such that there is a decline in a person's behaviour and ability to function socially, physically and emotionally over time (Kitwood 1997; De Bellis et al. 2009; World Health Organisation (WHO) 2012).

It's important to note that dementia is not a normal part of ageing; many older people are able to have a good quality of life, live at home and maintain independence. However, the disease is progressive and can affect a person's ability to perform everyday activities, leading to total dependence on caregivers. The burden of dementia on public health is increasing, with an associated intensification of health and social care issues (De Bellis et al. 2009). The WHO estimates that the total number of new cases of dementia each year worldwide is nearly 7.7 million, implying one new case every four seconds. The number of people with dementia is expected to nearly double every 20 years, to 65.7 million in 2030 and 115.4 million in 2050.

An Umbrella Term

Dementia is an umbrella term for approximately **60** different types of neurological disorders. Manifestations of the various types can be very different and therefore will require a variety of management and treatment strategies. This section will take you through some of the conditions under that umbrella.

Flickr / Pame Figueroa

References

De Bellis, A. Bradley, SL, Wotherspoon, A., Walter, B., Guerin, P., Cecchin, M. and Paterson, J. (2009) *Come Into My World: How to Interact with a Person who has*

Dementia educational resource for undergraduate healthcare students on person€• centred care. South Australia: Flinders University.

Hughes, JC. (2011) *Thinking Through Dementia.International Perspectives in Philosophy & Psychiatry*. Oxford: University Press

Kitwood, T. (1997) *Dementia Reconsidered: the Person Comes First*. Buckingham: Open University Press.

World Health Organisation (WHO) (2012) *Dementia: a public health priority* (online)http://www.who.int/mental_health/publications/dementia_report_2012/en/ (Links to an external site.) (accessed 29/1/15)

[7945] Unit 1: The carer's voice

Before we look at some of the conditions under the 'dementia umbrella', let's hear a personal experience of what it's like to care for someone with dementia:

Transcript

[7946] Unit 1: Alzheimer's Disease

The most common type of dementia, Alzheimer's, accounts for 60-80% of cases. In Alzheimer's there are abnormal deposits (plaques) of proteins and twisted strands, so messages aren't able to get through clearly. There is also evidence of nerve cell damage and cell death. People often have difficulty remembering things and can often be apathetic or depressed. Impaired communication comes later, as do poor judgment, confusion, behaviour changes and problems with swallowing and walking. It has been proposed that Alzheimer's should be considered a disease of three stages that begins a long time before the development of symptoms.

Transcript

[7947] Unit 1: Vascular Dementia

Previously known as post-stroke dementia, Vascular Dementia is less common as a cause of dementia. It accounts for around 10% of cases. There are blood vessel problems, detected by imaging the brain, implicated in vascular dementia. These blood vessel problems lead to reduced blood flow, which can result in damage and eventual brain cell death. This can result in impaired judgement, poor ability to plan and difficulty getting organised.

Transcript

[7948] Unit 1: Dementia with Lewy Bodies and Parkinson's Disease

Dementia with Lewy Bodies

Lewy bodies are clumps of proteins that develop in the cortex, resulting in dementia. These brain changes alone can cause dementia, but they can also be present alongside Alzheimer’s disease and vascular dementia. If the person has more than one type, they have mixed dementia. Dementia with Lewy Bodies results in memory loss, thinking problems and sleep disturbances. The individuals with this type of dementia may also have hallucinations, muscle rigidity and other Parkinsonian features.

Parkinson's Disease

Clumps of proteins form in an area of the brain called the substantia nigra, causing degeneration of the cells producing dopamine. This reduced amount of dopamine results in movement problems. As the condition progresses, there are many symptoms similar to that of dementia with Lewy bodies. The treatment for Parkinson’s is drug replacement of dopamine; in some cases, people can have deep brain stimulation (DBS). For more information about Parkinson's Disease, please watch the video below.

Transcript

[7949] Unit 1: Frontotemporal Dementia and Huntington's Disease

Frontotemporal Dementia

Frontotemporal dementia (FTD) includes a number of conditions including behavioural variant frontotemporal dementia, primary progressive aphasia and Pick’s disease. People with FTD typically develop the condition around the age of 60 and generally survive for a shorter time than those with Alzheimer’s. They have symptoms of strange behaviour and difficulty with speech.

Huntington's Disease

A progressive brain disorder, Huntington’s is caused by a gene defect that causes abnormalities in a brain protein. This abnormality leads to worsening symptoms over time, including involuntary movement, a severe decline in thinking and reasoning skills, irritability, depression and mood changes. Huntington's is inherited through DNA: if a parent has the disease, there is a 50% chance their child will also have it. There are specialist advisors for people who are aware they have Huntington's and are thinking of having a family.

Transcript

[7950] Unit 1 Activity: Experience of Dementia Patients

[7951] Unit 1: A History of Dementia Care

The history of dementia care and how cognitive impairments in general have been defined is complicated (Kitwood 1995). The experience of old age varies considerably around the world. In Western Europe, the older person’s role within the family and the community has changed. In the past, involvement and productive activity from older people were expected and encouraged (Nolan 2003). If and when it was needed, older people received care within that same community. Women were the main providers of care, with the main burden of care often falling disproportionally on daughters, daughter-in-laws, wives and mothers. Today, governments are expected to take a greater role in the provision of care, mainly due to smaller family sizes and the higher involvement of women in the labour force (Nolan 2003). However, Lewis et al. (2014) state:

> ***€œthe majority of social care costs fall on unpaid "informal€• carers €“ usually the spouse or a child of the person with dementia€•***

Lewis et al. 2014, p.35.

We've put together a timeline covering the history of dementia care. Read through the information below and then select the tabs to find out more.

The 19th Century

1901 - 1910

1915

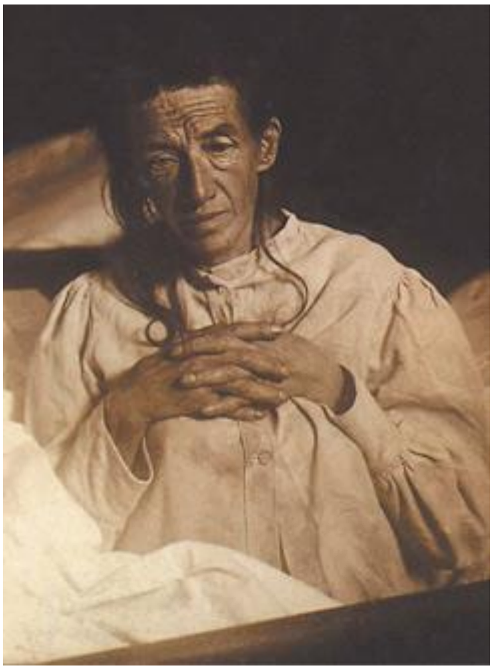
Recent Findings

Even in the past, not everyone was fortunate enough to be supported at home. The number of people in institutions increased considerably during the 19th century. These very large institutions, referred to as asylums, had space for 1,000 inmates each (Kitwood 1997).

Philippe Pinel Ã la SalpÃªtriÃ¨re by Tony Robert-Fleury, image in the public domain

Later, as medical knowledge grew, €˜abnormal behaviours’ previously thought to be regarded as a moral inadequacy or congenital deficit began to be categorised as disease conditions (Kitwood 1997). This coincided with increased medicalisation and expectations of a €˜cure’ for many disorders, particularly in the area of psychiatry. At this time, the prevailing model for understanding dementia was based on a biomedical approach: a perspective that concerned itself largely with the biological aspects of an illness (Cahill et al. 2012).

The first scientific investigations, including the work of Alzheimer, occurred around this time (Berrios and Freeman 1991). In November 1901, Dr Alois Alzheimer, a German neurologist, made his first examination of a 51-year-old woman named Auguste Deter who was experiencing problems with memory and language, as well as various psychological problems (such as disorientation and hallucinations) (McGill University 2014). Auguste Deter died on 8 April 1906. With her family’s permission, Dr Alzheimer performed an autopsy on her brain. When he examined it, he observed extensive brain atrophy (meaning shrunken or wasted away), especially in the cortex, which is the thin outer layer of grey matter that is involved in memory, language, judgement and thought in general (McGill University 2014).



Auguste Deter, the first person to be diagnosed with Alzheimer ‘s disease. 'Auguste D aus Marktbreit' by Unknown, image in the public domain

When Dr Alzheimer sampled thin slices of this brain tissue, stained them with silver salts and examined them under the microscope, he observed two types of abnormal deposits inside and between the nerve cells. Other scientists had already observed such deposits, but this was the first time they had ever been observed in anyone so young (McGill University 2014). His boss, Emil Kraepelin, a leading psychiatrist at the laboratory in Munich that had recruited Alzheimer a few years earlier, included a description of the case of Auguste Deter in the 8th edition of his book *Psychiatrie*, published in 1910 (McGill University 2014).

On 19 December 1915, five years after Kraepelin’s book had been published, Alois Alzheimer died prematurely at the age of 51 as a result of heart and kidney problems. Disdained for much of his lifetime as €˜only an anatomist’, he is now well recognised for his contribution to modern neuropathology. His greatest success was to correlate his anatomical findings with his clinical observations - something not at all common at the time (McGill University 2014).

This and other scientific approaches have greatly increased our understanding of dementia and how it affects brain function, the possible risk factors that predispose people and the treatment options available (Cahill et al. 2012).

In recent years, important changes have begun to take hold in the way people with dementia are viewed. The late Tom Kitwood and the Bradford Dementia Group broke new ground with their emphasis and focus on the person (the person€“centred approach), and not just for dementia. Kitwood urged us to consider that people with dementia are human beings whose subjective experience is greatly influenced by contextual, environmental and cultural factors including societal attitudes (Kitwood 1997). In recent years, much of the research in this area has been aimed at understanding the experiences of individuals with dementia, rather than concentrating on dementia as a problem that needs to be solved (Cahill et al. 2012).

Based on this approach, experts have more recently attempted to extend Kitwood's (1997) theory by moving beyond personhood and by arguing that people with dementia are also citizens with rights and responsibilities (Bartlett and O’Connor 2010). People with dementia may then demand the same rights as any other citizen €“ the right to live within their local communities and within society at large (Cahill et al. 2012).

This approach allows us to consider:

€œ... the salient role that public perceptions of dementia play and draws attention to the role of public and professional attitudes in advocacy work and in the care of people with dementia.€•

Cahill et al. 2012 p.16.

References

Bartlett, R. and O’Connor, D. (2010) *Broadening the Dementia Debate: Towards Social Citizenship*. Bristol: The Policy Press.

Berrios, GE and Freeman, HL. (1991) *Alzheimer and the dementias* (ends). London: Royal Society of Medicine Services.

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[7952] Unit 1: The Normal brain and ageing

The brain consists of two major components: white matter and grey matter. Grey matter is composed of neurons that communicate with each other by releasing chemical transmitters on to the surfaces of other neurons, where specifically sensitive receptor sites are located (Cantley 2009). Neurotransmitters include acetyl-choline, glutamate, serotonin and dopamine. These are involved in the regulation of memory, mood, sleep, appetite and behaviour. The grey matter supplies nutrients to the neurons and repairs damage €“ neurons are incapable of duplicating themselves (Cantley 2009). The brain reaches a maximum size of 1,700-2,000 grams by late adolescence.

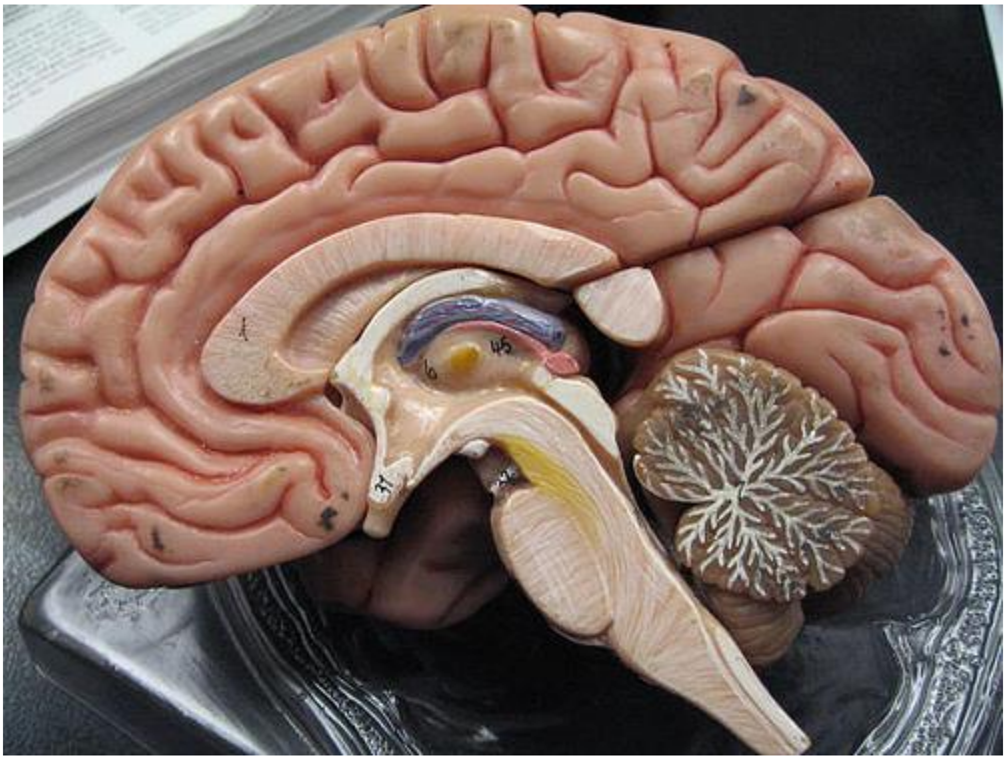

Image from Flickr by GreenFlames09

As a person ages, changes occur in the brain, including:

Certain parts of the brain shrink, especially the prefrontal cortex (an area at the front of the frontal lobe) and the hippocampus. Both areas are important to learning, memory, planning and other complex mental activities.

Changes in neurons and neurotransmitters affect communication between neurons. In certain brain regions, communication between neurons can be reduced because white matter (myelin-covered axons) is degraded or lost.

Changes in the brain’s blood vessels occur. Blood flow can be reduced because arteries narrow and less growth of new capillaries occurs.

Damage by free radicals increases (free radicals are a kind of molecule that reacts easily with other molecules).

Inflammation increases (inflammation is the complex process that occurs when the body responds to an injury, disease or abnormal situation) (National Institutes of Health 2014).

People age in different ways: some notice a modest decline in their ability to learn new things and retrieve information (National Institutes of Health 2014), while others often improve in certain cognitive areas, such as vocabulary and other forms of verbal knowledge (National Institutes of Health 2014).

It also appears that additional brain regions can be activated in older adults during cognitive tasks, such as playing cards or completing crossword puzzles. This has become known as 'cognitive reserve theory', which refers to the brain’s ability to operate effectively even when some function is disrupted. It also refers to the amount of damage that the brain can sustain before changes in cognition are evident. Moreover:

> ***"People vary in the cognitive reserve they have, and this variability may be because of differences in genetics, education, occupation, lifestyle, leisure activities, or other life experiences.€•***

National Institutes of Health 2014, p.18.

The brain is also known to use €˜cognitive reserve’ tactics to compensate in some cases of brain injury (Boyle et al 2013). A number of factors appear to contribute to a greater cognitive reserve. For example, people with more education have a greater cognitive reserve (Boyle et al. 2013; Singh-Manoux 2011).This is supported by Bigler (2014), who notes that neuroimaging studies have shown that brain networks can be strengthened by educational training. He also suggests that cognitive reserve has been shown to influence the timing and expression of dementia. It is not yet fully understood how this occurs, but it is important to stress that a variety of interacting factors, such as lifestyle, overall health, environment and genetics, may also play a role (National Institutes of Health 2014).

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[7953] Unit 1: Diagnosis and Trajectory of Dementia

Like with most other disorders, early detection of dementia is crucial. Currently, the diagnosis of dementia is mainly dependent on clinical suspicion on the basis of patient symptoms or caregivers' concerns and is prone to be missed or delayed (Bradford et al. 2009).

€œThe true prevalence of missed and delayed diagnoses of dementia is unknown but seems to be high. Until the case for dementia screening becomes more compelling, efforts to promote timely detection should focus on removing barriers to diagnosis€•

Bradford et al. 2009, p.1.

Identifying and slowing the progress of dementia is as much as can be hoped for at present. The National Institute of Neurological Disorders and Stroke (2014) points out that the specific type of dementia that a person has may not be confirmed until after the person has died and the brain is examined.

Estimates of the number of people in the UK with dementia vary. The most recent UK study (Matthews et al. 2013) estimated that there were 670,000 people aged 65 and over with dementia in 2011 (Lewis et al. 2014). Few countries have accurate data on the numbers of people who develop dementia, and most are reliant on best estimates, which can vary considerably. The risk of developing dementia increases greatly with age. Lewis et al. (2014) estimate that the likelihood of developing dementia is around 1% for women and 1.5% for men in people aged 60-69 years. For those aged 90 or more, around a quarter of men and one-third of women live with dementia (Lewis et al. 2014). In addition to the economic costs of dementia, as the disease progresses there is immense deterioration in the quality of life the person previously enjoyed (Lewis et al. 2014).

€œChanging this trajectory requires new preventive measures and new treatments€•

Lewis et al. 2014, p.35.

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[7954] Unit 1: Risk Factors of Dementia and Current Treatment Options

The following risk factors can increase a person's chance of developing one or more kinds of dementia. Some of these factors can be modified, while others cannot.

Select each of the headings below to reveal information about the subject.

AGE

The risk increases with advancing age.

ALCOHOL USE

Most studies suggest that drinking large amounts of alcohol increases the risk of dementia, while drinking a moderate amount may be protective.

ATHEROSCLEROSIS

The accumulation of fats and cholesterol in the lining of arteries, coupled with an inflammatory process that leads to a thickening of the vessel walls (known as atherosclerosis), can hinder blood from getting to the brain, which can lead to stroke or another brain injury. For example, high levels of low-density lipoprotein (LDL, or 'bad' cholesterol) can raise the risk for vascular dementia. High LDL levels have also been linked to AD.

DIABETES

People with diabetes appear to have a higher risk for dementia, although the evidence for this association is modest. Poorly controlled diabetes, however, is a well-proven risk factor for stroke and cardiovascular disease-related events, which in turn increase the risk for vascular dementia.

DOWN'S SYNDROME

Many people with Down's syndrome develop early-onset Alzheimer's disease, with signs of dementia by the time they reach middle age.

GENETICS

One’s likelihood of developing a genetically linked form of dementia increases when more than one family member has the disorder. However, in some cases, such as with CADASIL, having just one parent who carries a mutation increases the risk of inheriting the condition. In other instances, genetic mutations may underlie dementias in specific populations. For example, a mutation of the gene TREM2 has been found to be common among people with a form of very early-onset frontotemporal dementia that runs in Turkish families.

HYPERTENSION

High blood pressure has been linked to cognitive decline, stroke, and types of dementia that affect the white matter regions of the brain.

MENTAL ILLNESS

Depression has been associated with mild mental impairment and cognitive function decline.

SMOKERS

Smokers are prone to diseases that slow or stop blood from getting to the brain.

Treatment Options

Treatments and therapies to stop or slow neurodegenerative diseases are limited, although some dementias are treatable (National Institute of Neurological Disorders and Stroke 2014).

Many governments throughout the world have formulated strategies and have committed increased funding for dementia research, support for those affected by dementia and their families, increased public awareness about dementia, and improved data collection and analysis to better understand the impact of dementia on people with the disease, families, and the health and long-term care systems (National Institute of Neurological Disorders and Stroke 2014).

One of the most exciting research studies is currently being conducted at University College London, under the direction of Professor M. Francesca Cordeiro. Her group's work is focused on the mechanisms of neurodegeneration and vision loss and is particularly related to the early diagnosis and management of age-related neurodegenerative processes. The main aim of this work is to identify early markers of cell processes in neurodegenerative diseases in the eye (including glaucoma, Alzheimer’s disease and Parkinson’s disease) and to establish new methods of early diagnosis and treatment of these diseases €“ using the eye as a window to the brain (UCL 2014).

Let’s hear about diagnosis, treatment, and the medical aspects of dementia from Dr Lizzie Moriarty, a doctor at the Royal Derby Hospital:

Transcript

References

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[7955] Unit 1: Myths and Stereotypes

There are many myths and stereotypes associated with dementia, the majority of which can be considered as negative and may have been reinforced by the media. Myths and stereotypes unfortunately lead to stigmatisation and discrimination, which prevent people from seeking diagnosis and treatment and ultimately even prevent research from being undertaken. Stigma makes it hard for people to even talk about dementia.

People with dementia are often seen as being irrational, €˜crazy’, €˜mad’ and €˜senile’ and with a high degree of dependency. Actually, the reality is far from this, and many people living with dementia lead full and independent lives. Some people with dementia do live in care and residential homes; however, the majority live either by themselves or with family members. It’s clear that the stigma attached to dementia needs to be removed; as a society, this has been successfully achieved with conditions like cancer, so we know it is possible. The first objective of the UK’s National Dementia Strategy is all about improving public and professional awareness and understanding of dementia, so this is a good first step.

[7956] Unit 1 Talking Point

[7957] Unit 1 Activity: End of Unit Quiz

[7958] Unit 1: Bridging the Dementia Divide Plus

What is this section?

In this section we have included outstanding content items created by previous learners on Bridging the Dementia Divide that are related to this week’s theme. You will find various forms of content including text, poetry, PowerPoints, images €“ all for you to extend and enhance your learning. These were created as final assessments and we’re hoping to do the same with the items presented at the end of this course.

The content is aimed mainly at people that have taken the Bridging the Dementia Divide MOOC previously. If this is your first time then **this content is entirely optional**. It provides valuable insights, but will almost certainly take well beyond the advertised two hours per week schedule for this course.

Angora, Sadie: Supporting those living with dementia.

Bell, Kim: Dementia: My Learning Journey.

Bristow, Filiz: A brief summary of dementia and two case examples.

Docker, Elizabeth: Dementia: An overview.

Dowling, Sara: What have I learnt?

Guyatt, Michelle: Dementia.

Haxeltine, Heidi: A dementia mind map.

Hellal, Paula: Dementia and Down Syndrome.

Hinds, Adrian: Dementia & you.

Jawahar, Kaanthan: Reflection on a challenging dementia case.

Popoviv, Marija: Dementia care concept - employee induction.

2: Unit 1 Badge

3: Unit 2: Communication and Compassion

[7961] Unit 2: Communication and Compassion

Why is effective communication important, and how can you show compassion?

During the week it will take to complete this unit, you will use the opportunity to identify key concepts in relation to compassion and communication.

The learning outcomes for this unit are:

Learners will evaluate the main theoretical perspectives applicable to the study of compassion in care.

Learners will demonstrate a critical awareness of enhanced communication skills to enable them to better communicate with people with dementia.

Badge

You will earn the Communication and Compassion badge for this unit, which recognises that you have met the learning outcomes. To earn the badge you have to successfully complete the following criteria:

Read all of the Unit pages

Complete the Activity - using Google Form

Take part in Unit Discussion forum: "The role of education in promoting compassion"

Successfully complete the Unit Quiz

The badge will appear on the page that comes after completing the unit. If you do not see a badge then you still have some tasks left to complete. Don't worry. Look at the list on that page, complete the necessary tasks, and then return to get your badge.

For more information on how you can track your progress, look at the FAQ entry for How do I get a badge.

[7962] Unit 2: Compassion Is a Core Concept

Transcript

Select the tabs to find out about the different contexts that compassion may fall into.

The six 'Cs'

The seven dimensions

The Dalai Lama's definition

Other dimensions

Compassion is seen as a valuable component of care, whatever the context. It has been identified as one of the six 'Cs':

Care

Compassion

Competence

Communication

Courage

Commitment

(The Commissioning Board NHS 2012).

The six 'Cs' were identified as a result of the Francis report, which focused on the Mid Staffordshire NHS Foundation Trust (The Mid Staffordshire NHS Foundation Trust Public Inquiry 2013).

Image Source: NHS England

Compassion has recently become a focus of research, especially in terms of understanding attitudes to compassion and how it can be a motivation to provide care (Gilbert 2010). According to Van der Cingel (2011, p. 676), compassion is a process of intuition and communication, of which there are seven dimensions:

Attention

Listening

Confronting

Involvement

Helping attitudes

Presence

Understanding.

The Dalai Lama’s (1995) definition is:

> ***"an openness to the suffering of others with a commitment to relieve it€•***

Dalai Lama (1995)

Compassion is also linked to feelings of empathy, kindness, gentleness, and warmth (Gilbert et al. 2011; Fehr et al. 2009).

However, there are many other dimensions to compassion. Gilbert et al. (2011) found in their study that a fear of compassion for the self and compassion from others were significantly linked to fear of compassion for others. They also believed that in the student population being studied, fear of being compassionate to others was significantly associated with insecure attachment styles:

€œthis means that people may actively resist engaging in compassionate experiences or behaviours€•

(Gilbert et al. 2011, p. 251)

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[7963] Unit 2 Activity: Share a site related to compassion

[7964] Unit 2: Models and Principles of Compassion

Professor Paul Gilbert (a British clinical psychologist and a professor at the University of Derby) developed compassion-focused therapy, which later led to a particular model of compassion that focuses on the core features of suffering and the alleviation of suffering. According to Cole-King and Gilbert (2011), the model can help to identify problems when organisations attempt to introduce a compassionate approach. The essential elements of compassion appear to include the following:

Essential elements towards a compassionate approach (adapted from Cole-King and Gilbert, 2011)

Gilbert’s (2009) model outlines six core components essential for a compassionate approach. These are: motivation, knowing how to pay attention, what to look for when working compassionately, sympathy, distress tolerance and empathy (Crawford et al. 2011, p.3). Centred on these components is a list of the attributes of a compassionate mentality, and these are outlined in the table below.

A list of attributes of a €˜compassionate mentality’

Kind
Gentle
Warm
Loving
Affectionate
Empathic
Patient
Non-judgemental
Soothing

Caring
Sensitive
Helpful
Considerate
Sympathetic
Friendly
Supportive
Understanding
Validating

Comforting
Reassuring
Calming
Open
Concerned
Tolerant
Encouraging
Giving
Respectful

Adapted from Crawford et al. (2011, p.3)

However, there are many limitations on compassion in organisations. These include time constraints, reward systems and bureaucratic paperwork (Darren-Thompson et al. 2003). Other explanations are the routines and rituals that hamper the delivery of person-centred care (Kelly 2007).

References

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[7965] Unit 2 Activity: Compassion

What does compassion mean to you? Complete this Google form with your views (the box is free for your text).

You can then review everyone's responses in this publicly viewable summary. The document contains the responses from everyone who has undertaken this MOOC over the past few years.

How do your views compare to those of others on the course?

Loading...

[7966] Unit 2: The Communication of Empathy and Compassion in Dementia Care

Transcript

According to Jazaieri et al. (2013), compassion is a rational response to suffering. It combines the recognition of suffering with the desire to help those who are suffering (Jazaieri et al. 2013; Goetz et al. 2010, p. 351). The Commissioning Board NHS (2012), in its publication €˜Compassion in Practice: Nursing, Midwifery and Care Staff: Our Vision and Strategy', states that compassion is:

€œhow care is given through relationships based on empathy, respect and dignity€•

(NHS Commissioning Board 2012, p.13).

Strong evidence also exists that kindness and compassion are necessary for survival, well-being, health and social competence (Seppala et al. 2013). These concepts are strongly linked to increased social connection, which is defined as:

€œa person’s subjective sense of having close and positively experienced relationships with others in the social world€•

(Seppala 2013, p. 420).

On the other hand, Seppala et al. (2013) contend that a lack of social connection is:

€œlinked to psychological distress, dysfunctional interpersonal behaviour, accelerated mortality and antisocial tendencies in a deleterious and mutually-reinforcing set of variables€•

(Seppala 2013, p. 421).

Considering the very public failures in standards of care recently (Francis Report 2013; Primetime Investigates RTE 2014; BBC News Bristol 2012), discourse now centres on whether it is possible to cultivate compassion and thereby increase social connection and cohesion. The Stanford Centre for Compassion and Care promotes compassion and altruism within individuals and society through education, research and scientific and academic collaborations.

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[7967] Unit 2 Activity: The role of education in promoting compassion

[7968] Unit 2: Communication is the key

The Commissioning Board NHS (2012), in a section on communication, states that:

€œlistening is as important as what we say and do and essential for €˜no decision about me without me'. Communication is the key to a good workplace with benefits for those in our care and staff alike€• .

(Commissioning Board NHS 2012, p.13).

Griffiths et al. (2013) explored how doctors, nurses and allied health professionals viewed their preparation to care for confused, older patients on general hospital wards. There was agreement among participants that education, induction and in-service training left them inadequately prepared and under-confident to care for confused, older patients. Many doctors reported initial assessments of confused, older patients as difficult and described emotional and behavioural responses including frustration, stress, empathy, avoidance and low job satisfaction. Communication with confused patients was regarded as particularly challenging, both in terms of patients making their needs known and in terms of staff conveying information to patients. Many doctors admitted inadequate knowledge of mental health disorders, including the diagnostic features of delirium and dementia. Handling agitation and aggression was considered a top priority for training, particularly for nurses.

It is now well-documented that a person-focused approach is vital to achieving goals of greater patient satisfaction and inclusive decision-making (Bach and Grant 2009; Charlton et al. 2008). A key aspect of this approach is based on effective communication between healthcare providers and patients, co-workers and carers. Charlton et al. (2008) differentiate between biomedical and biopsychosocial communication styles. The biomedical focuses on giving specific information on the physical aspects of the disease or condition of the patient. On the other hand, the biopsychosocial concentrates on patient-centred communication, using the key skills of listening, showing empathy, providing information and offering support in a therapeutic context (Bach and Grant 2009). Being empathic requires an understanding and an ability to identify emotionally with an individual's feelings (Greenberg 2007). This understanding of another's feelings, through verbal and non-verbal interaction, is an ability that needs to be developed, given the complexity of many healthcare interactions (Bach and Grant 2009).

€œEmpathic attunement suggests that nurses and midwives who convey genuine interest, acceptance and caring are more likely to achieve a secure emotional bond with their patients€• .

(Bach and Grant 2009, pp. 37-38).

Greenberg (2007) argues that patients’ and clients’ right brain hemispheres respond more to nurses’ facial communication than to nurses’ words. Workers who convey genuine interest, acceptance, caring, compassion and joy create the environment for a secure, emotional bond (Bach and Grant 2009). With this in mind, non-verbal facial communication is extremely important, particularly in dementia care. Much can be observed from the facial expressions of healthcare staff (Greenberg 2007).

Let’s hear from David Foreman, Senior Lecturer at the University of Derby, about communication and how you can effectively communicate with a person with dementia.

Transcript

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[7969] Unit 2: Practical Communication Skills

Let’s consider a few practical skills that you can employ when communicating with others. Select the tabs to find out more.

Attending Skills

Removing Distractions

Non-verbal Communication

Use of Silence

Before we begin listening to another person, we can demonstrate that we are attending to them by being ready. At the same time, the person that needs to be listened to can also feel ready to concentrate on what they want to say.

We can prepare ourselves as much as possible by eliminating distractions. Distractions can be external or internal. We may not be able to control all environmental factors, but we can make the best of the situation. When we are distracted, we become unavailable and removed from psychological contact. By 'external', we are referring to environmental factors. Sometimes external noise cannot be avoided.

Non-verbal communication is often referred to under the initialism **S-O-L-E-R**

S-O - Seating /Open Posture

The way we sit can convey a great deal about whether we are actively listening. Most skill books recommend an open posture, sitting with arms resting on chair arms or in the lap, and there are often debates about whether legs (or ankles) should be crossed. Basically, the whole point is for the listener to feel as comfortable as possible.

L - Trunk Lean

The degree of lean can also influence the perception of whether we are listening or not. Leaning too close may communicate too much intensity or a lack of respect for the other person's personal space. Sitting without moving may communicate a lack of engagement or interest.

E - Eye Contact

Eye contact in a Western European culture denotes interest and being listened to. However, in some cultures such as American Indian or Aboriginal groups, eye contact is avoided when serious subjects are being discussed. It is therefore very important to be aware of any cultural difference where eye contact carries a different meaning.

R - Relax

Either the listener or the person being listened to can often pick up nervousness and tension. Being mindful of the tension in our bodies can help us to pick up tensions and learn to relax.

Seating/ Open posture - when practising your listening skills think about and note your posture - observe this when you videotape your skill practice sessions.

Lean - think about how much you lean or not depending on the situation.

Eye contact - observe your eye contact; very often you may pick up cues about what you attend to or what you avoid by the pattern of eye contact.

Relax - think about where you hold your tension. For example, some people hold tension in their shoulders and neck, some hold tension in their jaw or face (such as frowning), and other people hold tension in their hands and arms. Practise releasing this tension.

Another aspect of non-verbal communication that becomes problematic is touch. For some people, touch is difficult, but for others it is not. This will depend on our cultural and personal experiences. Touch can convey different meanings. Below are some examples of how touch can convey meaning.

Positive meanings - such as nurturing, reassurance, protection, gratitude, psychological closeness, affection, positive regard, sexual interest or playfulness

Control - we can touch someone to indicate that they should 'move over', 'hurry', 'stay here' and 'do it'

We can touch someone to gain their attention 'look over here' or 'look at me'

In some cultures, it is the higher-status person that is allowed to touch the lower-status person

Ritual - touch that relates to greetings and departures, such as handshaking, hugs and kisses

Task-relatedness - tasks that are associated with performing a function such as assisting someone out of a car or removing dust from another person's clothing

Responding is not only about how we respond to words but also how we respond to silence and how we use silence. Can you recall the last time that you were in the company of another person that included some long periods of silence? What was your experience of the silence?

How comfortable do you feel with silence? Some people can find silence anxiety provoking; Corey (2000) comments:

"It is not uncommon to be threatened by silence to the point that we frequently do something counter-productive to break the silence and thus relieve our anxiety" (Corey 2000, p. 35).

There may also be some cultural differences in how silence is perceived; for example, in the US, silence is often taken as negative (DeVito 2004). However, attentive silence in counselling sessions can allow space for thinking, feeling and reflection, forming a basis for dialogue. It's important to remember that not speaking is not the same as showing no response.

References

Corey, G. (2000) Theory and Practice of Counseling and Psychotherapy. Belmont: Wadsworth

DeVito, J.A. (2004) (5th Edition) The Interpersonal Communication Book Cambridge, Harper & Row Publishers

[7970] Unit 2 Activity: Techniques for communication

[7971] Unit 2 Talking Point

[7972] Unit 2 Activity: Reflection

At the end of this Unit, and others, you will be encouraged to reflect on your learning this week. Complete this Google form with your reflections (the box is free for your text).

You can then review everyone’s responses in this publicly viewable summary. The document contains responses from others who have undertaken this MOOC over the past few years.

How do your views compare to those of others on the course?

Loading...

[7973] Unit 2: Bridging the Dementia Divide Plus

What is this section?

In this section we have included outstanding content items created by previous learners on Bridging the Dementia Divide that are related to this week’s theme. You will find various forms of content including text, poetry, PowerPoints, images €“ all for you to extend and enhance your learning. These were created as final assessments and we’re hoping to do the same with the items presented at the end of this course.

The content is aimed mainly at people that have taken the Bridging the Dementia Divide MOOC previously. If this is your first time then **this content is entirely optional**. It provides valuable insights, but will almost certainly take well beyond the advertised two hours per week schedule for this course.

Abayomi, Adewumi Peace: Ten Tips for Communicating with a Person with Dementia.

Charlish, Steve: Care home alone.

Cooper, Sue: Connecting with the person with dementia.

Farida, Andre: Banishing coomunication barriers in dementia.

Hider, Sharon: Communication.

Jefferies, Averil: A view of dementia.

Maunders, Rhiannon: Visual images of dementia.

Shaw, Kayleigh: Living with dementia booklet.

Weiland, Amina: Ways to communication effectively with AD individuals.

4: Unit 2 Badge

5: Unit 3: Independence, Control and Quality of Life

[7976] Unit 3: Independence, control and quality of life

How can you help the person living with dementia to maintain independence, control and a good quality of life?

The learning outcome for this unit is:

Learners will discuss techniques to defend independence, control and quality of life within the context of dementia, evaluating relevant ethical and legal frameworks.

There is a shared understanding between health professionals and older people on the need for dignity in care. However, as Webster (2004) points out, concerns about the standards of care for many people abound, despite global efforts to address the shortfalls. Moise et al. (2004) emphasise that because there are no reliable health care measures available, social care aspects play an important part in treating the disease. The best hope of maintaining independence and an acceptable quality of life for people with dementia appears to be through social innovations. This unit will challenge you to critically evaluate these aspects of care provision.

Badge

You will earn the Independence, Control and Quality of Life badge for this unit, which recognises that you have met the learning outcomes. To earn the badge you have to successfully complete the following criteria:

Read all of the Unit pages

Take part in Unit Discussion forum: "Is telling a lie wrong?"

The badge will appear on the page that comes after completing the unit. If you do not see a badge then you still have some tasks left to complete. Don’t worry. Look at the list on that page, complete the necessary tasks, and then return to get your badge.

For more information on how you can track your progress, look at the FAQ entry for How do I get a badge.

References

Moise, P., Schwarzinger, M., Um, M-Y and the Dementia Experts’ Group (2004) *Dementia Care in 9 OECD Countries: A Comparative Analysis* [Online] http://www.oecd-ilibrary.org/social-issues-migration-health/dementia-care-in-9-oecd-countries_485700737071 (Links to an external site.) (Accessed: 17/2/15).

Webster, R. (2004) *Dignity and Older Europeans Consortium* [Online] http://www.scie-socialcareonline.org.uk/dignity-and-older-europeans-final-report-of-focus-groups-of-irish-

professionals/r/a11G0000001810VIAQ (Links to an external site.) (Accessed: 14/1/15).

[7977] Unit 3: Self-Determination and the Maintenance of Independence

€œSince my father can no longer cross the bridge into my world, I have to cross over to him.€•

(Arno Geiger, Der alte KÃ¶nig in seinem Exil - The Old King in Exile 2011)

The maintenance of independence is paramount but will most likely change with the stages of dementia. The National Clinical Practice Guideline, published in 2007 by The British Psychological Society and The Royal College of Psychiatrists, points out that this means facilitating performance of, or engagement in, as much activity as is reasonable and tolerable for the individual. It is this balance between personal care and productive, leisure, social and spiritual activities that is important for quality of life and well-being (National Collaborating Centre for Mental Health UK 2007). For details, visit the National Institute for Health and Care Excellence and download CG42 Dementia: Full Guideline, including appendices 1 to 7.

The main focus currently is on early diagnosis. This has implications far beyond the clinical aspects of the disease, since it is now recommended that the diagnosis be shared with the person who has dementia (Department of Health 2001), and draws attention to how best to respond to the needs of patients and their families for more information on the person’s condition (National Collaborating Centre for Mental Health UK 2007). The illness narrative methodology, already mentioned in Unit 5 of this module, is suitable for listening to the voices of people with dementia and their care-givers.

Carers providing care for people with dementia suffer high levels of stress, depression, loneliness and guilt (Brodaty et al. 2002; Sorensen et al. 2002). The National Collaborating Centre for Mental Health UK (2007) points out that the effect of the condition on carers is often overlooked and their needs may not be properly met.

€œCaring for a person with dementia is often compared to bereavement and there may be many losses for carers. These may, for example, include losing the companionship of a spouse or partner, loss of a parent figure, of income and of freedom to live one’s own life. Plans for the future may be dramatically altered and consequently carers may need to learn many new skills. For example, a wife may have to take on house maintenance and bill payments, if these were responsibilities that her husband had always undertaken. In

contrast to such practicalities, carers may have to provide intimate personal care, which is a difficult role, especially when looking after a parent€• .

(National Collaboration Centre for Mental Health UK 2007, p. 280).

In terms of self-determination and the maintenance of independence, the disease will have an impact on carers and family members, as well as patients. Their views will have to be considered because they will be faced with important decisions. Additionally, they are the best resource available in most instances. The National Collaborating Centre for Mental Health UK (2007) states that people with dementia benefit when carers are well-supported and well-informed and, as a result, are enabled to live longer in their own communities (National Collaborating Centre for Mental Health UK 2007).

References

Arno Geiger, *Der alte KÃ¶nig in seinem Exil -The Old King in Exile* (2011) MÃ¼nchen:Carl Hanser Verlag

Brodaty, H., Pond, D., Kemp, N.M., et al. (2002) The GPCOG: a new screening test for dementia designed for general practice, *Journal of the American Geriatrics Society,* 50(3), pp.530€“534.

Department of Health (2001) *Reference Guide to Consent for Examination or Treatment.* London: Department of Health. [Online]. Available at: https://www.gov.uk/government/publications/reference-guide-to-consent-for-examination-or-treatment-second-edition (Links to an external site.) (Accessed: 1/1/15).

National Collaborating Centre for Mental Health (UK) (2007) Dementia: A NICE-SCIE Guideline on Supporting People With Dementia and Their Carers in Health and Social Care. Leicester (UK), British Psychological Society, (NICE Clinical Guidelines, No. 42.) *Guideline Development Group Membership*. [Online] Available athttp://www.nice.org.uk/guidance/cg42/evidence (Links to an external site.) (Accessed 2/1/15).

Sorensen, S., Pinquart, M. and Duberstein, P. (2002) How effective are interventions with caregivers? An updated meta-analysis, *The Gerontologist,* 42(3), pp. 356€“372.

[7978] Unit 3: The Ethical and Legal Challenges to Enabling and Respecting Self-Determination

Dementia presents a whole new set of challenges and predicaments for the individual and care-givers. The German Ethics Council (2012) points out that, apart from health and well-being, ability and autonomy, particularly in relation to decision-making, are adversely affected by dementia.

€œPersons with dementia become less and less able to make decisions for and about themselves and are more and more dependent on the solidarity and responsibility of others€•

(The German Ethics Council 2012, p. 47).

Preserving self-determination requires a mixture of respect for what remains of the person’s personality and a compassionate caring action, which will help to alleviate the suffering experienced through the various stages of the disease. Graumann (2011) suggests that the term "assisted self-determination€• is also appropriate on the basis of person-centred attention. The nature of the assistance is adapted and assessed, depending on how far the remaining elements of independence and self-determination can be activated.

Kitwood (1997) emphasises the importance of recognising the person, not just the disease. In common with other disorders, people with dementia are all too often defined by the disease itself. He further notes that some of the deterioration seen in people with dementia is caused not by the disease itself but by how people are treated. Smebye and Kirkevold (2013) argue that personhood is a creation of relationships with others, which can be supported or reduced:

€œ€˜Malignant social psychology’ exists in relationships which devalue, dehumanise and diminish the person with dementia and for example, when the person is stigmatised, infantilised, objectified or ignored, a loss of personhood ensues"

(Smebye and Kirkevold 2013, pp. 12-29).

Alzheimer’s Europe (2015) states that self-determination is a key component in health care, which is gradually moving away from a paternalistic approach towards a more individualistic, person-centred approach that allows the individual to be more actively involved in their own health and well-being. However, it cautions that such an approach requires people to take responsibility for making their own decisions.

The Finnish National Advisory Board on Health Care Ethics (ETENE), though recognising the benefits for many people with dementia of exercising some degree of autonomy, through advance consent or refusal of medical treatment and/or care, warns against concentrating almost entirely on the principles of autonomy and self-determination. It states:

€œit is important to understand that help for a human being cannot be based on just a single, isolated principle €“ and far less on its mechanical application. Alongside self-determination, the principles of the common good, community and equity, among others, demand to be taken just as seriously€•

(ETENE 2001, p. 23)

A debate currently intensifying centres on the topic of surrogate decision-making. Koppelman (2002) presents a strong argument, and a range of strategies, to support patients in need of surrogate decision-making so as to enjoy the dignity of being free to express who they are through choice and action. He claims that surrogates should strive to, at least, make sure that decisions made on behalf of the patient reflect that patient's self.

References

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Etene (2008) *Report on elderly care* [Online] http://www.etene.fi/en/materials/publications/report_2008 (Links to an external site.)(Accessed: 17/2/15).

German Ethics Council (2012) *Dementia and self-determination* [Online]http://www.ethikrat.org/publications/opinions/dementia-and-self-determination (Links to an external site.) (Accessed: 17/2/15).

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Koppelman, E.R. (2002) Dementia and Dignity: Towards a New Method of Surrogate Decision Making, *J Med Philos,* 27(1), pp. 65-85.

Smebye, K. and Kirkevold, M. (2013) The influence of relationships on personhood in dementia care: a qualitative, hermeneutic study, *BMC Nursing 2013*, pp. 12-29 [online] Available at:http://www.biomedcentral.com/1472-6955/12/29 (Links to an external site.) (Accessed: 18/02/15).

[7979] Unit 3: Accommodation of Change and Recognising Potential

Smebye and Kirkevold (2013) offer the concept of 'positive person work', or person-centred care, which aims at restoring and sustaining personhood. Similar to Kitwood's (1997), this acknowledges that the individual is a person who can experience life and relationships, despite the progressive disease, concentrating on strengths rather than losses. Decision-making capacities will vary by the type and stage of the illness.

Edvardsson et al. (2008, p. 363) outline person-centred care in Alzheimer's disease as having the following components:

Regard personhood in people with Alzheimer’s disease as increasingly concealed rather than lost.

Acknowledge the personhood of people with Alzheimer’s disease in all aspects of care.

Personalise care and surroundings.

Offer shared decision-making.

Interpret behaviour from the person’s viewpoint.

Prioritise the relationship to the same extent as the care tasks.

Brooker (2007, p. 13) stresses the importance of a caring culture, which has four major elements and can be articulated in the following equation:

PCC (person-centred care) = V + I + P + S

Select the tabs to find out more about each element of the equation.

V

I

P

S

A **Value** base that asserts the absolute value of all human lives, regardless of age or cognitive ability.

An **Individualised** approach, recognising uniqueness.

Understanding the world from the **Perspective** of the service-user.

Providing a **Social** environment that supports psychological needs.

The nature of the relationships between care-givers and those with dementia, is an important focus of research and study. Wilson et al. (2009) identified three types of positive relationships in a study of interactions between staff and residents in a care home:

Pragmatic relationships

Personal and responsive relationships

Reciprocal relationships.

Smebye and Kirkevold (2013), in their study, aimed to increase the understanding of the nature and quality of relationships between people with dementia and their family carers and professional caregivers, as well as how these relationships influence personhood. A number of key findings identified a variety of relationships that exist between the people involved and the unique context of these caring interactions. The authors state that personhood can be maintained or reduced in these different contexts.

One of the key findings was that: family carers wanted to contribute and collaborated with professional care-givers for the well-being of the person with dementia. In family relationships where personhood was sustained, past history and family coherence explained why current relationships were close.

€œProfessional care-givers took account of opinions and concerns expressed by persons with dementia and their family carers, and acknowledged their contributions such as sharing life-stories and using this knowledge to personalise care. On the other hand, family carers were grateful for information from care-givers about the disease, how the persons with dementia thrived and how services were organised. This, in turn, especially helped family carers to understand the pressures of the staff and their difficult working conditions.€•

(Smebye and Kirkevold 2013, pp. 12-29).

A comparative analysis of dementia care in nine OECD countries (Moise et al. 2004) concluded that it is not difficult to get everyone to agree that the coordination of dementia services is a good idea, but the numerous players involved in the provision of services (including healthcare providers, and the various government departments and health insurers involved in the funding and planning) complicate the task of agreeing to who shall do the co-ordination. Also stated in this report is the need for dementia-specific social care for dementia patients.

References

Brooker, D. (2007) *Person-Centred Dementia Care: Making Services Better*. Bradford: Jessica Kingsley Publishers.

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Wilson, C.B., Davies, S. and Nolan, M. (2009) *Developing personal relationships in care homes: realising the contributions of staff, residents and family members,* Aging Soc , 29(7), pp. 1041-1063.

[7980] Unit 3: Ethical Theories

To understand the specific challenges related to the ethical and legal aspects of dementia, we need to understand the background theories and law. To begin with, let’s hear from Dr Bill Whitehead, Head of Nursing and Healthcare at the University of Derby, about utilitarianism and deontology.

Transcript

Select the tabs to find out more about Deontology and Utilitarianism.

Utilitarianism

Deontology

Utilitarianism

Utilitarianism has its origins in the 18th century and the work of Jeremy Bentham and, later, John Stuart Mill. It is a consequentialist theory: it supports the view that the only morally relevant features of an act are its foreseeable consequences.

In simple terms, a utilitarian approach states that, given a choice of possible actions, the morally correct act is one that aims to achieve the best overall outcome for all concerned.

In order to determine which outcomes are morally relevant, the theory takes as its starting point the apparent fact that people seek out and enjoy happiness, while they dislike and avoid pain. In this sense, utilitarianism claims to be an objective ethical theory, as the capacity to experience happiness or suffer pain is universal. ('Happiness' may also be interpreted as pleasure, benefit, etc. Similarly, 'pain' may indicate harm, suffering etc.)

For the utilitarian, correct moral conduct is a matter of the impartial mathematical calculation of happiness and pain. For example:

It is calculated that action A will make five people happy and one person unhappy (five €˜units of happiness’ and one €˜unit of pain’) whereas action B will make eight people happy and leave two people unhappy (eight €˜units of happiness’ and two €˜units of pain’). The utilitarian would opt for action 'B' because, although it will result in a greater number of unhappy people, it will achieve a net gain over action A of two €˜units of happiness’.

Utilitarian moral value attaches importance to consequences rather than moral rules or duties (to a utilitarian, rules are only important to the extent that they contribute to overall utility).

A utilitarian will claim that 'good' actions maximise overall happiness, or minimise overall pain, and 'bad' actions do the opposite. Although it identifies happiness as morally desirable, utilitarianism is not a selfish approach since it promotes the view that every individual's happiness deserves equal attention and that the decision-maker (moral agent) should therefore aim for overall happiness, rather than simply their own. For a utilitarian, what matters morally are ends (i.e. 'The ends justify the means').

Deontology

Deontology (duty-based ethical theory) is concerned with adhering to moral rules or moral duty, rather than assessing the consequences of actions. A deontological approach requires that we act out of a sense of moral obligation to do the right thing (and avoid the wrong) and not because of any inclination, emotion, etc.

For a deontologist, the ethically correct act is one that is 'right in itself' (or, at least, not 'wrong in itself') - regardless of its consequences. In fact, applying a duty-based theory may support an action that brings about morally undesirable consequences.

In seeking to apply a deontological approach to resolving ethical problems, a difficulty arises when two or more moral rules or duties conflict. However, most modern deontologists believe that rules must be regarded as prima facie (i.e. they are morally obligatory). However, if rules conflict, the moral agent must decide which is the more important so as to avoid an ethical deadlock. Consider the following example:

A potential murderer comes to your door demanding to know the whereabouts of his intended victim. If you can convince him that the person (who is hiding in the attic) left the country last week, you may save the person's life. In this instance, the application of a hierarchy of rules (saving a life outweighs telling a lie) may be considered morally acceptable by the deontologist.

[7981] Unit 3 Activity: Is telling a lie **wrong?**

[7982] Unit 3: Virtue Ethics and the Four Principles

Transcript

Virtue Ethics

Virtue ethics is concerned with the personification of the virtues: patience, humility, simplicity, courage, integrity, etc. Whereas consequentialist and deontological theories are concerned with what we should do, virtue ethics is concerned with how we should be.

One of the major premises of virtue ethics is that intelligence (rationality, knowledge, etc.), which enables a person to calculate consequences or comprehend moral rules and duties, is not sufficient to enable a person to make moral judgements. According to a virtue ethicist, character and virtue take precedence over intelligence, as they are the foundations of moral life. A virtue ethicist would claim that a morally good person with the right blend of virtues and motives is more likely than others to know what ought to be done in a given situation and be disposed towards doing it.

The Four Principles

Ethical principles provide a framework for ethical thinking and decision-making. They can help to identify the key ethical aspects of a situation, decision, etc. A popular and influential example of applied ethics is the four principles approach to bioethics, incorporating the principles of respect for autonomy, non-maleficence, beneficence and justice (Beauchamp and Childress 2013).

Select the headings to find out more about each of the four principles.

Beneficence

We should actively contribute to the welfare of others (i.e. we should 'do good'. Defining 'good' may be problematic. For example, within a healthcare setting, who should determine what is good for an individual patient? A moral obligation to 'do good' is very demanding, as it requires some form of active intervention in other people's lives. It would be virtually impossible to always adhere to a principle that requires us to do good.

Non-maleficence

We are obliged to not inflict harm intentionally. This is possibly an easier principle to adhere to than beneficence - it is generally the case that we are not intentionally harming another person. Although a degree of intentional 'harm' is inherent in many health interventions (such as surgery, which demands that the skin is broken), such harm is clearly outweighed by the perceived benefits of the intervention.

Respect for autonomy

We are obliged to respect other people's autonomy. This principle holds that individuals should be allowed to think, decide and act freely and independently, the only limit being the extent to which exercising their autonomy infringes upon the autonomy of others.

Justice

We should treat all others fairly and equally. Problems arise when trying to determine 'fairness'. Does it mean giving everyone an exact share? Is the principle of justice reflected in the ways in which health resources are currently distributed?

References

Beauchamp, T. L. and Childress, J. F. (2013) Principles of Biomedical Ethics. 7th ed. New York: Oxford University Press.

[7983] Unit 3: Consent

Consent is the means by which patients authorise interventions in their care, either in regard to unambiguous clinical treatment (such as surgery) or in regard to less-direct interventions (such as the use of frozen embryos). Central to issues relating to consent is the need for patients to maintain control over their own care.

It is generally accepted that for an individual's consent to be effective, it must be informed. In other words, patients need to acquire and understand relevant information prior to agreeing to undergo treatment.

The principal benefits of seeking informed consent are that it:

enables patients to exercise autonomy

obliges health practitioners to make appropriate disclosure of information

potentially safeguards practitioners from legal action

All healthcare interventions must be authorised. Healthcare practitioners are not allowed (legally or morally) to treat a patient without having first secured some sort of permission to do so. This even applies to emergency, life-threatening situations where the patient is unable to give €“ and it would be inappropriate to seek €“ formal consent. Treatment in such situations is authorised via the concept of best interests and the principle of necessity.

Select the tabs to find out more about consent.

Validity of Consent

Consent and the Law

Validity of Consent

The ethical and legal validity of consent relates to four key aspects of the consent process:

Information: the consenting individual must have received sufficient information appropriate to their particular circumstances.

Competence: they must have the cognitive and emotional capacity to understand the nature and consequences of treatment or non-treatment.

Understanding: they must comprehend what they have been told (i.e. understand the nature, risks, benefits and alternatives associated with the proposed treatment).

Independence: their decision must be made independently, free from interference or coercion by others.

Consent and the Law

A patient may give legally valid consent in two ways:

i) **Express Consent:** The patient authorises therapy to go ahead either verbally or in writing. Although there is no general legal requirement that consent should be in writing, it may be felt that the nature of the procedure demands evidence that consent was obtained - for example, prior to surgery. Although a written agreement reinforces a claim that consent was obtained, it is still capable of being challenged should it emerge that the provision and understanding of appropriate information did not occur. In other words, a signature, in itself, does not indicate that a patient's informed consent has been obtained.

Circumstances where a patient's express consent is not legally required:

Where consent is implied

Where the patient is unconscious (actions are taken in the patient's 'best interests')

Where the patient is a minor

Where the principle of necessity applies €“ for example, in emergency, life-saving situations

Where the patient is not deemed competent to give their consent

In some cases, where the patient is subject to mental health legislation

ii) **Implied Consent:** In most cases, implied consent is accepted and acted upon. For example, a patient who rolls up their sleeve at the sight of a nurse approaching with a sphygmomanometer (blood pressure monitor) has indicated that they understand, in general terms at least, what the nurse intends to do and has agreed to the procedure. However, implied consent is not legally effective if it does not follow adequate information disclosure and understanding. If, for example, the patient did not understand that the nurse was going to apply a cuff to their upper arm (unlikely though this may be), they may have a valid claim that they did not give their consent and that any physical contact made by the nurse was therefore unlawful.

[7984] Unit 3 Activity: The law where you are

[7985] Unit 3: Capacity

The Mental Capacity Act (2005) provides a statutory framework to empower and protect vulnerable people who are not able to make their own decisions. It makes it clear who can take decisions, in which situations and how they should go about this. It enables people to plan ahead for a time when they may lose capacity. The Act applies to people aged 16 and over and is underpinned by five key principles:

A presumption of capacity: Every adult has the right to make their own decisions and must be assumed to have capacity to do so unless it is proved otherwise.

The right for individuals to be supported to make their own decisions: People must be given all appropriate help before anyone concludes that they cannot make their own decisions.

Unwise decisions: Individuals must retain the right to make what might be seen as eccentric or unwise decisions.

Best interests: Anything done for or on behalf of people without capacity must be in their best interests.

Least-restrictive intervention: Anything done for or on behalf of people without capacity should be the least restrictive of their basic rights and freedoms.

Although these concepts may seem difficult to understand and apply, they are important because there are challenges from a legal and ethical perspective for people living with dementia. For example, at the end of their lives, they may be unable to make decisions or to consent to care. In these circumstances, the law now provides guidance on how people can still receive care. It’s important to understand that these laws only apply to England and Wales and are likely to be different if you are in another location.

[7986] Unit 3: Maintaining Independence, Autonomy and Dignity

By this stage of the course you will be aware of the physical causes of dementia which prevent the affected person from living their life the way they used to. The ability to undertake all of the normal activities of living, which we take for granted, is denied to our friends and relatives with the disease. Simple tasks, like making a meal, moving around the house or going out become fraught with danger as they become less aware of hazards and forget to turn off gas or electric appliances.

Until recently this pattern of behaviour would have resulted in the person being taken into a care home, or to live with a son or daughter and their family. Neither of these options are always the most suitable. In the latter case it presents challenges to the family whose routines are altered, possibly resulting in tensions, frustrations and guilt. In the former case the relocation of a confused person into an unfamiliar building with unfamiliar people can add to a sense of bewilderment and fear.

However, modern technology has presented us with resources which were unheard of not very long ago. In the BBC iWonder special €˜Can technology help defuse the dementia time bomb’ Dr Kevin Fong explores how technology can support people with dementia. Watch the introduction video and read section 4 €“ how a €˜smart house’ can help , which graphically illustrates how digital technology can help a person to remain safe in their own home by the use of strategically placed sensors.

For example if a person gets out of bed at night a sensor could trigger a light, so the person isn’t in danger of tripping in the dark. A review paper published by the Centre for Policy on Ageing €“ The potential impact, for older people, of new technologies - details the resources that are currently available, which could reduce the need to remove the person from their home.

It is not only practical day to day matters that can make a difference; the ability to keep in touch with friends and family is possible by use of Skype, Facetime and other forms of social media. When the author was a student neither he nor his parents had a telephone so there was effectively no contact between them for months at a time. Now he can have a live, real time face to face conversation with relatives 12000 miles away. His own daughter can track his daily exercise, food intake and sleep pattern from over 200 miles away because of a piece of wearable technology, a Fitbit. Similar technology, adapted for purpose can permit remote monitoring, doing away with the need for close supervision in a care home, at least until the person’s condition deteriorates to the point where they need more immediate care. Social contact can be maintained, regardless of distance.

However these possibilities raise ethical concerns. Whereas the author can choose to share his information with his daughter, and indeed can decide to make it unavailable, a person with dementia is less able, if able at all, to have control. In this unit you are also looking at ethical considerations so, taking smart technology into account, to what extent should autonomy and dignity be compromised in order for independence be maintained?

References

BBC (2017) *iWonder: Can technology help defuse the dementia time bomb?* (online) http://www.bbc.co.uk/guides/z3d99j6#zgj887h (accessed 04/04/17)

Centre for Policy on Aging (CPA) (2014) *The potential impact of new technologies* (online) http://www.cpa.org.uk/information/reviews/reviews.html (accessed 04/04/17)

[7987] Unit 3 Activity: Debate

[7988] Unit 3 Talking Point

[7989] Unit 3: Bridging the Dementia Divide Plus

What is this section?

In this section we have included outstanding content items created by previous learners on Bridging the Dementia Divide that are related to this week’s theme. You will find various forms of content including text, poetry, PowerPoints, images €“ all for you to extend and enhance your learning. These were created as final assessments and we're hoping to do the same with the items presented at the end of this course.

The content is aimed mainly at people that have taken the Bridging the Dementia Divide MOOC previously. If this is your first time then **this content is entirely optional**. It provides valuable insights, but will almost certainly take well beyond the advertised two hours per week schedule for this course.

Allison, Victoria Lynee: Best Interests End of Life Care Plan.

Beardsall, Sabine: A presenation for carers who support a person with dementia.

Brannon, Agnes: Story: Living with dementia.

Fothergill, Rachael: Sue.

Hill, Ann Elizabeth: How we set up a local dementia support group, a dementia cafe and a home visiting service.

Hollingworth, Georgina: Every day is different.

Huffen, Natalie: Supporting a person with dementia.

Kirk-Pitts, Nicola: Dementia & Dysphagia.

Lefevre, Tarnia: 5 key messages: children's cue cards.

Micklethwaite, Lucy: Behavioural symptoms - How to respond/prevent.

O'Neill, Michele: Dementia daze.

Ordan, Julie Roasalind: Looking at each person with dementia a little more creatively.

Soppet, Angela: An introduction for volunteers working with people with dementia.

Walker, Rosalyn: Traffic light care.

Wiggins-Jamieson, Deborah: Impact of caring for a patient with dementia.

6: Unit 3 Badge

7: User Experience Survey

[]

[U] U

8: Unit 4: Dementia as a Global Health Priority

[7994] Unit 4: Dementia as a Global Health Priority

Are governments and organisations meeting the needs of people living with dementia?

Dementia has been recognised as a worldwide medical, social, political, economic and cultural issue. Populations are getting older as a result of advancements in medical care, which in turn increases the prevalence of dementia. The number of people living with dementia globally will double by 2030 and triple by 2050, with 60% of these people living in low- and middle-income countries (World Health Organisation (WHO) 2012). The cost of care is extremely high; in many countries without developed health and social care systems, these needs are met by family members in the absence of formally trained professional individuals. In 2008, the WHO launched the Mental Health Gap Action Programme, which included increasing the recognition of dementia as a significant public health challenge requiring an integration of governments, third-sector organisations and formal health and social care systems (WHO 2008).

This week, we'll look at dementia as a global issue and ask if governments and organisations are meeting the needs of people living with dementia.

The learning outcome for this week is:

Learners will discuss and challenge global policies as related to dementia, considering what could be learned from other societies.

Badge

You will earn the Dementia as a Global Health Priority badge for this unit, which recognises that you have met the learning outcomes. To earn the badge you have to successfully complete the following criteria:

Read all of the Unit pages

Take part in the Unit Discussion forum

The badge will appear on the page that comes after completing the unit. If you do not see a badge then you still have some tasks left to complete. Don't worry. Look at the list on that page, complete the necessary tasks, and then return to get your badge.

For more information on how you can track your progress, look at the FAQ entry for How do I get a badge.

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World Health Organisation (2008) mhGAP Mental Health Gap Action Programme. WHO Press: Geneva

World Health Organisation (2012) Dementia: A Public Health Priority. WHO Press: Geneva

[7995] Unit 4: The Global Response to Dementia

To start this unit, let's hear from Cath Williams, Programme Leader for the BA (Hons) Health and Social Care at the University of Derby, on the global response and approach to dementia:

Transcript

[7996] Unit 4: Global action against dementia: the G8 Dementia Summit

In 2007, the UK's Department of Health declared dementia as a national priority. Through consultation, the National Dementia Strategy was developed and published in 2009 (Department of Health 2009). The strategy recommended actions that would enable people to live well with dementia, rather than simply exist. The strategy concentrated on improving awareness and understanding of dementia, facilitating early diagnosis, managing the use of anti-psychotics, fostering collaborative relationships, and focusing on well-being from diagnosis through to end-of-life care.

€œThe world has plans for dealing with a nuclear accident, cleaning up chemical spills, managing natural disasters, responding to an influenza pandemic, and combating antimicrobial resistance. But we do not have a comprehensive and affordable plan for coping with the tidal wave of dementia that is coming our way.€•

Dr Margaret Chan, WHO's Director General

The UK held the presidency of the G8 in 2013 and used this opportunity to start addressing the issue of dementia. A summit was held in London, hosting scientists, health and social care professionals, health and science ministers, and world-leading experts on dementia. Jeremy Hunt, UK Secretary of State for Health, opened the summit, followed by Dr Peter Dunlop, previously an obstetrician and gynaecologist, who gave a moving speech. You can watch this below.

Transcript

The discussion during the summit concentrated on three key topics:

How life and care can be improved for people living with dementia

How dementia can be prevented or delayed

What social adaptation could be supported in respect to ageing and dementia (Alzheimer's Society 2013)

Ministers from each G8 country agreed to a number of actions:

To set an ambition to identify a cure, or a disease-modifying therapy, for dementia by 2025

To significantly increase the amount spent on dementia research

To increase the number of people involved in clinical trials and studies on dementia

To establish a new global envoy for dementia innovation, following in the footsteps of global envoys on HIV and Aids and on climate change

To develop an international action plan for research

To share information and data from dementia research studies across the G8 countries to work together and get the best return on investment in research

To encourage open access to all publicly funded dementia research to make data and results available for further research as quickly as possible

(Department of Health, 2014)

References

Department of Health (2009) The National Dementia Strategy. London: TSO

Department of Health (2014) G8 Dementia summit: Global action against dementia €“ 11 December 2013 [Online] Last accessed 10th June 2015 at https://www.gov.uk/government/publications/g8-dementia-summit-global-action-against-dementia/g8-dementia-summit-global-action-against-dementia-11-december-2013 (Links to an external site.)

[7997] Unit 4: United Kingdom National Dementia Strategy

€œIt will transform the quality of dementia care€•

Alan Johnson, UK Secretary of State for Health, 2009

In 2007, the UK government announced an initiative to develop a national approach to dementia. A period of consultation and development followed, which resulted in the National Dementia Strategy, published in 2009. Developed by Sube Bannerjee and Jenny Owen, the strategy’s aim was that all people with dementia and their carers could live *well* with dementia, rather than just existing. There was a strong focus on service integration, which would include not just health and social care services but also other agencies, such as councils, the police, and fire and rescue services.

The 17 Objectives

The strategy set out 17 objectives:

Improving public and professional awareness and understanding of dementia

Ensuring good-quality early diagnosis and intervention for all

Ensuring good-quality information for those with diagnosed dementia and their carers

Enabling easy access to care, support and advice following diagnosis

Developing structured peer-support and learning networks

Improving community personal support services

Implementing the Carers’ Strategy

Improving quality of care for people with dementia in general hospitals

Improving intermediate care for people with dementia

Considering the potential for housing support, housing-related services and telecare to support people with dementia and their carers

Helping people with dementia in care homes to live well

Improving end-of-life care for people with dementia

Developing an informed and effective workforce for people with dementia

Creating a joint commissioning strategy for dementia

Improving the assessment and regulation of health and social care services and of how systems are working for people with dementia and their carers

Establishing a clear picture of research evidence and needs

Developing effective national and regional support for the implementation of the strategy

The five-year strategy was to cost £150 million in its first two years and planned to set up a memory clinic in every city and town in England (Eaton 2009). The strategy focused on the quality and integration of care, rather than on the specific clinical guidance for the early recognition, diagnosis and treatment of dementia (Eaton 2009), due to the existence of NICE Guideline CG42, which includes guidance of this nature.

Results

While some clinicians have been critical of the National Dementia Strategy (Greaves and Jolly 2010; Hilton 2010), there have been some observable results (both good and bad) in the time since its publication:

The number of people assessed by memory clinics has risen fourfold since 2010

Over half of carers still report difficulties in gaining a diagnosis

Less than half have been given information on legal issues

Many carers still feel ill-equipped to deal with more-agitated behaviours

More than two-thirds of carers said they have not received training on how to deal with agitated behaviour

82% of carers said that caring has adversely affected their ability to work

There are good examples of local innovation from commissioners and providers who have remodelled services, improved conditions and used new technology

143 acute trusts and 24 non-acute trusts have joined Dementia Action Alliances

The number of anti-psychotic prescriptions decreased by 52% between 2006 and 2011

By October 2013, 108,888 NHS staff had received a basic level of training in dementia, which was mandated by Health Education England

(Department of Health, 2013)

References

Department of Health (2013) Dementia €“ a state of the nation report on dementia care and support in England. London: Williams Lea

Eaton L (2009) Every town and city in England to have a memory clinic, says health secretary. BMJ 338:b464

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Hilton C (2010) The National Dementia Strategy: innovation or reiteration. The Psychiatrist 34(7) pp292-294

[7998] Unit 4 Activity: Your country's dementia strategy

[7999] Unit 4: The situation in the developing world

The UK has a well-developed health and social care system. Although there are gaps, coverage is comparably good compared to that in developing countries. The population is ageing throughout the world, which is as a result of increased life expectancy due to improved healthcare. There has also been a reduction in fertility as birth rates have slowed; as a result of these two factors (an increase in life expectancy and a reduction in fertility), countries in the West with developed health and social care systems have experienced a rapid increase in the elderly population.

While developed countries are experiencing dementia as a significant challenge, those countries in the developing world are feeling the impact more. Over two-thirds of the world’s older people live in low- or middle-income countries €“ a number that will rise to four-fifths by 2050. In these health and social care systems, the healthcare costs are comparatively low, and there is a focus on family care at home rather than in organised facilities. In Nigeria, for example, social work is not yet a regulated profession, which could prevent the formal organisation of the social care system.

Under-use of services is an issue in developing countries, where as many as 90% of people living with dementia have not yet received a diagnosis. The predicted increase of numbers of people living with dementia will be significantly contributed to by people living in developing countries (Prince 2015).

Care at home with Dementia, Tigray, Ethiopia

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Prince, M (2015) Dementia as a global issue. [Online] Last accessed 26th April 2017 at: http://www.ageuk.org.uk/professional-resources-home/research/health-wellbeing/dementia-as-a-global-issue/

[8000] Unit 4 Activity: WHO Dementia: A public health priority

[8001] Unit 4 Activity: A personal development strategy

This unit has discussed the UK's National Dementia Strategy, the G8 summit and briefly the WHO's initiatives on dementia as a public health issue. These strategies and documents deal with dementia on an international level and have high-level objectives for the population as a whole. In this activity, you are to develop your own personal dementia development strategy. What can you do to support people living with dementia, within the context of these strategies?

Write or select a maximum of five objectives for you to adhere to in the future. An example may be that you will support a friend who is a carer for someone living with dementia or you will write to your Member of Parliament (UK) to highlight the importance of dementia in your community. You may volunteer at a local memory clinic or drop-in centre. Your objectives should be SMART: specific, measureable, achievable, realistic and time-bound. Once you've formulated your objectives, submit them to the Google form below.

Everyone's submissions can be seen in the publicly visible summary.

Loading.... The document contains responses from others who have undertaken this MOOC over the past few years.

[8002] Unit 4 Talking Point

[8003] Unit 4: Bridging the Dementia Divide Plus

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Carter, Gill: Equality and diversity in dementia care: trainer notes.

Orton, Lindsay: Dementia friends.

Veinott, Judy: Role play.

Warburton, Kathleen: Overview and application of learning.

9: Unit 4 Badge

10: Unit 5: Integrating Care

[8006] Unit 5: Integrating Care

Is integrative care able to support people living with dementia?

Historically, care for people with complex conditions like dementia has been fragmented, and there have been high-profile examples where people have received suboptimal care or have even been harmed by the care they received. A proposed solution to these problems is integrated care: a concept whereby systems and services work as one to support people, patients and service users. This unit will introduce you to the concept of integrated care, and we'll look at how we can design service models that are integrated.

The learning outcome for this unit is:

Learners will appraise the concept of integrative care and consider why it is important in care generally, as well as specifically in dementia.

Badge

You will earn the Integrating Care badge for this unit, which recognises that you have met the learning outcomes. To earn the badge you have to successfully complete the following criteria:

Read all of the Unit pages

Take part in Unit Discussion forum

The badge will appear on the page that comes after completing the unit. If you do not see a badge then you still have some tasks left to complete. Don't worry. Look at the list on that page, complete the necessary tasks, and then return to get your badge.

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[8007] Unit 5: Definition and Logic of Integrated Care

The starting point for integrating care is an understanding that the dominance of a single professional view is problematic, which allows us to challenge the established hierarchies that exist (Hartgerink et al. 2013). Integrated care requires a celebration of the differences between professions and a collaboration of multiple professions to lead to effective and high-quality care delivery.

The literature tells us that healthcare systems that are influenced by the medical perspective are highly focused on the €˜curing’ processes of an illness and find it difficult to cope with chronic diseases, disabilities and people requiring long-term care (Leichsenring 2012). The division, decentralisation and specialisation in healthcare introduce risks of fragmentation and a loss of coherence (Andersson and Karlberg 2000). Boone et al. (2005) believe that people who seek treatment and care often struggle with multiple health problems, significant stresses and relatively low quality of life. Therefore, integrating services can create interactions and connections between the parts in all healthcare systems, independent of budgets, finances and responsibilities, which can create meaningful outcomes for patients living with these complex conditions, who could not otherwise be captured in simple black-and-white terms; they cannot be seen as separate from their lives, experiences, unique contexts and the meanings they give to their healing and caring process (Andersson and Karlberg 2000; Boon et al. 2005). In simple terms, integrated care deals with individual needs in a holistic manner, rather than dealing with patient diseases as isolated problems.

Integrated care goes beyond the medicalisation of care to develop integrated care systems with their own identities, structures, processes and resources that connect to and care for the €˜lifeworlds’ of people in need of care, their families and informal carers (Leichsenring 2012). Integrated care is defined as the coherent and coordinated sets of services that are planned, managed and delivered to individual service users across a range of organisations and by a range of cooperating professionals and informal carers in order to achieve common goals and optimal results (Kodner and Spreeuwenberg 2002; Minkman et al. 2009). Integrated care is conceived as a collaborative process of assessment, planning, facilitation and advocacy for options and services to meet individual health needs through communication and available resources to promote high-quality and cost-effective outcomes (Butler et al. 2011).

Let’s hear from Nick Goodwin on what integrated care is and why it’s important:

Transcript

The integration of healthcare institutions and services includes administrators, managers, doctors, nurses and allied professionals (Kodner and Spreeuwenberg 2002). Also, it should include the integration of intersectoral boundaries (e.g. integration between healthcare, mental healthcare and social care), funding streams, and institutional and professional cultures (Kodner and Spreeuwenberg 2002). Integrated models of care can be implemented in a variety of practice areas, but the most frequently identified areas of integrated care are for those with one or more chronic illnesses or areas of community care, including open psychiatric care and the treatment of drug abuse (Axelsson et al. 2014; Mastellos et al. 2014). The increasing pressure of chronic conditions, palliative care and community care suggests not only that these conditions are not curable (or that the curing aspect is a secondary issue) but also that these conditions require much more care, rather than curing. It makes more sense to have a more socially orientated process of care, rather than a medically orientated one, for supporting people with chronic conditions and those needing palliative care and community care (Andersson and Karlberg 2000).

Integrated care can avoid the fragmentation and discontinuity of care, making care more affordable for both patients and the healthcare system, preventing the duplication of activity and dealing not only with what may be defined as medical issues but also with social and psychological issues (Hartgerink et al. 2013; Mastellos et al. 2014; Sun et al. 2014). Integrated care is a process of comprehensive and continuous care combining health risk prevention, diagnosis, treatment and rehabilitation, which both increases the quality of care and prevents patient safety being compromised (Sun et al. 2014).

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Axelsson, R., Axelsson, S., Gustafsson, J. & Seemann, J. (2014) Organizing integrated care in a university hospital: application of a conceptual framework. *International Journal of Integrated Care*, 14(19), [Online]. Available at: http://www.ijic.org/index.php/ijic/article/view/1529/241 (Links to an external site.)1 (Accesed : 28 January 2015).

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Butler, M., McAlpine, D., Kathol, R., Fu, S., Hagedorn, H. & Wilt, T. (2011) Does Integrated Care improve treatment for depression? *Journal Ambulatory Care Manage*, 34(2), pp. 113€“125.

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Mastellos, N., Gunn, L., Harris, M., Majeed, A., Car, J. & Pappas, Y. (2014) Assessing patients' experience of integrated care: a survey of patient views in the North West London Integrated Care Pilot. *International Journal of Integrated Care*, 14(9), [Online]. Available at:http://www.ijic.org/index.php/ijic/article/view/1453/2406 (Links to an external site.) (Accessed : 28 January 2015).

Minkman, M., Ahaus, K. & Huijsman R. (2009) A four phase development model for integrated care services in the Netherlands. *BMC Health Services Research*, 9(42), [Online]. Available at:http://www.biomedcentral.com/1472-6963/9/42 (Links to an external site.) (Accessed : 28 January 2015).

Sun, X., Tang, W., Ye, T., Zhang, Y., Wen, B. & Zhang, L. (2014) Integrated care: a comprehensive bibliometric analysis and literature review. *International Journal of Integrated Care*, 14(12), [Online]. Available at: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4059213/ (Links to an external site.) (Accessed : 28 January 2015).

[8008] Unit 5 Activity: Strengths and Limitation of Integrated Care

[8009] Unit 5: Implementing Models of Integrated Care

The implementation of programmes and models of integrated care in practice requires both organisational changes and network developments. The integrated models of care focus on the quality of care, performance management, interprofessional teamwork, a delivery system with explicit roles and tasks, patient-centeredness, commitment to integrated care, and result-focused learning (Andersson and Karlberg 2000). Most models of integrated care are based on the principles of change theories and sequential steps, which could include the initiative and design phase, the experimental and execution phase, the expansion and monitoring phase, and the consolidation and transformation phase (Minkman 2012). For successful application in practice, frequent communication between different systems is central to integrated care models. This is so that different systems can agree on specific administrative activities, produce guidelines and develop IT systems that can facilitate the integration of care (Andersson and Karlberg 2000; Hartgerink et al. 2013). Finally, care managers can be considered the central hub for communication and collaboration efforts (Butler 2011).

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Andersson, G. & Karlberg, I. (2000) Integrated care for the elderly: The background and effects of the reform of Swedish care of the elderly *International Journal of Integrated Care*, 1(1), [Online]. Available at:http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1534007/ (Links to an external site.) (Accessed : 28 January 2015).

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[8010] Unit 5: Phases of implementation

Select the tabs to find out about the four phases of implementation.

Phase 1: Initiative and Design Phase

The starting point for developing an integrated care programme is the identification of a common problem and the realisation of a need for cooperation among care professionals. There is a sense of urgency in this phase, and there are possibilities for working on these challenges in collaboration. The key issues in the initiative and design phase include:

Defining the ambitions and aims of the collaboration in the care chain

Defining the targeted client group

Defining and assessing the characteristics of the collaboratively delivered care

Assuring the leadership commitment of the partners involved in the care chain

Committing to a joint responsibility for the final goals and results to be achieved

Describing the tasks and authorities of leaders, coordinators and advisory boards in the care chain

Reaching agreements on referrals and transfers of clients through the care chain

Signing collaboration agreements among care partners

Reaching agreements on procedures for the exchange of client information (Minkman et al. 2009)

The targeted patient group, the care chain and the care process need to be defined, as do the needs of patients and stakeholders. The collaboration can be created through an agreement among care partners. In this phase, possibilities and impossibilities are explored, ambitions and chances for collaboration are identified, and a collaborative design (project) is agreed upon (Minkman et al. 2009).

Phase 2: Experimental and Execution Phase

In this phase, the aims, content, roles and tasks in the care chain are clarified and written down in care pathways and protocols. Coordination is secured in the care chain by installing coordinators and/or setting up meetings. Information about patient groups, working procedures and professional knowledge is exchanged. There are experiments within the collaboration; results are evaluated in order to learn from them and to reflect on the key issues in the experimental and execution phase. These include:

Realising direct contact among professionals in the care chain

Using shared client treatment and care plans

Bringing specialised nurses into action through the care chain

Achieving adjustments among care partners by means of direct contact

Using evidence-based guidelines and standards

Monitoring successes and results during the development of the integrated care chain

Reaching agreements among care partners by means of direct contact

Working in multidisciplinary teams, ensuring that professionals in the care chain are informed of each other’s expertise and tasks

Gathering data on client logistics (e.g. volumes, waiting periods and throughput times) in the care chain (Minkman et al. 2009)

In this phase, the aims and content of the collaboration are written down, there is explicit coordination in the care chain and there is continuous experimentation and reflection on the integrated care processes (Minkman et al. 2009).

Phase 3: Expansion and Monitoring Phase

In this phase, agreements on the content, tasks and roles within the care chain are clear and adhered to. Collaboration is no longer on an informal basis. Results are systematically monitored, and improvement areas are identified. The targeted population will have been surveyed. More-collaborative initiatives emerge, such as mutual education programmes. The key aspects in the expansion and monitoring phase include:

Using a systematic procedure for the evaluation of agreements, approaches and results

Flexibly adjusting integrated care according to individual clients’ needs

Monitoring and analysing mistakes

Reaching agreements on introducing and integrating new partners in the care chain

Using collaborative education programmes and learning environments for the professionals of care partners

Involving client representatives in improvement projects in the care chain

Designing care for clients with multi- or co-morbidities

Encouraging collaborative learning in the care chain in order to innovate integrated care

Developing connections between databases of partners in the care chain

Making the effects of the collaboration on the production of the care partners transparent (Minkman et al. 2009)

In the expansion and monitoring phase, there is a steady commitment to the ambition of the integrated care programme; addressing inter-organisational barriers and fragmented financial structures is on the agendas of care partners (Minkman et al. 2009).

Phase 4: Consolidation and Transformation Phase

In this phase, the integrated care programme is a consistent way of working and providing care. Coordination at the care-chain level is operational, and information is shared, transferred and fed back. A monitoring system is implemented and periodically shows if results are sustained, what specific improvement possibilities have been identified and to what extent the needs of patients have been met. The programme builds further on successful results. Organisational structures transform or are newly designed around the integrated care programme. Partners in the care chain explore new options for collaboration in the external environment with other partners. The key aspects in the consolidation and transformation phase include:

Linking consequences to the achievement of agreed goals

Integrating incentives for rewarding the achievement of quality targets

Hosting structural meetings with external parties, such as insurers, local government and inspectorates

Sharing knowledge among care partners about effectively organising sustainable integrated care

Using collaborative education programmes and learning environments for the professionals

Monitoring and analysing mistakes or near-mistakes in the care chain

Developing care programmes for relevant client subgroups

Reaching agreements on the financial budget for the integrated care programme

In the consolidation and transformation phase, there are: continuous improvements and amendments of the programme, the development of new ambitions, and the development of structures fitting the integrated care programme (organisational structures, integral financing, etc.), in order to achieve the materialisation of the integrated care programme.

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[8011] Unit 5: Examples of Integrated Care

In this section, we’ll discuss some good examples of where integrated care is working for the benefit of the people using it.

Kaiser Permanente Integrated Care Model

Kaiser Foundation Hospitals (McCreary, 2010) in the US have embraced the integrated care system, where the focus is not only on episodic care and general practice but also on actively seeking to address health promotion, self-care, preventative screening, the active management of people with long-term conditions in the community, and keeping patients out of hospital. Doctors, nurses and others in

Kaiser’s hospitals work as a team and share the budget and responsibility for care across acute, secondary and tertiary services. This creates a financial incentive for care providers to keep people healthy and out of hospital by increasing accessibility in the community (e.g. through out-of-hours services, where patients can email doctors, nurses and other clinicians to discuss health concerns). Kaiser’s hospitals make use of electronic health records and IT systems that enable practitioners to deliver continuous care by sharing and communicating patient medical histories and treatment plans across varied provider and care settings.

The electronic health records and the IT system have been integral in delivering integrated care, as they have helped to promote joint working and have increased the efficiency of the system by reducing waste and cutting bureaucracy. Online health services enable patients to view, schedule or cancel appointments; request repeat medications; email their doctors or nurses to get advice on health issues; and even contact the pharmacist to discuss side effects and drug-to-drug interactions (Royal College of Nursing 2014).

Veterans Health Administration Integrated Care Model

The Veterans Health Administration implements the integrated model of care, with a strong focus on coordination across health and social care services; the €˜personalisation’ of care is the key feature (Petersen 2013). A health or social worker is often the first point of contact when assessing health and social care needs and refers patients to the appropriate services or interdisciplinary teams, moving away from hospital-centric care by increasing the number of community-based out-patient clinics. There is a strong focus on the personalisation agenda through the delivery of patient-centred care closer to home and reduced reliance on hospitals and accident and emergency (A&E) services. An essential part of the integrated care is the use of electronic health records and sophisticated telehealth systems, such as live interactive videoconferencing, remote monitoring, store-and-forward imaging and provider education (Health Resources Services Administration 2014).

Telehealth is different from telemedicine because it refers to a broader scope of remote healthcare services. While telemedicine refers specifically to remote clinical services, telehealth can refer to remote non-clinical services, such as provider training, administrative meetings and continuing medical education, in addition to clinical services (Health Resources Services Administration 2014). Such telehealth systems can monitor and manage patients with long-term conditions through portable devices in patients’ homes, enabling remote access and the monitoring of vital signs, blood glucose levels and other health indicators (Royal College of Nursing 2014).

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[8012] Unit 5: Levels of Integration in Integrated Care Programmes

The integration of care is a structural and process issue. The success in developing integrated care programmes relies on the expert knowledge of the individuals leading the process of care integration, the development of a network and of coherent inter-organisational cooperation to deliver integrated care, and on the joint responsibilities of all care providers involved (this could go beyond care providers to include insurers and other non-care providers) (Andersson and Karlberg 2000; Minkman 2012). The focus of integrated care programmes can be aimed at various aspects of the caring processes, such as the length of stay, patient logistics, the transfer of information between healthcare professionals, the improvement of after-care facilities and the implementation of treatment (Minkman 2012).

An integrated care programme often involves the construction of new support systems that change the instrumental and technical aspects of care delivery. These new support systems allow patients and professionals to be properly informed and can assist in improving the quality of care by facilitating the provision of feedback on outcomes. The collective learning and cognitive diversity that lead to shared models underlie the effectiveness of the delivery of integrated care. Improved cooperation and coordination result in more-effective evaluation and planning of patients' needs. Integrated care programmes in hospitals are assumed to be a systematic and comprehensive approach to improve the management of complex health problems (Hartgerink et al. 2013).

The literature identifies that there are various levels of integration various levels of integration which follow a continuum from collaboration to integration (National Council for Community Behavioral Healthcare, 2013).

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[8013] Unit 5: Derby Hospitals NHS Foundation Trust

Derby Hospitals NHS Foundation Trust has made dementia one of its primary concerns. Lets hear from Sue Abdulla, Lead Dementia Nurse for Royal Derby Hospital, who shares the work going on at Royal Derby:

Transcript

[8014] Unit 5 Activity: Identify an area in your health and social care system...

[8015] Unit 5 Talking Point

[8016] Unit 5: Bridging the Dementia Divide Plus

What is this section?

In this section we have included outstanding content items created by previous learners on Bridging the Dementia Divide that are related to this week’s theme. You will find various forms of content including text, poetry, PowerPoints, images €“ all for you to extend and enhance your learning. These were created as final assessments and we’re hoping to do the same with the items presented at the end of this course.

The content is aimed mainly at people that have taken the Bridging the Dementia Divide MOOC previously. If this is your first time then **this content is entirely**

optional. It provides valuable insights, but will almost certainly take well beyond the advertised two hours per week schedule for this course.

Brewer, Hannah: Supporting a person living with dementia.

Dalla-Vecchia, Jodie: Identifying symptoms of dementia.

Edwards, Kikelomo: Attempts at creating a national dementia strategy for Nigeria.

Foster, Evangeline: Comparison with family experience.

11: Unit 5 Badge

12: Unit 6: End of Life Care

[8019] Unit 6: End of life care

The end: how can you support people living with dementia and their families during the final phase of life?

€˜No-one discussed end of life until he was in the first care home and we had a meeting with the manager about various issues I had, and it was raised out of the blue at the end of the meeting. With five minutes to go to the end of the meeting it was raised as an €œoh, by the way€• . I was sat there thinking €œExcuse me? What is this all about?€• It was very, very badly handled, sort of thrown in as an afterthought and it took me by surprise. It was something which hadn’t really crossed my mind until they threw it in at the end of the meeting and I thought €œmy goodness, this is not the way to handle relatives.€•

€˜How people die remains in the memory of those who live on.’

(Department of Health, 2013)

Although most people living with dementia are not at the end of their lives, there is a recognition that all people die and, unfortunately, dementia may contribute to a premature death. During this unit, we’ll talk about the loss of personhood, what suffering means in the dementia context and also some of the concepts related to end-of-life care.

The learning outcome for this week is:

Learners will evaluate current approaches to the end-of-life care of people with dementia, maintaining personhood and quality of life.

Badge

You will earn the End of Life Care badge for this unit, which recognises that you have met the learning outcomes. To earn the badge you have to successfully complete the following criteria:

Read all of the Unit pages

Take part in Unit Discussion forum

The badge will appear on the page that comes after completing the unit. If you do not see a badge then you still have some tasks left to complete. Don’t worry. Look at the list on that page, complete the necessary tasks, and then return to get your badge.

For more information on how you can track your progress, look at the FAQ entry for How do I get a badge.

References

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[8020] Unit 6: Disconnectedness

Disconnectedness occurs in dementia as a result of multiple losses. Social constructions of dementia focus on loss €“ the aspects of the person that are gradually disappearing through illness.

The reality of living with dementia is not just wholly influenced by the physical aspects of the disease, such as a loss of cognitive function, but is rather determined by the many interactions with others. Person-centred care, focusing on the individual, offers the most appropriate approach. Methods that allow individuals to tell their unique stories will help towards the development of more-imaginative services for those affected with dementia.

In this video, Dr Wendy Wesson talks about her experience of end of life care for individuals with dementia.

Transcript

[8021] Unit 6: Loss of personhood

Many cultures label older people as burdensome, incompetent and ugly (Bytheway 1995). It is of little wonder, then, that notions of uselessness, loss and despair summarise the prevalent view of dementia. Kitwood, who wrote extensively on the need to develop a better approach to dementia, one that recognises the uniqueness of each human being, offers the following definition of personhood:

€œa standing or status that is bestowed upon one human being by others, in the context of relationship and social being. It implies recognition, respect and trust€•

(Kitwood 1997, p. 8).

The integration and maintenance of quality relationships with family and friends improves life experiences for those with dementia (Moyle et al. 2014). Kitwood (1997) recommended a model that would take account of the person instead of the illness. This was in response to a commonly held belief that the self (personhood) is gradually lost in dementia, and behaviour is a response to brain death, which leads to social death. This is marked by experiences of being ignored and forgotten (Chenoweth et al. 2009).

Kitwood (1997, pp. 46-47) identified ten elements of what he termed €˜the malignancy’ of our cultural inheritance.

Select the titles to learn more about each element.

TREACHERY

Using forms of deception in order to distract or manipulate a person or to force them into compliance.

DISEMPOWERMENT

Not allowing a person to use the abilities that they do have; failing to help them to complete actions that they have initiated.

INFANTILISATION

Treating a person very patronisingly (or €˜matronisingly’), as an insensitive parent might treat a very young child.

INTIMIDATION

Inducing fear in a person, through the use of threats or physical power.

LABELLING

Using a category such as dementia, or €˜organic mental disorder’, as the main basis for interacting with a person and for explaining their behaviour.

STIGMATISATION

Treating a person as if they were a diseased object, an alien or an outcast.

OUTPACING

Providing information, presenting choices etc, at a rate too fast for a person to understand; putting them under pressure to do things more rapidly than they can bear.

INVALIDATION

Failing to acknowledge the subjective reality of a person’s experience, and especially what they are feeling.

BANISHMENT

Sending a person away, or excluding them €“ physically or psychologically.

OBJECTIFICATION

Treating a person as if they were a piece of dead matter or an item of furniture rather than as the real person they are.

He later added a further seven elements including:

IGNORING

Carrying on (in conversation or action) in the presence of a person as if they were not there.

IMPOSITION

Forcing a person to do something, overriding desire or denying the possibility of choice on their part.

WITHHOLDING

Refusing to give asked-for-attention, or to meet an evident need.

ACCUSATION

Blaming a person for actions or failures of action that arise from their lack of ability, or their misunderstanding of the situation.

DISRUPTION

Intruding suddenly or disturbingly upon a person’s action or reflection; crudely breaking their frame of reference.

MOCKERY

Making fun of a person’s €˜strange’ actions or remarks; teasing, humiliating, or making jokes at their expense.

DISPARAGEMENT

Telling a person that they are incompetent, useless, worthless, etc., giving them messages that are damaging to their self-esteem.

However, Bartlett et al. (2010) offer a critique of Kitwood’s theory of €˜malignant social psychology’, pointing out that there was no reference to the agency of people with dementia. Smebye and Kirkevold (2013) also argue that:

> ***€œthey were depicted as passive recipients of external forces mainly within an institutional setting as family carers were not a primary focus in Kitwood’s work€•***

(Smebye and Kirkevold, 2013, p. 2)

The suggested way forward is to integrate Kitwood’s person-centred care into a more holistic ideal that allows people with dementia to be active agents, promoting a greater sense of self (Bartlett et al. 2010).

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[8022] Unit 6: Key Concepts of Stigma and Burden of Care

The concept of stigma is frequently associated with disability, is often culturally influenced and is largely a social construct. Erving Goffman (1963, p. 14) defines stigma as any attribute, trait or disorder that marks a person as being different. His themes of disability and stigma focus attention on the way societal response has a negative impact on the reality of living with a condition such as dementia. Goffman (1963, p. 45) uses the term €˜normal' to distinguish between those in society who are not visibly stigmatised or disabled. Stigma consists of attitudes, behaviours and feelings (Morgan et al. 2002). How people react to this is of some importance. Goffman (1963) summarises the techniques used by people in order to manage their self-concept as to either hide or accept their disability. He adds that:

> ***€œthe stigmatised person learns and incorporates the standpoint of the €˜normal', acquiring thereby the identity and beliefs of the wider society€•***

(Goffman 1973, p. 45).

The pressure to appear normal is extraordinarily challenging for people with dementia, particularly in the early stages. Goffman (1963) argues that a person has two possible options: either to hide the effects of the condition, making it invisible to others and thereby avoiding stigma, or to disclose all information and, in doing so, risk labelling and stigma (Goffman 1963; Joachim and Acorn 2000). Goffman (1963) also points out that loss of control is stigmatising, and special attention is necessary to avoid this. He argues that it is essential for the stigmatised person to avoid embarrassing others with out-of-control actions in situations where control is expected. Thus, he contends that the responsibility lies with the ill person in terms of how they present themselves; therefore, the individual must always avoid embarrassing others. Goffman called this €˜passing' or the keeping from public view a spoiled identity (Frank 1995, p. 23).

Downs and Bowers (2008) point out that people with dementia represent one of the most stigmatised and marginalised groups of older people in society. The decision to socially isolate oneself following a diagnosis of dementia can have a negative impact and delay contact with health services (Illiffe et al. 2005). In a study on the quality of life of people in early-stage dementia, Katsuno (2005) reported that participants told of being ignored, devalued and isolated, as well as feeling hurt and afraid.

Stigma is also experienced by family members and carers, known as €˜courtesy stigma' or €˜stigma by association' (McCarron 2006, p. 27). In a Swedish multi-centre study that measured burden and need for support in relatives of people with mental illness, a high proportion of relatives reported that the illness had affected the possibility of having company and relationships with others and had led to mental health problems for themselves (Ostman and Kjellin 2002).

References

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Goffman, E. (1963) *Stigma: Notes on the Management of Spoiled Identity*. New York: Simon and Schuster Publishers.

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Morgan, D., Semchuk, K., Steward, M. and D’Arcy, C. (2002) Rural families caring for a relative with dementia: barriers to use of formal services, *Social Science and Medicine*, 55(7): pp. 1129-1142.

Ostman, M. and Kjellin, L. (2002) Stigma by association: psychological factors in relatives of people with mental illness, *British J Psychiatry,* 181, pp. 494-8.

[8023] Unit 6: Suffering

€œSuffering is not a concept but a lived reality that resists articulation€•

(Frank 2001, p. 353)

Discourses around suffering continue to develop in the sociological and medical fields. Frank (1995, 2001) and Kleinman and Kleinman (1991, 1997) wrote extensively on people’s experience of illness. While the meaning of suffering is difficult to define, Lawson (2009) points out that people use narratives to give meaning and voice to their concept of suffering over time.

Cassell (2004, p. 32), a clinician, argues that suffering, as experienced by people,

€œoccurs when an impending destruction of the person is perceived and continues until the integrity of the person can be restored in some manner€•

(Cassell 2004, p. 32, cited in Seymour, 2007)

Similarly, Seymour’s (2007) view is that suffering is widespread, without respect for time or culture. Therefore, as Charmaz (1983) points out, physical pain, psychological distress and the damaging effects of medical procedures all cause the chronically ill to suffer as they experience their illnesses. However, she warns that:

€œa narrow medicalised view of suffering, solely defined as physical discomfort, ignores or minimises the broader significance of the suffering experienced by debilitated chronically ill adults€•

(Charmaz, 1983, p. 1)

It was found in her study of 57 chronically ill people that their suffering entailed the crumbling away of a positive self-image. As a result of their illnesses, which intruded in their lives, they experienced social isolation, felt discredited and were considered a burden to others (Charmaz 1983, p. 1).

References

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[8024] Unit 6: Illness Narratives

The use of illness narratives is central to gaining an understanding of the changed circumstances of the lives of people with dementia and their families. Illness narratives document the key changes experienced and add to the existing theories to explain the context of living with dementia. Serious illness compels the person to rethink their purpose and end goal. Ill people have to think differently; they learn by telling their stories and by the reactions of others to these stories (Blaxter 2004).

Prigatono (1991) argues that the expression of the individual’s conscious experience is an effective indicator of the supports necessary to facilitate adjustment and to guide therapy. Illness stories do not just describe the experience: they are repair work, creating a new self (Blaxter 2004). After a diagnosis of dementia, there are multiple losses with which to cope (Howes et al. 2005). Narratives can also be emancipatory, allowing self-reflection and expression (Chamberlain 2006).

Frank’s (1995) influential book *The Wounded Storyteller* shows how medical notes (a record of the patient’s illness) offer only the official voice (Reissman 2002). Frank (1995, 2001) suggests that the body’s suffering during illness creates a need for stories; the stories can play an important role in:

€œrepairing narrative wreckage, as the self is gradually reclaimed in the act of telling€•

(Smith and Sparks 2007, p. 219).

These personal narratives about illness serve to give voice to the body so that the altered body and mind can once again become recognisable (Frank 1995). Thus, through these wounded storytellers (Frank 2004), the experience of events is given due recognition, inspiring confidence that these are lives worth reclaiming (Smith and Sparks 2007). Frank (1995) was one of the first to recognise that:

€œillness stories mix and weave different narrative threads€•

(Frank 1995, p. 76).

Kleinman (1995) also acknowledges:

€œ[the] patient’s and the family’s moral needs to have a witness to the story of suffering, to find support for the experience of illness, and to collaborate with others in the struggle to fashion a meaningful interpretation of what is at stake for them in their local world€•

(Kleinman 1995, p. 33)

Kleinman (1988) outlines three different representations of illness: a biomedical episode (disease), a personal experience (illness) and a socio-cultural event (sickness). Each phase is influenced and determined by the experience the person has with: the biomedical aspect (doctors, hospitals, procedures and therapies); how the disease was represented by people or groups (family, friends, community and work colleagues) (Lonardi 2007, p. 1622); and the coping strategies employed (e.g. avoidance of social situations and hiding physical aspects, such as memory loss) (Lonardi 2007).

Allowing people to tell their stories of their illness experiences has significant merit and must be an approach worth considering for all patients. Person-centred care is a laudable goal for all health professionals. Listening to people about their experiences is one way of attempting to achieve this objective.

References

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Frank, A. (1995) *The Wounded Storyteller*, Chicago: University of Chicago Press.

Frank, A.W. (2001) Can we Research Suffering? *Qual Health Res*. Vol. 11 no. 3, pp. 353-362.

Howes, H., Benton, D. and Edwards, S. (2005) Women’s experience of brain injury: An interpretative phenomenological analysis, *Psychology and Health,* Vol. 20, Issue 1, pp.129-142.

Lonardi, C. (2007) The passing dilemma in socially invisible diseases: Narratives on chronic Headache, *Social Science & Medicine* 65 (2007), pp. 1619€“1629.

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Prigatono, G.P. (1991) The relationship of frontal lobe damage to diminished awareness: studies in Rehabilitation. *Frontal Lobe Function and Dysfunction*, Oxford: Oxford University Press.

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Smith, B. and Sparkes, A.C. (2007) Changing bodies, changing narratives and the consequences

[8025] Unit 6 Activity: Share a visual representation of dementia

[8026] Unit 6: Care at the end of life

Palliative care is the care that people receive towards the end of their lives, the goal of which is the achievement of the best possible quality of life for people and their families (World Health Organisation 1990). There is often a focus on medical palliation, relieving symptoms or problems without reducing or affecting lifespan. This is important to consider, as many treatments given in the end of life could also reduce lifespan; therefore, any decisions on treatment should be made using the four ethical principles that we discussed in Week 3. The aim of palliative care is not to prolong life and suffering but to promote comfort and meaning for the remainder of an individual’s life, however long that may be.

Let’s hear from Sue Abdulla, Lead Dementia Nurse for Derby Hospitals NHS Foundation Trust, on the strategies used to support people with dementia at the end of their lives:

Transcript

References

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[8027] Unit 6: Challenges with end of life care

Symptoms can seriously affect quality of life. The oft-cited symptoms such as nausea, vomiting, pain, etc. may not apply so easily to people with dementia, and the reason for this is that palliative care has historically focused on people who have cancer. There is now a shifting perspective of palliative care to account for people who may be approaching the end of their lives but with different conditions, such as dementia or chronic obstructive pulmonary disease (COPD).

Let’s hear from Dr Wendy Wesson on the specific challenges of end-of-life support for people with dementia:

Transcript

It’s important that we all work together. If the nurses, doctors, hospital staff, community staff, social care staff and the family all come together into one integrated team, the care received by the person and the family will be much better and more holistic. The focus of palliative care in the community should be on respecting a person’s wishes where practicable; however, this is within the context of limited resources, safety and the wider responsibilities of the interprofessional team. It is important to think ahead about potential scenarios and to be prepared for any that may arise.

Although commonly forgotten, psychological care is just as important as physical care (Bracegirdle 1990). Care providers often focus on physical symptoms, but they need to have highly developed communication and interpersonal skills (Lloyd-Williams 2003). They need to show care and empathy while also staying positive and being supportive to the family. Related to psychological care, spirituality also plays an important role. Spirituality is linked to religion but is not the same: it is seen as the vital €˜life essence’ of an individual or their uniqueness related to a sense of well-being, humanity and personhood.

So, how do we support people at the end of their lives? Whether you are a healthcare professional or a family member, it is hard, but some of the most important steps are to build a rapport, offer supportive listening and empathy, and recognise and respond to individual emotions. You also need to recognise when concerns arise and know your own limitations; knowledge of referral pathways is important so that you can seek additional help if required (Mitchell and Gordon 2003).

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Mitchell D, Gordon T (2003) Spiritual and Religious Care Competencies for Specialist Palliative Care. Marie Curie Cancer Care

[8028] Unit 6 Talking Point

[8029] Unit 6: Bridging the Dementia Divide Plus

What is this section?

In this section we have included outstanding content items created by previous learners on Bridging the Dementia Divide that are related to this week’s theme. You will find various forms of content including text, poetry, PowerPoints, images €“ all for you to extend and enhance your learning. These were created as final assessments and we’re hoping to do the same with the items presented at the end of this course.

The content is aimed mainly at people that have taken the Bridging the Dementia Divide MOOC previously. If this is your first time then **this content is entirely optional**. It provides valuable insights, but will almost certainly take well beyond the advertised two hours per week schedule for this course.

Arme, Sophie: Skills needed and important to Maintain when caring for a person with dementia.

Calladine, Sarah: Team feedback.

Cuomo, Amory: A dementia patient's diary.

Farrington, Stephen: Dementia (a poem).

Gill, Kathleen: Self criticism.

Greenan, David Laurence: Three poems.

Harrold, Margaret: 13 years of care.

Limmer, Stephanie: How to support a person with dementia.

Mott, Jayne: A care givers guide: teaching package for people who work with dementia.

Shootet, Cheryllea: My story.

Staal, Rachael: My grandma.

Trivett, Angela: Sally.

Vail, Nadine: My dad; "My big Giant".

Waugh, Julie: My summation.

Wharton, Jane: Scenario.

13: Unit 6 Badge

14: Course Completion Certificate

[8032] Summary of the course

Over the last six weeks, we have covered many topics related to supporting a person living with dementia. We’ve considered what dementia is and isn’t, discussed compassion and communication principles, and examined some of the legal and ethical challenges around independence, control and quality of life. We have talked about dementia and its importance as a global health priority, how care services can be integrated and what you can do if you are supporting a person with dementia at the end of their life. We hope this course has encouraged you to think of dementia not just as a medical €˜problem’ but as a multi-dimensional biochemical, social, political, economic and cultural issue.

The reality is that many of us will be diagnosed with dementia or will know someone living with dementia. In Australia, for example, there is a new diagnosis of dementia every six minutes (Fight Alzheimer’s, Save Australia 2015). Dementia is a global issue and requires a global response. Equipping yourself with knowledge, getting informed and getting together with people who have dementia can help to forge the networks and links needed to fight this issue.

The final word for this course goes to Cath Williams, Lecturer in Social and Community Studies at the University of Derby, who shares her thoughts on how we can improve the lives of people living with dementia:

Transcript

What can I do next?

You may have enjoyed this course or have further questions about dementia and are wondering what you could do next. You could become a Dementia Friend, an initiative started by the Alzheimer's Society aiming to transform the way people think, talk and act in relation to dementia. They have face-to-face and online courses you can attend, and over one million people in the UK have become Dementia Friends.

Alternatively, you could study a more formal course than this one, and the University of Derby has a number of these on offer, available both online and face to face. For a comprehensive list of courses, please visit our website. The following may be of interest to you: health and social care courses online and on campus.

Or study another one of our Free Courses.

How do I get my certificate?

Now that you have completed your course on Bridging the Dementia Divide, you have earned a certificate of completion. Go to the next page to find out more.

Reference

Fight Alzheimer's, Save Australia (2015) Summary of dementia statistics in Australia [online] Last accessed 8th June 2015 at https://fightdementia.org.au/about-dementia-and-memory-loss/statistics

[8033] Invitation to take part in a research study €“ second survey

Invitation to take part in a research study - second survey

During this course we have asked you to reflect upon your learning, but also your perception of dementia. This survey is a **repeat of the one taken at the beginning of the course**, and we would like to see if your perceptions have changed. That concept (that your perceptions towards dementia may change) is an interesting one, and one that we as an academic team would like to do some further investigation into. As you may know, dementia is one of the greatest social issues of our time and undertaking research is one of the ways we can seek to understand the condition and its impact. This document includes further information about the study we are undertaking; please read on for further information about the study and how you can take part.

Participate in the research study

Thank you for considering participating in this study.

It's entirely optional and you can still study the course without participating.

Best wishes

David Robertshaw on behalf of The Course Team

[8034] Completion Certificate

Congratulations!

Now that you have completed all six units, you have earned all six badges. If you're not sure what to do with your badges, visit the 'Badges' section on the Frequently Asked Questions page.

Because you have successfully completed the course, you have been awarded the course completion certificate. **Please process to the next page** to download and print your own personalised certificate.

What next?

The course doesn't end there! You can now have the option of completing the course summative assessment. For the assessment, you are required to create an artefact to demonstrate your learning. This could be an oral history of a person with dementia, or a video about how to support a person with dementia, for example. It could be a reflective essay or a teaching package for people who work with dementia, but the emphasis is on you being creative and approaching the assessment from your own perspective. If you complete the final activity, you will be awarded with a 'Super Badge' on top of your completion certificate and six unit badges.

You will also get the chance to peer review other learners' work, just as they will have the opportunity to peer review yours. More information on this will follow after the assessment deadline date. Only learners who have submitted a piece of work will have the opportunity to review another learner's work. Please note, the peer review is not essential in order to earn the 'Super Badge'. Find out more about the task after the certificate page.

[8035] Course Summative Assessment

Well done, you made it to the end of the course! If you would like to earn the additional 'Super Badge' for the course you will need to complete this assignment.

This assessment involves you creating an artefact to demonstrate your learning. This could be an oral history of a person with dementia, or a video about how to support a person with dementia. It could be a reflective essay or a teaching package for people who work with dementia. How you present this and what you upload is down to you. Be as creative as you can be!

Once you have submitted your assignment you’ll receive an invitation to review another learner’s work. This review is important as it gives you an opportunity to provide feedback on another person’s work and someone else to give you feedback on your work. Try to be constructive and encouraging in your feedback.

Grading advice:

Please complete your peer review using the listed criteria. For each of the six points listed here, one point can be awarded where the learner has demonstrated knowledge and awareness of the concept listed. A total score of 3 or more can be considered a good submission. You may also wish to leave a comment using the comments field.

[8036] Acknowledgements

Lead Academic for Bridging the Dementia Divide

Interviews

Alison Kilduff, Senior Lecturer in Mental Health, University of Derby

Carole Stanley, retired Registered Nurse

Cath Williams, Senior Lecturer in Social and Community Studies, University of Derby

David Foreman, Senior Lecturer in Nursing, University of Derby

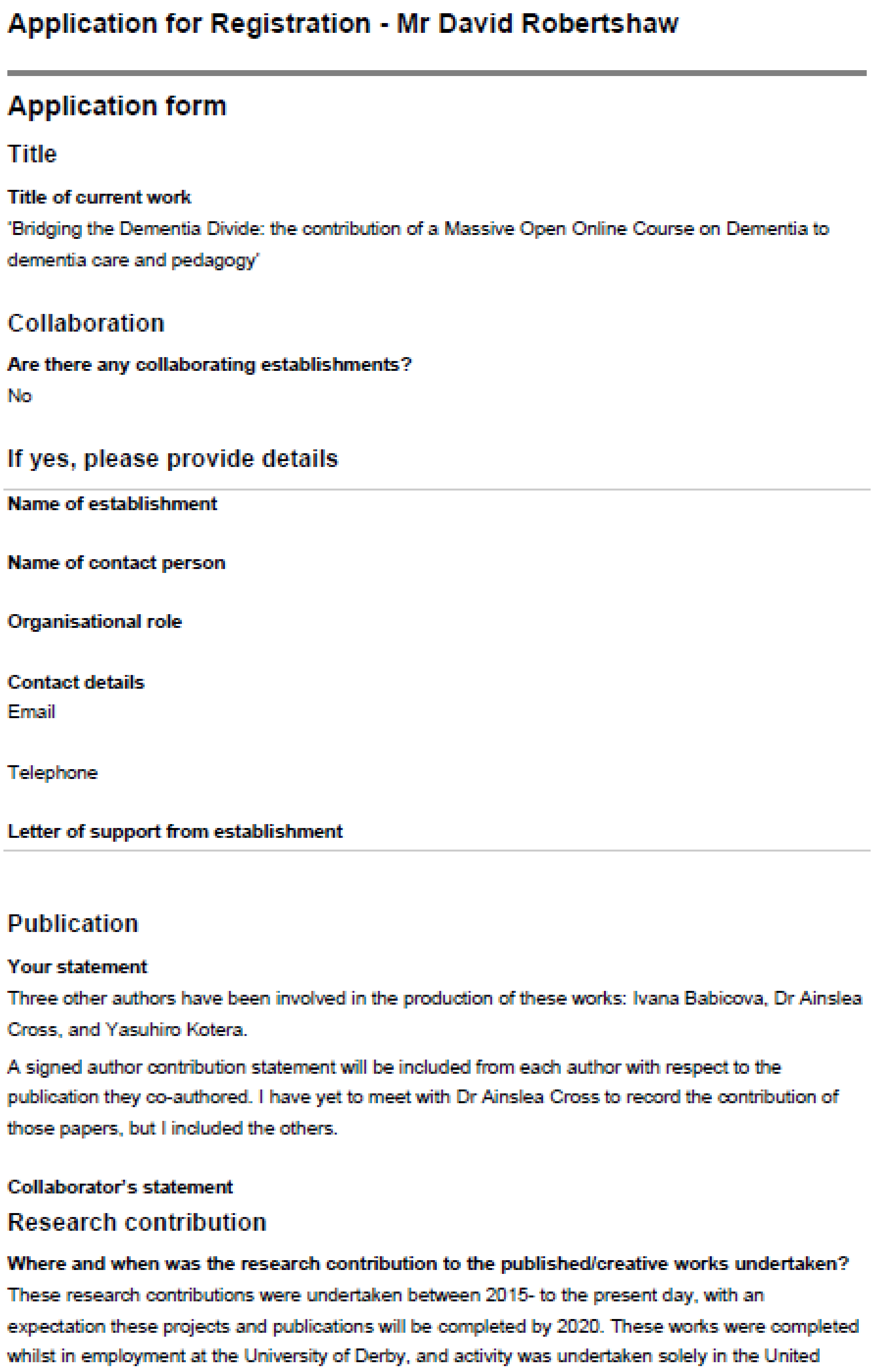
Dr Bill Whitehead, Head of Department, Healthcare Practice, University of Derby

Dr Lizzie Moriarty, Registrar, East Midlands Deanery

Dr Wendy Wesson, Head of Post-qualification Healthcare, University of Derby

Sue Abdulla, Lead Dementia Nurse, Royal Derby Hospital

Appendix 26: RD5



Application for Registration - Mr David Robertshaw

Application form

Title

Title of current work

'Bridging the Dementia Divide: the contribution of a Massive Open Online Course on Dementia to dementia care and pedagogy'

Collaboration

Are there any collaborating establishments?

No

If yes, please provide details

Name of establishment

Name of contact person

Organisational role

Contact details

Email

Telephone

Letter of support from establishment

Publication

Your statement

Three other authors have been involved in the production of these works: Ivana Babicova, Dr Ainslea Cross, and Yasuhiro Kotera.

A signed author contribution statement will be included from each author with respect to the publication they co-authored. I have yet to meet with Dr Ainslea Cross to record the contribution of those papers, but I included the others.

Collaborator's statement

Research contribution

Where and when was the research contribution to the published/creative works undertaken?

These research contributions were undertaken between 2015- to the present day, with an expectation these projects and publications will be completed by 2020. These works were completed whilst in employment at the University of Derby, and activity was undertaken solely in the United

Kingdom with the exception of the contribution to the EMOOCs conference. Papers were published in journals registered in the United Kingdom and the European Union. One chapter included in this work was published as part of a book in the United Kingdom. This doctorate includes creative works: the massive open online course is hosted on Canvas.net (which is in the United States of America) and the TEDx talk, although given in Derby, is hosted on YouTube.

Published works

List and upload all your published and pending works on which the application is based and which will be submitted in the final body of the work and/or the cited creative works which are or have been in the public domain (e.g. public exhibitions with published catalogues) together with independent critical reviews of the work and/or a list of the edited texts or collection of artefacts which are or have been in the public domain together with appropriate textual and explanatory annotations.

Bridging the Dementia Divide Massive Open Online Course

Robertshaw, D., Babicova, I. (2020) Discovering the memory thief: MOOC participants' personal experiences of dementia. Nurse Education in Practice 42(2020)102693 https://doi.org/10.1016/j.nepr.2019.102693

Robertshaw, D., & Babicova, I. (2019) New perspectives on great questions: what can MOOCs tell us? European Journal of Open, Distance and E-learning (fully accepted, will appear in a future edition)

Robertshaw, D., & Babicova, I. (2019) Tweeting on dementia: a snapshot of the content and sentiment of tweets associated with dementia (accepted pending revision)

Robertshaw, D., & Cross, A. (2016) 'MOOC as a platform for social learning, research and social change in Dementia'; Published in conference proceedings eMOOCs conference

Robertshaw, D., & Cross, A. (2019). Experiences of integrated care for dementia from family and carer perspectives: a framework analysis of massive open online course discussion board posts. Dementia, 18(4), 1492-1506. https://doi.org/10.1177/1471301217719991

Robertshaw, D., & Cross, A. (2019). Roles and responsibilities in Integrated Care for dementia. Journal of Integrated Care, 27(2), 131-140. https://doi.org/10.1108/JICA-05-2018-0037

Robertshaw, D., & Kotera, Y. (2019) Changing Attitudes with a MOOC on Dementia. European Journal of Open, Distance and E-learning 22 (2), 27-39. Retrieved from http://www.eurodl.org/?p=current&sp=full&article=802

Robertshaw D (2019) Technologisation of nursing education, in Dyson S E and McAllister M (Eds) (2019) Routledge International Handbook of Nurse Education. Abingdon, Oxon: Routledge. ISBN: 9780815358862

Robertshaw D (2016) Online Learning as a vehicle for social change. TEDx video https://youtu.be/63lobffry6s

Contribution to Knowledge

Provide a summary (max 1000 words) of the contribution to knowledge represented by the published works establishing how the works constitute a coherent study.

Five years ago, the University of Derby decided to explore a new avenue of education: massive open online courses (MOOCs). At that time, the University had no framework for MOOCs, didn't really know what courses to run or even how to run them. In my position as the Academic Lead for Healthcare for online programmes, I became heavily involved in the MOOC project. I was able to influence the design of the quality assurance framework for MOOCs at the University (Robertshaw, Owen and Hadi, 2015) and was a key member of the team that secured the OpenUpEd quality label (Rosewell and Jansen, 2014). I was the first member of staff at the University to develop a MOOC, and because of this I was able to make decisions and set the approach for the courses that would follow. Every subsequent MOOC the University offered used much of my MOOC's pedagogic and quality approach, and increased the appetite for open education and knowledge sharing.

The course was developed to give information on and raise awareness of dementia. At that time, dementia was becoming a major focus for government policy culminating in the Prime Minister's challenge on dementia 2020 (Department of Health, 2015). The University also developed ambitions to share its knowledge for free with others, and MOOCs were climbing in popularity as open source vehicles with two purposes: for members of the public to access complex knowledge for free, and for Universities to share their knowledge in an altruistic way (Rodriguez, 2012).

So, in 2014, I start designing the MOOC which would become 'Bridging the Dementia Divide'. At that time I was an experienced registered nurse, I was an experienced academic and was a programme leader for a large degree programme supporting nurses to 'top up' their diplomas to degrees. I was not a 'researcher' in the traditional sense. My MSc had included research training and I had research skills which would be further developed over the subsequent years. However, I soon realised that there should be form of evaluation of the programme and that this should be conducted in a robust way. MOOCs were an experiment for the University, they were also an experiment for society, and a lot of faith was placed in MOOCs as being an answer to many educational and societal problems. The issue at that time was that the evidence base for MOOCs was almost non-existent. MOOCs had been breathed into life by George Siemens and colleagues in 2008 and there were many thousands of MOOCs (Conole, 2013). But we didn't know if MOOCs were useful, if people learnt anything, or if they should exist at all (Baturay, 2014). I also realised, whilst designing 'Bridging the Dementia Divide' that there would be many thousands of participants, and that they would supply a lot of data. I realised I could use this data, with participants' consent, to answer some serious questions. These questions tied in with the Prime Minister's challenge: David Cameron wanted everyone to know about dementia; he wanted people to raise awareness of dementia so that it would become a public priority. At that time, heart disease was still the main cause of death but this would quickly be replaced by dementia (Office for National Statistics, 2016). So it was imperative that the public knew about dementia and would do something about it. Over 9000 people participated in the MOOC, with the videos being watched over 45,000 times. The impact of the course has been immense, and is still ongoing in its recently updated form.

What followed was four years of research, development and dissemination related to the evaluation of the course, and what the course told us about dementia. The early publications consisted of reports and some elemental research: a TEDx talk (Robertshaw, 2016) and a conference proceedings (Robertshaw and Cross, 2016). Subsequent projects increased the rigour of inquiry, adopting Framework Analysis approaches to analyse the data, developing themes and concepts (Robertshaw and Cross, 2019a; Robertshaw and Cross, 2019b; Robertshaw and Babicova, 2019). As the data became more complex and expansive, electronic analysis methods were employed

(Robertshaw and Kotera, 2019; Robertshaw and Babicova, 2019c). The final research project included in this doctoral work involved big data linguistic analysis with software packages (Robertshaw and Babicova, 2019c). The level, nature and complexity of my research has increased over time. I have been on a research journey developing as a researcher, academic and nurse. I have had the opportunity to discuss the wider implications of my work for example speaking at the House of Commons (Robertshaw, 2015), and contribute a chapter to a book (Robertshaw, 2019) which will allow my work to have impact on others, influencing the development of other MOOCs and pedagogy more broadly. This body of work demonstrates a growing competency and proficiency in academic capability, and an increasing autonomy and performance in research and scholarship.

This work has generated unique and new knowledge of dementia; it has increased our understanding of how society views and perceives dementia. It has increased our understanding of the context of dementia, evaluating attitudes towards dementia discovered what people actually think about integrated dementia care (and considered the roles and responsibilities people perform in relation to dementia). The body of work has also characterised the language associated with dementia in public for a, as well as evaluating the impact of MOOCs (in particular the 'Bridging the Dementia Divide' MOOC). There is demonstrable coherence with each of the included published works: each paper, publication or project has informed the next as well as increasing in complexity. The narrative produced as part of this doctoral study will articulate the links, coherency and contribution of this body of work.

Ethical consideration

Has any of the work involved ethical considerations/clearance?
Yes

If yes, please provide details, including details of relevant professional bodies; basis for approval given and details of relevant Codes of Practice; has the ethical view of the work changed since publication, and if so, how, and what is the significance and would this have influenced how the work was undertaken. This form is part of the final submission, and therefore, can be referred to in the critical review.
Ethical approval has been gained from the University of Derby Online Learning's Research and Ethics Committee, and the University of Derby Health and Social Care Research and Ethics Committee. The British Psychological Society's Code for Internet Mediated Ethics has been used as a code of practice throughout this research, in addition to being guided by the Nursing and Midwifery Council Code (2018). The ethical view of the work since publication has not changed. Where changes were identified, modifications were sought from the relevant ethics committee.

APPROVED ETHICS APPLICATION 1 Project title: 'MOOC' as a platform for social learning, research and social change in dementia UDOL-02DR-AC-2015-16. Date of approval: 09/02/16

Publications relating to approved ethics application 1:

- Robertshaw D, Cross A (2016) 'MOOC as a platform for social learning, research and social change in Dementia'; Published in conference proceedings eMOOCs conference;
- Robertshaw, D., Cross, A. (2019). Experiences of integrated care for dementia from family and carer perspectives: a framework analysis of massive open online course discussion board posts. Dementia, 18(4), 1492-1506;

- Robertshaw, D., Cross, A. (2019). Roles and responsibilities in Integrated Care for dementia. Journal of Integrated Care, 27(2), 131-140. https://doi.org/10.1108/JICA-05-2018-0037;
- Robertshaw D, Babicova, I (2019) Discovering the memory thief: MOOC participants' personal experiences of dementia. Nurse Education in Practice [paper under consideration]).

APPROVED ETHICS APPLICATION 2 Project title: Can massive open social learning change perception of dementia? UDOL- 07DR-2015-16. Date of approval: 04/03/16

Publications relating to approved ethics application 2:

- Robertshaw, D. & Kotera, Y. (2019) Changing Attitudes with a MOOC on Dementia. European Journal of Open, Distance and E-learning 22 (2), 27-39. Retrieved from http://www.eurodl.org/?p=current&sp=full&article=802)

APPROVED ETHICS APPLICATION 3 Project title: Tweeting on dementia: a snapshot of the content and sentiment of tweets associated with dementia. Date of approval: 28/06/19

Publications relating to approved ethics application 3:

- Robertshaw D, Babicova I (2019) Tweeting on dementia: a snapshot of the content and sentiment of tweets associated with dementia. Dementia [paper under consideration]).

If no, please state why

Declaration

I confirm that I am not registered at any other institution for a research degree or any other award, based upon any publication contained within the submission and that no material contained in the work for examination has been used in any other submission for an academic award.

Supervisor report

Supervisor report

Recommendation

I support the application.

If you do not support the application please provide justification for this

David has addressed the concerns of the assessor and the board and has the full support of the supervisory team in his application.

Assessor report

Assessor report

Recommendation

Approve - registration for intended award

Report and feedback

I now believe my concerns have been addressed and both the supervisors and candidate are aware of the risks involved with this submission. The regularoty issue being that if the examiners do not consider that the work is substantial enough there would be no possibility of adding in further works post examination. It would be a straight failure. I think they have been mitigated with the papers now in press/published and the clarity around the MOOC and its role within the overall case.

Notes

College Research Committee report

College Research Committee report

Decision

Approve - registration for intended award

Feedback and required amendments

Notes

happy to approve

Appendix 27: List of MOOCs related to Coronavirus during the 2020 COVID-19 Pandemic

FutureLearn

1. COVID-19 in Africa: Managing the Outbreak in Primary Care Settings by St George's, University of London
2. COVID-19: Diagnostics and Testing by Foundation for Innovative New Diagnostics
3. COVID-19: Psychological First Aid by Public Health England
4. Social Care During COVID-19: Coping with Self-Isolation and Social Distancing by The Tavistock and Portman NHS Foundation Trust
5. Managing COVID-19 in Primary Care by St George's, University of London
6. COVID-19: Adapting Child Protection Case Management by University of Strathclyde
7. Anxiety in Children and Young People during COVID-19 by UEA (University of East Anglia)
8. Teaching Young Learners Online by British Council
9. COVID-19: Psychological Impact, Wellbeing and Mental Health by Maudsley Learning
10. Teaching for Home Learning: Secondary Science by National STEM Learning Centre
11. COVID-19: Tackling the Novel Coronavirus by London School of Hygiene & Tropical Medicine
12. COVID-19: Effective Nursing in Times of Crisis by Johns Hopkins University
13. Teaching for Home Learning: Primary Science by National STEM Learning Centre
14. COVID-19 Critical Care: Understanding and Application by The University of Edinburgh
15. COVID-19: Pandemics, Modelling, and Policy by UNESCO UNITWIN Complex Systems Digital Campus
16. Understanding Food Supply Chains in a Time of Crisis by EIT Food

Coursera

1. COVID-19 Contact Tracing Johns Hopkins University
2. COVID-19 - A clinical update by University of Florida COVID-19 - A clinical update
3. COVID-19: What You Need to Know (CME Eligible) by Osmosis
4. Fighting COVID-19 with Epidemiology: A Johns Hopkins Teach-Out by Johns Hopkins University
5. Mind Control: Managing Your Mental Health During COVID-19 by University of Toronto
6. COVID19 Data Analysis Using Python by Coursera Project Network
7. Science Matters: Let's Talk About COVID-19 by Abdul Latif Jameel Institute for Disease and Emergency Analytics (J-IDEA), Imperial College London
8. Primeros Auxilios Psicológicos (PAP). Edición especial COVID-19 by Universitat Autònoma de Barcelona
9. Lecture Series for Preventing and Controlling COVID-19 by Xi'an Jiaotong University
10. Resilience Skills in a Time of Uncertainty by University of Pennsylvania

EdX

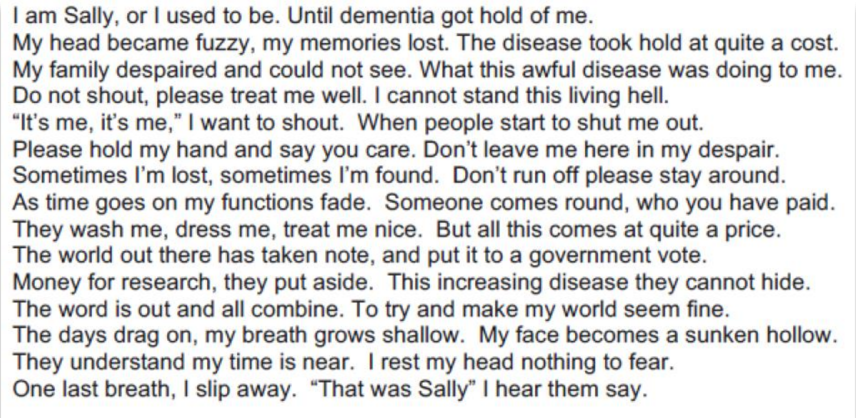
1. Mechanical Ventilation for COVID-19 by Harvard University

2. Safe Surgical Care: Strategies During a Pandemic by University of British Columbia
3. Re-Imagine Work: Strategies During COVID-19 and Beyond by the University of British Columbia
4. Global Health: Ebola, COVID, and Beyond by University of Maryland Global Campus, University of Maryland Baltimore, University System of Maryland

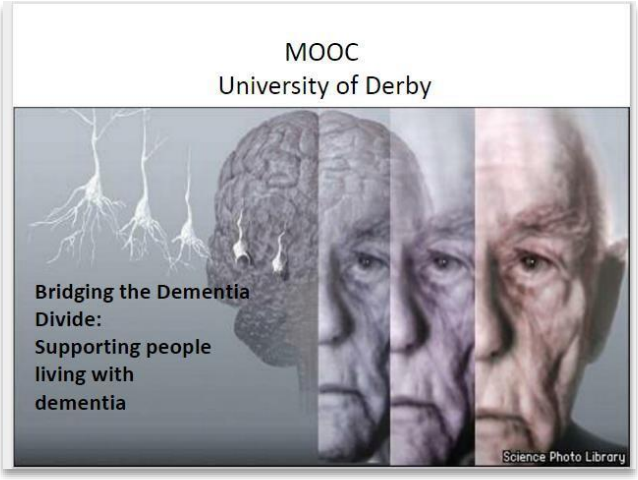
eLearning for Health (Health Education England)

1. Essential Guidance from the NHS, UK Government, WHO and BMJ
2. Public Health England – Personal Protective Equipment (PPE)
3. Infection Prevention and Control
4. Resources for Staff Working in Critical Care Setting
5. Resources for Staff Working in Acute Hospital Setting
6. Resources for Staff Working in Primary Care and Community Setting
7. Resources for Staff Working in a Mental Health and Learning Disabilities Setting
8. Resources for Nurses, Midwives and AHPs Returning to work, being Redeployed or Up-Skilled
9. Resources for other Healthcare Staff Returning to Work
10. Resources for End of Life Care COVID-19
11. Resources for Specific Professions
12. Resources for Volunteers supporting Health and Social Care
13. Critical Care and Ward-Based Equipment Guides
14. Staff Wellbeing and Resilience during COVID-19

Appendix 28 – Sample of assessments submitted for Bridging the Dementia Divide



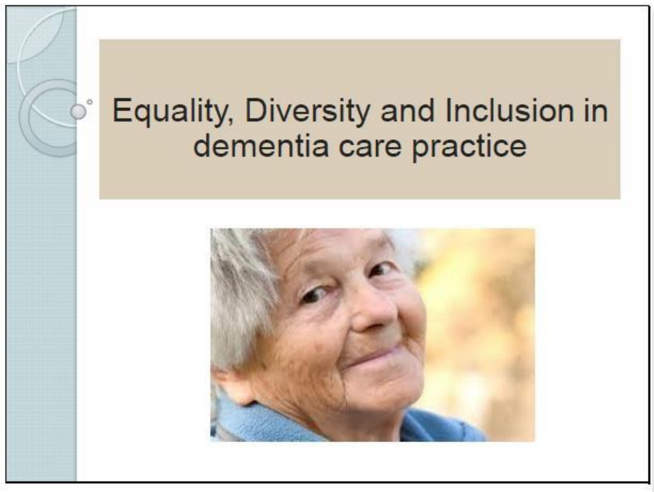
I am Sally, or I used to be. Until dementia got hold of me.
My head became fuzzy, my memories lost. The disease took hold at quite a cost.
My family despaired and could not see. What this awful disease was doing to me.
Do not shout, please treat me well. I cannot stand this living hell.
"It's me, it's me," I want to shout. When people start to shut me out.
Please hold my hand and say you care. Don't leave me here in my despair.
Sometimes I'm lost, sometimes I'm found. Don't run off please stay around.
As time goes on my functions fade. Someone comes round, who you have paid.
They wash me, dress me, treat me nice. But all this comes at quite a price.
The world out there has taken note, and put it to a government vote.
Money for research, they put aside. This increasing disease they cannot hide.
The word is out and all combine. To try and make my world seem fine.
The days drag on, my breath grows shallow. My face becomes a sunken hollow.
They understand my time is near. I rest my head nothing to fear.
One last breath, I slip away. "That was Sally" I hear them say.



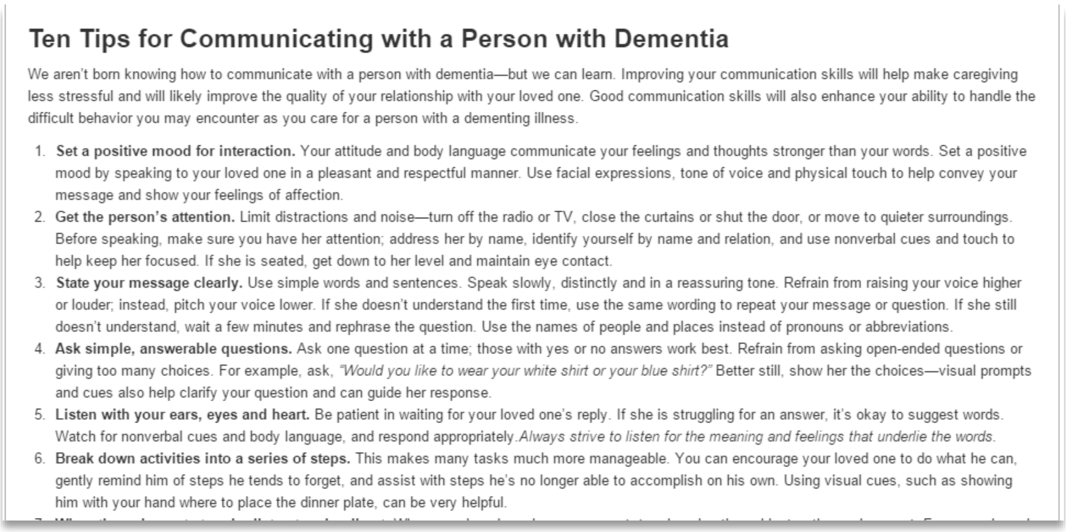
MOOC
University of Derby

Bridging the Dementia Divide:
Supporting people living with dementia

Science Photo Library



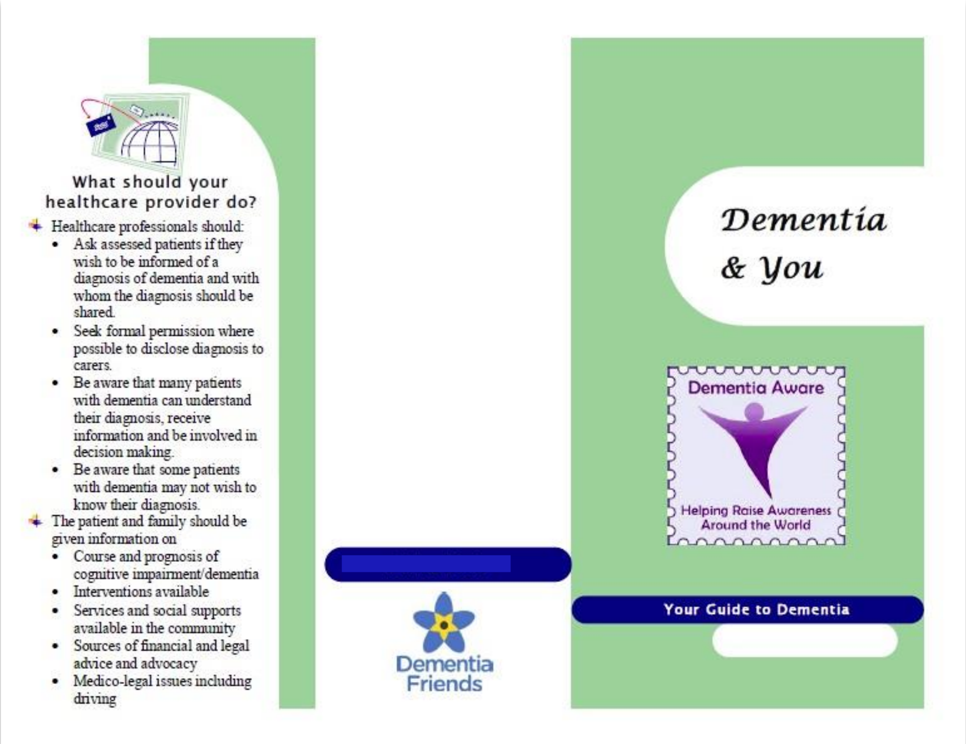
Equality, Diversity and Inclusion in dementia care practice



Ten Tips for Communicating with a Person with Dementia

We aren't born knowing how to communicate with a person with dementia—but we can learn. Improving your communication skills will help make caregiving less stressful and will likely improve the quality of your relationship with your loved one. Good communication skills will also enhance your ability to handle the difficult behavior you may encounter as you care for a person with a dementing illness.

1. **Set a positive mood for interaction.** Your attitude and body language communicate your feelings and thoughts stronger than your words. Set a positive mood by speaking to your loved one in a pleasant and respectful manner. Use facial expressions, tone of voice and physical touch to help convey your message and show your feelings of affection.
2. **Get the person's attention.** Limit distractions and noise—turn off the radio or TV, close the curtains or shut the door, or move to quieter surroundings. Before speaking, make sure you have her attention; address her by name, identify yourself by name and relation, and use nonverbal cues and touch to help keep her focused. If she is seated, get down to her level and maintain eye contact.
3. **State your message clearly.** Use simple words and sentences. Speak slowly, distinctly and in a reassuring tone. Refrain from raising your voice higher or louder; instead, pitch your voice lower. If she doesn't understand the first time, use the same wording to repeat your message or question. If she still doesn't understand, wait a few minutes and rephrase the question. Use the names of people and places instead of pronouns or abbreviations.
4. **Ask simple, answerable questions.** Ask one question at a time; those with yes or no answers work best. Refrain from asking open-ended questions or giving too many choices. For example, ask, *"Would you like to wear your white shirt or your blue shirt?"* Better still, show her the choices—visual prompts and cues also help clarify your question and can guide her response.
5. **Listen with your ears, eyes and heart.** Be patient in waiting for your loved one's reply. If she is struggling for an answer, it's okay to suggest words. Watch for nonverbal cues and body language, and respond appropriately.*Always strive to listen for the meaning and feelings that underlie the words.*
6. **Break down activities into a series of steps.** This makes many tasks much more manageable. You can encourage your loved one to do what he can, gently remind him of steps he tends to forget, and assist with steps he's no longer able to accomplish on his own. Using visual cues, such as showing him with your hand where to place the dinner plate, can be very helpful.



What should your healthcare provider do?

- Healthcare professionals should:
  - Ask assessed patients if they wish to be informed of a diagnosis of dementia and with whom the diagnosis should be shared.
  - Seek formal permission where possible to disclose diagnosis to carers.
  - Be aware that many patients with dementia can understand their diagnosis, receive information and be involved in decision making.
  - Be aware that some patients with dementia may not wish to know their diagnosis.
- The patient and family should be given information on
  - Course and prognosis of cognitive impairment/dementia
  - Interventions available
  - Services and social supports available in the community
  - Sources of financial and legal advice and advocacy
  - Medico-legal issues including driving

[redacted]

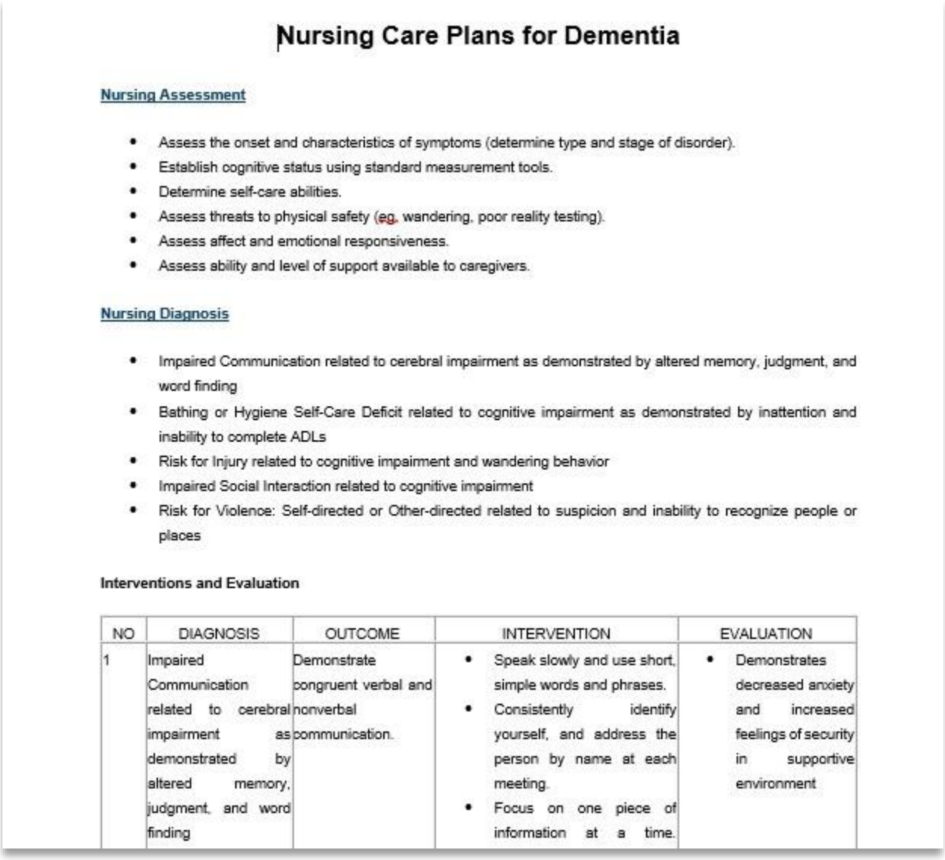
Dementia Friends

Dementia & You

Dementia Aware

Helping Raise Awareness Around the World

Your Guide to Dementia



Nursing Care Plans for Dementia

Nursing Assessment

- Assess the onset and characteristics of symptoms (determine type and stage of disorder).
- Establish cognitive status using standard measurement tools.
- Determine self-care abilities.
- Assess threats to physical safety (eg, wandering, poor reality testing).
- Assess affect and emotional responsiveness.
- Assess ability and level of support available to caregivers.

Nursing Diagnosis

- Impaired Communication related to cerebral impairment as demonstrated by altered memory, judgment, and word finding
- Bathing or Hygiene Self-Care Deficit related to cognitive impairment as demonstrated by inattention and inability to complete ADLs
- Risk for Injury related to cognitive impairment and wandering behavior
- Impaired Social Interaction related to cognitive impairment
- Risk for Violence: Self-directed or Other-directed related to suspicion and inability to recognize people or places

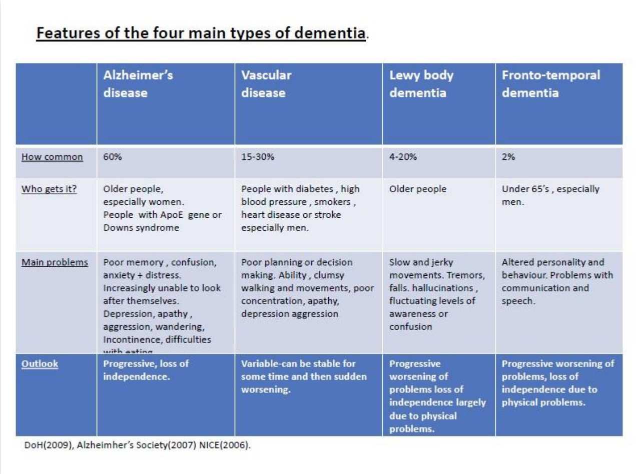
Interventions and Evaluation

NO	DIAGNOSIS	OUTCOME	INTERVENTION	EVALUATION
1	Impaired Communication related to cerebral impairment as demonstrated by altered memory, judgment, and word finding	Demonstrate congruent verbal and nonverbal communication.	• Speak slowly and use short, simple words and phrases. • Consistently identify yourself, and address the person by name at each meeting. • Focus on one piece of information at a time.	• Demonstrates decreased anxiety and increased feelings of security in supportive environment

My Grandma

By

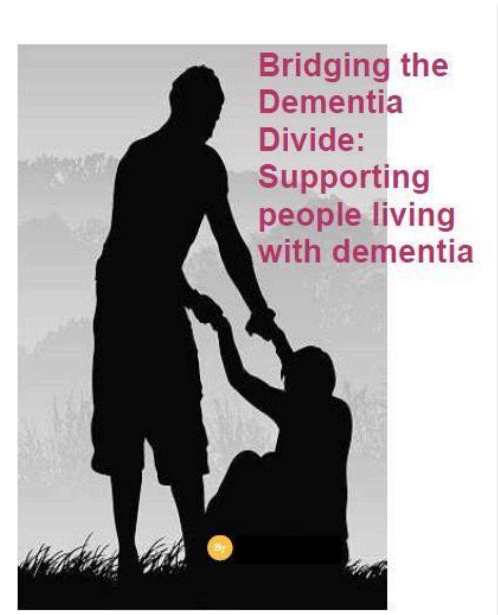
[redacted]



Features of the four main types of dementia.

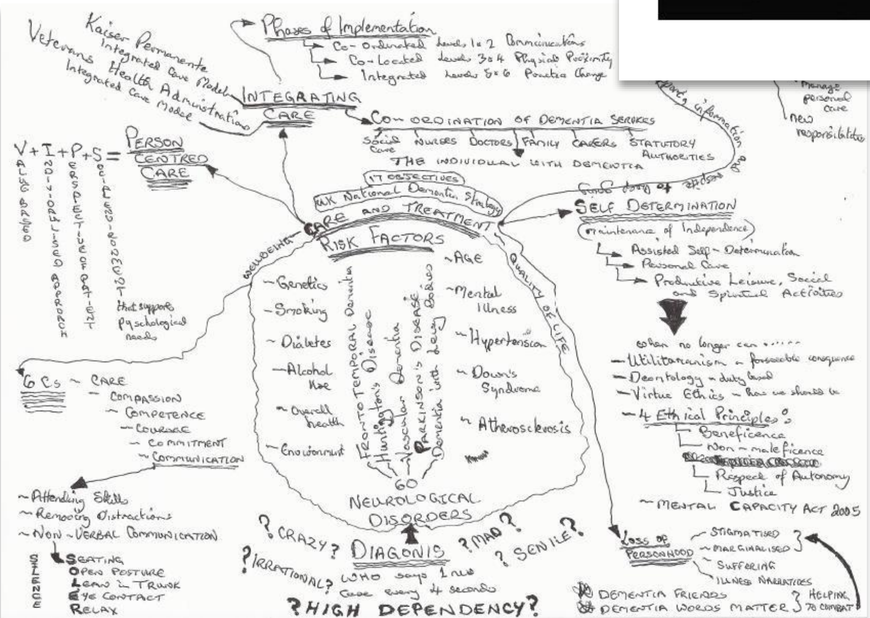
	Alzheimer's disease	Vascular disease	Lewy body dementia	Fronto-temporal dementia
How common	60%	15-30%	4-20%	2%
Who gets it?	Older people, especially women. People with ApoE gene or Downs syndrome	People with diabetes , high blood pressure , smokers , heart disease or stroke especially men.	Older people	Under 65's , especially men.
Main problems	Poor memory , confusion, anxiety + distress. Increasingly unable to look after themselves. Depression, apathy , aggression, wandering, Incontinence, difficulties with eating	Poor planning or decision making. Ability , clumsy walking and movements, poor concentration, apathy, depression aggression	Slow and jerky movements. Tremors, falls. hallucinations , fluctuating levels of awareness or confusion	Altered personality and behaviour. Problems with communication and speech.
Outlook	Progressive, loss of independence.	Variable-can be stable for some time and then sudden worsening.	Progressive worsening of problems loss of independence largely due to physical problems.	Progressive worsening of problems, loss of independence due to physical problems.

DoH(2009), Alzheimher's Society(2007) NICE(2006).



Bridging the Dementia Divide: Supporting people living with dementia

By [redacted]



Appendix 29: – list of programmes I have led the development of, or have been part of the development team

These programmes were influenced by the development of and research around Bridging the Dementia Divide.

As development leader

1. Bridging the Dementia Divide: supporting people living with dementia (Massive Open Online Course) (University of Derby, 2015)
2. BSc (Hons) Nursing Studies (Top up) modifications (University of Derby, 2013-16)
3. BSc (Hons) Integrative Health and Social Care (top up) (University of Derby, 2015)
4. BSc (Hons) Nursing Studies (top up) revalidation (University of Derby, 2016)
5. BSc (Hons) Perioperative Practice (top up) (University of Derby, 2016)
6. BSc (Hons) Perioperative Practice (top up) Association for Perioperative Practice Accreditation (University of Derby, 2016)
7. BSc (Hons) Nursing Studies (top up) RCN Accreditation (University of Derby, 2016)
8. Disaster Management (short course) (University of Derby, 2016)
9. FDSc Professional Development (Health and Social Care) (University of Derby and Virgin Care, 2017) [Collaborative]
10. FDSc Professional Development (Health and Social Care) (University of Derby and B'met, 2017) [Collaborative]
11. FDSc Nursing Associate Apprenticeship (2018)
12. FDSc Healthcare Assistant Practitioner Apprenticeship (2018)
13. FDSc Nursing Associate Apprenticeship (2019, with NMC Approval)
14. FDSc Nursing Associate (2019, with NMC Approval)
15. FDSc Assistant Practitioner Apprenticeship (2019)
16. FDSc Assistant Practitioner (2019)
17. PGCert Critical Care (in early development, 2020)
18. Listen without Prejudice – Music and Care (short course) (in early development, 2020)

As development team

1. MSc Integrative Health and Social Care (University of Derby, 2014)
2. PgCert Emergency Care (University of Derby, 2014)
3. PgCert Dementia Care (University of Derby, 2014)
4. PgCert End of Life Care (University of Derby, 2014)

5. PgCert Healthcare Education (University of Derby, 2014)
6. PgCert Leadership and Management (University of Derby, 2014)
7. PgCert Integrative Health and Social Care (University of Derby, 2014)
8. PgCert Sexual Health (University of Derby, 2014)
9. University Advanced Diploma in Dementia Care (University of Derby, 2014)
10. BSc (Hons) Cognitive Behavioural Therapeutic Approaches (University of Derby, 2015)
11. BSc (Hons) International Nursing (University of Derby, 2015)
12. BA (Hons) Health and Social Care (University of Derby, 2014)
13. Foundation Year Zero, Certificate in Higher Education (University of Derby, 2016)
14. UAD Cognitive Behavioural Studies and Skills (University of Derby, 2015)
15. Child and Adolescent Mental Health (short course) (University of Derby, 2016)
16. 21st Century Teaching (short course) (University of Derby, 2016)
17. Social Pedagogy (short course) (University of Derby, 2016)
18. Certificate of Credit in Health and Social Care Studies (University of Derby, University of Derby, 2016)
19. Master of Public Health (University of Derby, 2016)
20. MA Education modification (University of Derby, 2016)
21. MSc Intelligence, Security and Disaster Management (University of Derby, 2016)
22. FDSc Nursing Associate (University of Derby, 2017)
23. PGCert Interprofessional Practice Education (University of Derby, 2017) [with NMC approval]
24. Mentoring in Practice (University of Derby, 2017) [with NMC approval]
25. FDSc Professional Development (Health and Social Care) (University of Derby and Vision West Nottinghamshire College, 2017) [Collaborative]
26. BSc (Hons) Nursing (Adult) and (Mental Health) Apprenticeship (University of Derby, 2017)
27. BSc/MSc Adult/Mental Health/Learning disabilities/child Nursing Apprenticeship (2019)
28. BSc Midwifery/BSc Midwifery apprenticeship/shortened course Midwifery (2020)

Appendix 30: Harbour and Miller revised grading system

For recommendations in evidence based guidelines (from Harbour, R., and Miller, J. (2001). A new system for grading recommendations in evidence based guidelines. *BMJ* 323(7308) pp.334-336.)

Levels of evidence

1++ High quality meta-analyses, systematic reviews of RCTs, or RCTs with a very low risk of bias

1+ Well conducted meta-analyses, systematic reviews of RCTs, or RCTs with a low risk of bias

1− Meta-analyses, systematic reviews or RCTs, or RCTs with a high risk of bias

2++ High quality systematic reviews of case-control or cohort studies *or*

High quality case-control or cohort studies with a very low risk of confounding, bias, or chance and a high probability that the relationship is causal

2+ Well conducted case-control or cohort studies with a low risk of confounding, bias, or chance and a moderate probability that the relationship is causal

2− Case-control or cohort studies with a high risk of confounding, bias, or chance and a significant risk that the relationship is not causal

3 Non-analytic studies, eg case reports, case series

4 Expert opinion

Grades of recommendations

A At least one meta-analysis, systematic review, or RCT rated as 1++ and directly applicable to the target population *or*

A systematic review of RCTs or a body of evidence consisting principally of studies rated as 1+ directly applicable to the target population and demonstrating overall consistency of results

B A body of evidence including studies rated as 2++ directly applicable to the target population and demonstrating overall consistency of results *or*

Extrapolated evidence from studies rated as 1++ or 1+

C A body of evidence including studies rated as 2+ directly applicable to the target population and demonstrating overall consistency of results *or*

Extrapolated evidence from studies rated as 2++

D Evidence level 3 or 4 *or*

Extrapolated evidence from studies rated as 2+