

# Empathy and Dignity through technology: using lifeworld-led multimedia to enhance learning about the head, heart and hand

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**Abstract:** A person's sense of dignity is a complex phenomenon and is intertwined with their sense of feeling human and being respected as a human being. In 2010, the School of Health and Social Care developed a collaborative lifeworld led transprofessional curriculum for health and social work disciplines harnessing technology to connect learners to a wider view of evidence based practice. The purpose was to increase use of technology-enhanced learning, introduce lifeworld-led philosophy to the curriculum, release staff potential, and expose students to research undertaken within the School. Delivered to undergraduate students the Exploring Evidence to Guide Practice Unit was facilitated by a number of resources including lectures, group work and a variety of web-based learning materials.

Central to the unit were seventeen web-based case studies which included the human experience of the impact of specific illnesses (such as stroke and living with dementia) and more general experiences (such as social isolation and homelessness). Each case study provided stories and poems, qualitative and quantitative research and policy and practice issues related to specific topics.

At the heart of the philosophy underpinning the unit was an opportunity for students to integrate understandings about different kinds of knowledge for practice, conventional evidence, understandings about the person's or service user's experience and the student's own insights that came from imagining 'what it was like' for the person experiencing a condition or situation and encountering human. The project built on the successful development of Wessex Bay, a virtual community of case scenarios, used as problem-based triggers to engage students in learning activities relating to residents.

This paper discusses the development of the web-based case studies and how they integrated visual and audio materials with the aim of enhancing the lifeworld experience of students and helping to show the importance of humanising healthcare.

Keywords: Lifeworld, technology, transprofessional, web, humanising care, healthcare

#### 1. Humanising Healthcare and the Concept of Lifeworld

A person's sense of dignity is a complex phenomenon and is intertwined with their sense of feeling human and being respected as a human being. The Commission on improving dignity in care (2012a) has been trying to understand how and why older people's care is failing on dignity and in February 2012 it published a draft report and recommendations for public consultation (2012b). The report drew on the body of evidence that the Commission had gathered over eight months, including written evidence submitted from over 40 organisations, public hearings and expert opinion from academic, medical and nursing communities. On the day the report was launched, the Commission co-chairs suggested a need to trigger a major cultural shift in the way everybody in care thought about dignity.

The draft report (2012b) set out ten key recommendations for hospitals and ten key recommendations for care homes to help them tackle the underlying causes of undignified care, as well as recommendations on the changes the Commission believed needed to take place across the wider health and social care system. Amongst the ten recommendations for hospitals the report suggested that hospital boards must understand how people experience care in their particular hospital, and view dignity as a key measure of performance and that hospitals should introduce facilitated, practice-based development programmes - 'learning through doing' - to ensure staff caring for older people were given the confidence, support and skills to do the right thing for their patients. Amongst the ten recommendations for care homes the report suggested that Care homes needed to work with

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residents to create an environment that made their lives happy, varied, stimulating, fulfilling and dignified and that all care home staff must take personal responsibility for putting the person receiving care first, and also that staff should be urged to challenge practices they believed were not in the best interests of residents.

The Commission's use of written evidence (2012c) to help inform its questions during oral evidence sessions and to help shape the draft report and recommendations highlighted many areas of concern and problems noted throughout the care pathway of patients such as:

I just feel those receptionists just treat you as a number and not a person. I am really very upset.

As mum was not given anything to eat or drink for three days whilst awaiting a minor procedure she became distressed and aggressive as she was not given her anti-psychotic medication. I consider I was bullied and abused by these [Nursing] Aides who are not qualified nurses.

but

staff nurses were kind and helpful.

The report and written evidence submitted was another timely reminder that the humanisation of care agenda is something which still needs to be urgently addressed within the health and social care system.

The rise of technology could perhaps be seen as a distraction from compassion in the caring professions (Todres et al. 2009). However, technology can also be harnessed for educational development to support compassion in practice. In their article on the concept of lifeworld, Todres, Galvin and Dahlberg (2007) listed ideas about the values and philosophy of life world-led care, which could translate into practice. These included phenomenological and narrative studies, which deepened insights into lifeworld phenomena such as palliative care (Seymour and Clark 1998), myocardial infarction (Johansson, Ekebergh and Dahlberg 2003) and non-caring encounters in an emergency unit (Nyström, Dahlberg and Carlsson 2003). They also noted ways of disseminating qualitative research findings to make them valuable to users and help to deepen professionals' lifeworld understanding (Ziebland 2004). Todres et al. (2007) also highlighted the central foundations of life world-led care: its humanising value, the holistic contextuality of lifeworld experience, and its benefits of experiential credibility and citizen empowerment.

#### 2. Integrating Lifeworld with Technology - The Carer's World

In 2006, staff from the School of Health and Social Care (HSC) at Bournemouth University were investigating ways to make their health and social care curriculum more innovative and interactive (Pulman, Scammell and Martin 2009). One approach concerned integrating the methods and themes of lifeworld with Hypertext narrative into an interactive educational resource concerning the experience of Alzheimer's. The project began as a text-to-screen adaptation of Todres and Galvin's 2006 article, which aimed to contribute to a deeper understanding of caring for a partner with advancing memory loss with particular concern for communicating findings in evocative and empathic ways. In their article Todres and Galvin (2006) suggested that by engaging with descriptions and interpretations offered, carers, professionals and family could be better equipped to understand the issues discussed. The initial project idea was centred on an interactive hypertext narrative utilising the transposition model of adaptation (Pulman, Galvin and Todres 2010) aiming to generate a deeper understanding of six related phenomena within an intimate carer's journey. The carer - Mervyn Richardson - who featured in the article (Todres and Galvin 2006) was approached about participating in the project and agreed to work alongside HSC. He also gave permission to use personal photos, diary extracts and video clips from the award winning A Sweeter Pill to Swallow: Beryl's Story (Richardson 2002).

After production of two prototypes, a third iteration - *The Carer's World* - was created (Pulman, Galvin and Todres 2010) - designed to give users greater knowledge about, and insight into, the challenges

of caring for people with Alzheimer's. The package was based on the idea that learning to become a competent professional required not only knowledge about the condition and its treatment, but also what it was like to be with a person who was suffering from the condition in their everyday lives. An important access to this understanding might come from the experience of family carers who lived with them throughout the whole journey (Galvin, Todres and Richardson 2005). The aim of the resource was to offer users opportunities to engage not only with technical knowledge about the condition, but more importantly with understandings of the world of the carer. Imagining more deeply what the world of the carer might be like might provide direction for enhancing person-centred practice, which required situated judgement and ethical sensitivity. This capacity being important when applying evidence to unique situations requiring imagination and sensitivity. Work on *The Carer's World* was completed in Spring 2008.

## 3. Integrating Lifeworld with Technology - Exploring Evidence to Guide Practice

Pulman, Galvin and Todres (2010) had noted that there was exciting potential in working with healthcare professionals in their education, using new media to focus on the experiences of people in ways that could help them understand and learn from issues and personal views, becoming more effective and empathetic in supporting people. The use of interactive media to convey narrative stories around diseases and their effects also offered a uniquely potent way of harnessing public awareness and engaging policy makers, practitioners, students and carers in health and social care issues. With the potential to work with the public and health and social care professionals in exploring society's big issues in interesting new ways, it was hoped that other innovative resources based on the lifeworld framework could be created and utilised within the HSC curriculum.

During 2010, HSC began development of a collaborative lifeworld led transprofessional curriculum for health and social work disciplines through harnessing technology to connect learners to a wider view of evidence based practice. The purpose was to increase use of technology-enhanced learning, introduce lifeworld-led philosophy to the curriculum, release staff potential, and expose students to research undertaken within HSC. The project was supported by the Higher Education Academy (HEA) Discipline-focused Learning Technology Enhancement Academy through the HEA Subject Centre for Social Policy and Social Work (SWAP). The aim was to capitalise on the School's expertise and scholarship in utilising a range of evidence around lifeworld service user and carer stories (demonstrated in the creation of *The Carer's World*) in the form of clips from television and radio programmes, films, podcasts, poetry, drama and narrative case studies, and associated evidence from journal articles and policy documents, to immerse health and social care students in the lifeworld of the people they might encounter in their future professional roles.

A key feature of the project was to raise student awareness of a range of evidence, including narratives and material from the arts and humanities (such as film) to consider how practice could be guided. In this way, HSC wished to introduce students to evidence in a situated way, embedded in practice and to make transprofessional learning explicit. Interestingly, previous studies of the education of teachers by Bousted and Ozturk (2004) and Downey et al. (2003) had both noted that film might have particular advantages in helping those who worked in complex and demanding social situations to develop observational skills and become more adept at noticing. At the heart of the philosophy underpinning the educational resource (Figure 1) was an opportunity for students to integrate understandings about different kinds of knowledge for practice, conventional evidence, understandings about the person's or service user's experience and the student's personal insights that came from imagining 'what it was like' for the person experiencing a condition or situation and encountering human services (Todres 2008, Galvin 2010, Galvin and Todres 2011).

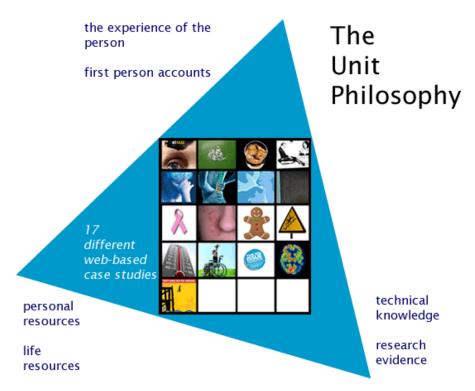


Figure 1 – The Unit Philosophy

Early evaluations of Wessex Bay (Pulman, Scammell and Martin 2009) confirmed that students had enjoyed the uniqueness of the problem based learning triggers used in the community as opposed to other methods experienced during a conventional academic year. However, feedback also suggested there was a thirst for more interactive experiences and pointed to the need to enhance profiles and structure of the community for future years. This particularly concerned the framework around the characters used in case studies - their neighbours, friends and supporting network that weren't currently in evidence. It was recommended that there was development of targeted interactive webbased learning embedded within case scenarios and a streamlining of scenarios to provide fewer more developed cases. The key beneficiaries of this initiative would be future HSC students, with the focus on creating an undergraduate intermediate (Level I, Year 2), transprofessional unit to be delivered to over 600 students in consecutive blocks of 300 from nursing fields, midwifery, social work and community development, occupational therapy, physiotherapy, operating department practice, and paramedic practice. The project implementation impacted directly on working practices within HSC and the wider University with key stakeholders including academics, programme leaders, the School's management team, and professional staff in advisory and support roles within the School and centrally, including web development, educational and learning technology, academic staff development, quality and enhancement and examination co-ordination. The scale of transformational change was immense given that all professional groups within the School were participating, with forty staff taking part as academic developers, champions and facilitators.

In the first quarter of 2011 the unit went live, facilitated by a number of resources including lectures, group work and a variety of web-based learning materials. Over five weeks groups of between five and nine students worked together on one of seventeen different case studies initially exploring evidence from poems, stories and qualitative research (what might be expressed in a metaphorical way as 'knowledge for the Heart'); then exploring quantitative research and policy ('knowledge for the Head') and finally considering how the evidence could be integrated with their other studies and own experience to inform their practice ('knowledge for the Hand'). This was supported by podcasts describing research terminology and student managed guided learning activities. Students wrote weekly individual blogs and a final group blog which was assessed (50%) and also undertook an online multiple choice examination (50%) during the final week of the unit. By building a lifeworld framework which informed and incorporated rational 'Head' knowledge it was felt students were more likely to develop the confidence to draw on evidence not only from research and policy documents, but also to value the stories of service users and their own human experiences to create the

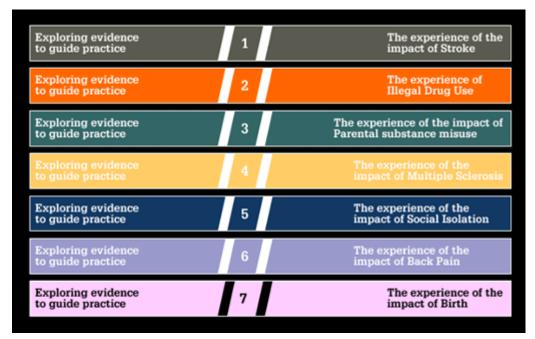
judgment-based care (Polkinghorne 2004) needed in complex caring situations.

## 4. Case Study Development

Central to the overall philosophy of the unit was the creation of seventeen different web-based case studies (Figure 2 and Figure 3) which included the human experience of the impact of specific illnesses (such as stroke and living with dementia) and more general experiences (such as social isolation and homelessness). A wide variety of cases was required to cope with the large cross-section of health and social care students taking the unit:

- EVP 01 The experience of the impact of Stroke
- EVP 02 The experience of Illegal Drug Use
- EVP 03 The experience of the impact of Parental Substance Misuse
- EVP 04 The experience of the impact of Multiple Sclerosis
- EVP 05 The experience of the impact of Social Isolation
- EVP 06 The experience of the impact of Back Pain
- EVP 07 The experience of the impact of Birth
- EVP 08 The experience of the impact of Learning Difficulties
- EVP 09 The experience of the impact of Mastectomy
- EVP 10 The experience of the impact of Long-term Skin Conditions
- EVP 11 The experience of the impact of Type 2 Diabetes
- EVP 12 The experience of Fall Management in the Elderly
- EVP 13 The experience of the Management of Fever in Young Children
- EVP 14 The experience of the impact of Spinal Cord Injury (knowledge for Occupational Therapy)
- EVP 15 The experience of the impact of Homelessness
- EVP 16 The experience of the impact of Dementia
- EVP 18 The experience of the impact of Spinal Cord Injury (knowledge for Paramedic Practice)

From the beginning of 2010, academic champions for each case study were identified and invited to complete a pro-forma with their initial ideas. They were prompted to look at *The Carer's World* as this might give them some useful ideas on how they might want their case to be designed. Academics were also advised that at the beginning of the creative process, the information supplied and the layout or design was not finalised, so that they could build their case studies iteratively before the actual live date. They were also requested to include a narrative from the person's perspective which could be written, or be from a video clip from Healthtalkonline (2011) or another similar resource.



**Figure 2 –** Case List (EVP 01 – EVP 07)



Figure 3 – Case List (EVP 08 – EVP 16, EVP 18)

The clips could be supplemented by the use of short extracts from films which had been on television or from television or radio documentaries that were about the wider issues in the case. Poetry or extracts from literature or diaries or images could be used, with the only limit being the imagination. The aim was to build up knowledge from many sources around the central narrative. The sources also needed to include three or more academic articles with a variety of quantitative approaches and three or more academic articles using qualitative approaches to highlight peoples' experiences and perspectives, the film clips and poetry as well as links to any interesting policy documents and relevant websites (such as associated charities or organisations).

Basic HyperText Mark up Language (HTML) - a language used to construct, arrange and present text and graphics through a user's web browser - was used for the creation of each case study. Internal audio visual elements were supported by using Apple's Quicktime technology for video clips and the MP3 audio file format - based on MPEG technology which creates a very small file suitable for streaming or downloading over the Internet - for audio clips and podcasts. Once all cases had been drafted, the central project team were able to look at each in turn and suggest changes, to ensure that the student experience would be equitable whichever case students studied. Individual sections of each case were continuously revised and redrafted before the live date to ensure there was an acceptable level of standardised content across each one.

## 5. Case Study 16: The experience of the impact of Dementia

Focusing on Case Study 16 - The experience of the impact of Dementia (Figure 4), this paper will now discuss the individual case components in depth.

The *Homepage* of each case serves two purposes: aiming to guide the user simply and effectively to the various learning tools and also highlighting a current campaign about the topic under discussion - in this case "Putting Care Right" (Alzheimer's Society 2011), a campaign to ensure that people with dementia have access to good quality care whether at home, in a care home or on a hospital ward.

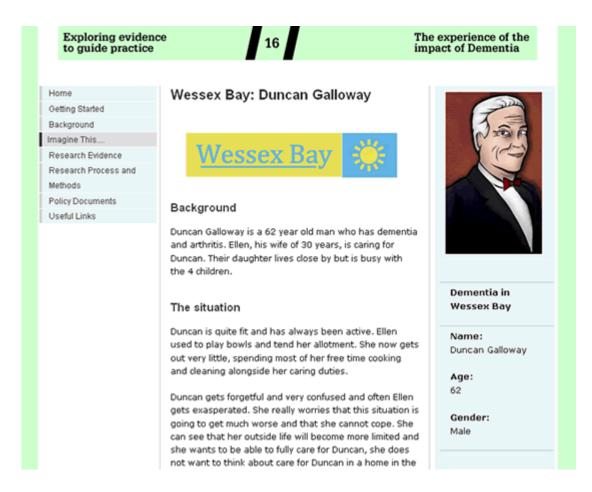


Figure 4 - Case 16: Part of the "Imagine This" Section

# 6. The Getting Started section sets the scene, describing what students will be experiencing:

- Learning about a range of issues in dementia.
- Watching and listening to video clips of people talking about their experience.
- Imagining what it might be like caring for someone they loved who had dementia and imagining what it might be like for the person with dementia, through a range of immersive materials.
- Imagining what dementia might feel like by reading Haiku poetry written by people with dementia.

This section also discusses the other parts of the case study and reminds students of the three qualitative and three quantitative papers that they need to read to support their experience and understanding. The *Background* section contains introductory information on the condition or situation - in this case a definition of dementia and some suggested additional reading, which includes journal articles and fact sheets from the Alzheimer's Society. For each case, these might be demographic papers, research pointing to the extent of the situation or condition and the difficulties it presents, or scientific, biomedical information about the case/condition, where relevant.

The focal point of each case study, the *Imagine This* section is where as well as resources there are a number of scenarios that are aimed at giving students insight and information on the experience of the impact of dementia. For this case study there are four different scenarios and a learning activity involves choosing one particular scenario to investigate in more depth.

The first scenario contains a character from Wessex Bay (Pulman, Scammell and Martin 2009) and is an extension of the theoretical approach previously used during the IPE curriculum. The character of Duncan Galloway (Figure 4) is a 62-year-old man who has dementia and arthritis. Ellen, his wife of 30 years, is caring for Duncan and their daughter lives close by, but she is kept busy with her children. A situation is described and students are asked to consider what can be done at a particular moment in time. In this case, Ellen sees that her outside life will become more limited and she wants to be able to fully care for Duncan - she does not want to think about care for Duncan in a home in the longer term.

The second scenario features the first person to be diagnosed with Alzheimer's - Frau Auguste Deter, a 51-year-old woman who was admitted to hospital and examined by Dr. Alois Alzheimer. Because of her age, Deter was diagnosed with presenile dementia; today, the diagnosis would be early-onset Alzheimer's Disease, which is defined as development of the condition before the age of 65. Frau Deter died in April 1906, aged 55. Psychiatrists rediscovered her medical records in 1995, in archives at the University of Frankfurt. The 32-page file contained her admission report, and three different case histories, including notes written by Alzheimer himself. An extract from the file, written by Alzheimer in 1901 is highlighted and the students are asked to imagine themselves back in that time and consider their reflections on his notes.

The third scenario concentrates on five different *Visions of Dementia*, portrayed through audio-visual materials that can be experienced by students:

- Malcolm and Barbara A Love Story (Watson 1999) won critical acclaim for the moving account of Malcolm and Barbara Pointon who had their lives radically altered when Malcolm developed Alzheimer's. Paul Watson's film told the story of how love sustained a relationship in even the most difficult of times. After spending eleven years with the couple, Malcolm and Barbara Love's Farewell (Watson 2007) followed Malcolm as Alzheimer's took control of his body, mind and marriage. This second film followed Malcolm just after he was diagnosed with the disease aged 51 through to his final conscious moments.
- Being Together (Cash 2009) is a film produced by Marilyn Cash who has worked with older people in both the voluntary and statutory sectors; in social care and as a researcher. Her research explores how the findings of qualitative research could be utilised to improve the quality of life for people with dementia and their carers. Being Together was made as part of Marilyn's PhD from Bournemouth University and relates to the experience of living with dementia from both partners' perspectives in a relationship.
- A Sweeter Pill To Swallow Beryl's Story (Richardson 2002) is a documentary, which tells the personal story of Mervyn Richardson's fight to get a prescription of Galantamine for his wife Beryl, who was diagnosed with Alzheimer's disease. An exposé of the immense difficulties faced by Alzheimer's disease sufferers and their carers in obtaining anti-dementia medication, the film highlights the first patient in Dorset to receive an NHS prescription for Galantamine, a drug that Mervyn would like to encourage.
- Ex Memoria (Appignanesi 2006) takes the viewer through a day in the life of Eva, putting them face to face with her experience of old age and dementia. In 2003, the director Josh Appignanesi wanted to make a short film based on his experiences of visiting his grandmother a Jewish refugee in a care home, when she had dementia. During the war, she had lost touch with her brother and his fate was never discovered, which became a key theme in her experience of dementia. The resulting film has been distributed to careworkers, residential home managers, charities and specialists in the field, as part of a Wellcome Trust scheme.
- The Lion's Face (2011) is a tale of love, loss and family with music by Elena Langer and words by Glyn Maxwell. When a man loses his way home it signals an irreversible return to childhood. Compassionate, heartfelt, strikingly dramatic and often witty, the work is an original, richly-textured story on ageing, memory and the incomprehension of getting old in the minds of the young. Working in partnership with Professor Simon Lovestone and his team, the Opera Group developed the opera over the course of two years to find a way of creatively exploring the experiences of the person with Alzheimer's, their carers and a research scientist. A BBC Wales news report on the drama and a link to the company's website offer a different perspective rather than featuring the actual opera.

The fourth scenario offers a viewpoint of dementia from the world of poetry. Haiku poetry celebrates the beauty of the ordinary moment. Derived from the Japanese tradition, it is characterised not only by simplicity, but also by reverence for nature. Haiku is one of the most important forms of traditional

Japanese poetry, and is, today, a 17-syllable verse form consisting of three metrical units of 5, 7, and 5 syllables. Philomene Kocher began writing haiku in 1991 and her work has been published internationally, most recently in a Canadian haiku anthology (Kocher 2008). In 2008, she completed her Master of Education studies in which she explored haiku as a way of connection with persons with dementia. Her haiku can be read by students in the September 2007 archives of a haiku website.

The Research Evidence section of the case study provides direct library links to PDF versions of the three qualitative (evidence that gives a rich perspective of the condition or situation) and three quantative (findings about the condition or situation which are technical evidence) papers which each student needs to access during the unit. Students are required to compare, explore and learn from a range of published research evidence embedded within a practice issue relevant to their field and consider how these research studies could usefully guide practice.

From the Research Process and Methods section, students can access a range of supplementary resources and material to facilitate their learning about research approaches and methods. There are links to a *Thinking about Research* guide - a web based resource which provides an overview of the research process and acts as a reference document to introduce students to core terms and differing research processes. There are also links to 45 short podcasts designed for students to listen to, in conjunction with other unit materials. The podcasts feature professors discussing and explaining a variety of key research approaches, methods, and aspects of the papers that students would be accessing in their case study. Students are also able to access a range of *Policy Documents*, which are relevant to their case and additional interesting information in *Useful Links*. In the dementia case study this included links to show students what charities and national and international agencies have been focusing on in relation to dementia, such as The Alzheimer's Society and the Social Care Institute for Excellence's Dementia Gateway.

#### 7. Evaluating the Impact of Integrating Lifeworld with Technology

Early indications from group blog postings undertaken during the first and second blocks of the unit highlighted the powerful effect that the dementia case study materials had on student perceptions and emotions. One student felt that although it was important to learn the facts of dementia, to understand the illness through the eyes of someone with the condition was an important opportunity as understanding patient's fears and how their life changed and how they coped with those changes were very important to the way that individual health professionals cared. Another student had not personally worked with someone with dementia or looked closely into the condition itself and was shocked at how little they actually knew. They had expected the primary caregiver to experience feelings of anger, stress, upset and confusion, but reflected that to watch the person with condition go from an active, happy, loving person to an aggressive person that could do very little for themselves in a short space of time as portrayed in Malcolm and Barbara - Love's Farewell (Watson 2007) was shocking and hard hitting. The film Ex Memoria (Appignanesi 2006) affected another student concerning the sort of care that some people received, and how important it was to think about the person behind the disease. They found that many of the resources had reminded them of a particular person they'd met or looked after in the past, and that this had affected them more than some of the other narratives had. When one student attempted to imagine what it was like, they felt quite upset because even after years of trying to understand the disease they acknowledged that it was still forgotten that, regardless of the condition, people with dementia were first and foremost individuals. They reflected that this feeling would guide them in future practice to always see the person behind the condition. These impacts were also noted in the other case study group blog postings.

The student experience of the unit was also monitored and evaluated by means of weekly deployment of questions using the ARS (audience response voting system) and an end of unit online evaluation completed by students following their online exam sittings (first block n=301, second block n-243). A staff focus group (n=12) was also conducted with academic champions and developers interested in, or contributing to, the unit. This evaluative data (Hutchings et al. 2011) showed that students appreciated the relevance of different kinds of research evidence for their practice and the value of engaging with service user and carers' stories:

The qualitative evidence stood out for me as I began to empathise with the patients. I was able to understand their thoughts and feelings, and began thinking of how this can be applied to practice.

They also appreciated the integration of lifeworld-led theoretical perspectives:

I just really loved the idea that the evidence comes from the arts and humanities as well as the sort of traditional research evidence.

The introduction of technology mediated learning also affected the roles of academics as developers, champions, and facilitators, demonstrating role transitions, from unit teachers and research staff to resource developers, from uniprofessional programme leads to transprofessional champions, and from research-focused professoriate to unit facilitators. Possible impacts on working practices and changing roles were identified by staff:

The model of the unit challenges the traditional way in which we have viewed how we carve out our time as academics and teachers. I'd quite like to develop a case study so how does that fit with my role in the rest of the world of my work. It's not a case of contact hours, but it's about what role do I play?

Staff also felt the technology would change how they interacted with students. One of the case study developers described how she felt distanced from the body of knowledge she had created and concerned the facilitators would do justice to her work:

I feel slightly detached now which has been quite difficult. It's like giving birth...! Well there you go and look after it and make sure that you get across what I want you to get across.

#### 8. Conclusion

Murray (1997) felt that the right stories could open hearts and change who we were. By exploring narratives and qualitative research (to obtain 'knowledge for the Heart'); exploring quantitative research and policy ('knowledge for the Head') and then reflecting on how that evidence could be integrated with other studies and their own experience to inform practice ('knowledge for the Hand') it is hoped that this unique lifeworld led approach will continue to assist and benefit health and social care professionals of all disciplines in their holistic understanding and further help them to guide and improve theirs and others future practice. Especially in helping to increase the levels of empathy and dignity in health and social care.

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