Joining the dots: Managing diabetes and schizophrenia

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The missing link
Could repurposing existing drugs help manage multiple conditions?

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Our ability to gather high quality evidence is crucial to filling the gaps that exist in our understanding of multimorbidity, and how we best help people who are trying to manage multiple conditions at the same time.

Professor Peter Bower

Lead for the Centre for Primary Care and Health Services Research at the NIHR School for Primary Care Research, University of Manchester, Health Services Research National Specialty Lead for the NIHR CRN

This is a crucial time for the NHS and social care. As a population, we are living longer, and more and more people are managing their lives with more than one long-term condition – multimorbidity.

However, our healthcare system is built on a diagnostic framework based around single health conditions that has shaped how we think about health and care delivery in the UK for many years. It hasn’t just been our health and care services that have been shaped by the single condition framework – research has also followed a similar model, focusing on particular diseases and doing research with strict exclusion criteria for taking part. This has meant that having more than one health condition automatically excluded many people from taking part.

So we need to begin to think carefully about how we re-design health and care for the people that use it most. Change is needed, but how do we achieve change in services that are already working at capacity? Clearly, research is key. Our ability to gather high quality evidence is crucial to filling the gaps that exist in our understanding of multimorbidity, and how we best help people who are trying to manage multiple conditions at the same time.

Managing patients with multimorbidity highlights the importance of a generalist approach to health, and that means ensuring that primary care is at the centre of our research. We also know that multimorbidity develops much earlier in patients living in areas of deprivation. This means it is important that our work takes account of the wider context in which our patients live, and that we include patients and communities in our research and communicate in a way that makes sense to people.

In the magazine you will discover some of the pioneering research that is being done by your colleagues. Research like this will ensure that we can support a successful future for the NHS, public health and social care, and make a genuine contribution to the lives of people in the UK. We know that multimorbidity research is not as well developed as it needs to be to meet the challenges we face. However, this is a great motivation for us to concentrate our efforts, start talking the same language, and get our research right. Without this, we won’t be able to influence the policy makers and decision makers and improve our healthcare system. This won’t come without its challenges. Working in a collaborative way provides us with an opportunity to share expertise and experience from different disciplines and communities, and rapidly grow what we know about improving the lives of patients with multimorbidity.

I hope that the articles in this issue of VISION inspire you to take part in this exciting research agenda.

Foreword by Professor Peter Bower
Research provides a powerful tool to help us understand how we cope with, and treat, multimorbidities and is key to learning how we need to work in the future. I’ve been involved and interested in research since my training at King’s College in London, and the evidence is strong that if you practice clinical research, you treat patients better and you’re more likely to deliver good quality care: something every clinician is striving for and an essential ingredient when managing and treating multimorbidities.

We’ve been aware for a while that there seems to be a link between inflammation in the body and disease in many organs, with inflammation increasing heart attacks, strokes and reducing cognitive function, but we needed to explore the area to provide a fuller evidence base around these issues. This may also explain how drugs used to treat rheumatoid arthritis may also improve Alzheimer’s disease.

Professor Clive Holmes from the University of Southampton has been researching dementia for a long time, so it seemed a logical step to team up with him alongside Dr Bernadette McGuiness from Queen’s University in Belfast, who also has an interest in Alzheimer’s and dementia.

Developing levels of understanding between us of how multiple long-term health conditions affect one another and how that could influence treatment for the future, is key to unlocking evidence that has the potential to impact a lot of lives. There are common mechanisms across a lot of different diseases and understanding these will help us to create studies and trials that make a difference to what we know and what we do.

RESIST STUDY

For the RESIST study, I am working alongside Professor Clive Holmes and Dr Bernadette McGuiness to explore the potential for medicines used to treat people with rheumatoid arthritis to slow down the effects of cognitive decline in patients.

It’s an exciting prospect – there hasn’t yet been a major medical breakthrough for the treatment of dementia so there is potential for us to provide more answers on the links between the two diseases.

RESIST is an observational study, where we have two sets of patients on two different types of rheumatoid arthritis drugs – conventional drugs including Methotrexate and biological drugs called TNF inhibitors that target inflammation.

The patients take a cognitive function test at the beginning of the study and then again after 18 months to see the comparison between the two results. 350 people will be recruited to the study across Southampton, Belfast and Antrim. Recruitment closes at the end of October 2019, so we won’t see the results for a while, but I am looking forward to analysing the data. If we see positive results, then it would be a constructive step in establishing a randomised clinical trial to gather even more data.

Awareness around research like this is essential for understanding its potential impact. Using drugs that already exist to treat conditions that they were not originally designed for, could have cost benefits for the NHS alongside health benefits for patients. It could transform the way we plan care for patients with multimorbidities and change the way we diagnose patients.

RESEARCH IS KEY

Research, even when the results aren’t quite what we expect, helps point us towards pathways for discovery and treatment of conditions and underpins how we work, how we diagnose and how we treat conditions. Historically we, as clinicians, have divided ourselves into specialties based on particular diseases rather than the underlying mechanisms of the diseases.

With the research being performed and the discoveries that are being made, we are potentially looking at the establishment of new pathways of patient care that ignore the traditional speciality boundaries where we look at genetics and common mechanisms in different diseases rather than singular diseases, isolated from each other. By looking at these genetic overlaps and the links in between them, there is potential to assist future diagnosis by identifying patterns and risks before symptoms occur. If we can raise the awareness of connected conditions then it will help to prevent some conditions from occurring and to better manage those that are developing.

Connecting and collaborating with organisations, pharmaceutical companies, clinicians and researchers is essential for moving our research forwards and reaching conclusions that benefit patients and the NHS.

RESIST is an observational study, medication and memory STudy (RESIST TNF) is funded by the Alzheimer’s Society and sponsored by Queen’s University Belfast. It is an NIHR CRN portfolio study.
It was around 18 years ago that we started clinical studies examining the link between peripheral inflammation and infections in Alzheimer's disease in Southampton. We conducted an initial retrospective pilot study of 85 patients with Alzheimer’s disease and then a larger study of 300 patients followed prospectively over six months and we found that there was a link between ordinary infections, like chest or urinary tract infections, and a permanent three to ninefold increase in memory decline in those patients. We also looked at the effect that gum disease had on patients with Alzheimer’s, and the results indicated a similar impact.

Ordinary infections that healthy people fight off, appear to have a dramatic negative impact on patients with Alzheimer’s. We think that this is to do with the protein TNF that is produced by the body when an infection is identified – it sends a signal to the brain that almost hyper-exciites the cells. In a healthy person, this wouldn’t be a problem. But in patients with Alzheimer’s, it destroys brain cells and this is why their cognitive functionality declines so rapidly when they have had an infection.

We began to explore ways that might allow us to block this protein, preventing it from causing additional damage to the brain and potentially slowing down the advance of Alzheimer’s and the decline of patients. Our research into this protein lead us to the potential of the drugs, TNF inhibitors, that are used in the treatment of rheumatoid arthritis. We wanted to know if there was potential for the drugs to slow down the inflammation in the brain caused by the protein. We have already performed a pilot randomised placebo control trial (RPCT) of a TNF inhibitor in Alzheimer’s disease with encouraging results.

The results of the RESIST study, I hope, will lead us closer to the clear evidence that these drugs, currently used in conditions such as rheumatoid arthritis, can slow down the progression or development of Alzheimer’s. The more research we are doing, the more we are learning about the links between the condition and other health issues that impact upon it.

A future where we have drugs that can be used to treat multiple conditions is exciting but in the short term, there are some simple steps we can take to help manage multimorbidity. In the case of Alzheimer’s and the link between infections and deterioration, better plans to manage and treat infections are key. Mild infections and their symptoms are often overlooked; sometimes misdiagnosed and their potential effects often underestimated.

We need to focus on better equipping our GPs with knowledge and support so that they can become the first pillar of successfully managing multimorbidity. They are a vital gateway for helping us spot links between conditions and how we can treat them together.

Treating multimorbidity is like putting together pieces of a giant jigsaw puzzle – we’re constantly learning about the body and why it behaves the way it does. By collaborating across specialisms we can unpick common themes which will help us to manage and treat multiple conditions far more easily than we do now.

As our research continues, I hope that our collaboration can extend to drug companies to ensure that this research goes further and is explored to its fullest potential.
Dr Christopher Kipps is a consultant neurologist and a divisional lead for NIHR CRN Wessex. More recently, together with Professor Roxana Carare, he leads the Interdisciplinary Dementia and Ageing Centre (iDeAC), a network of researchers and clinicians in Southampton, who are focused on interdisciplinary collaboration across the clinical pathway in order to increase research opportunities for an ageing population living with dementia.

iDeAC is a joint initiative sponsored by the Institute for Life Sciences at the University of Southampton in partnership with University Hospital Southampton and other NHS partners.

More information about the Centre can be found by visiting www.ideac.org
A MISSION: TO IMPROVE RESPIRATORY CARE

Jayne Longstaff and Emily Heiden are part of the MISSION ABC team. Alongside colleagues in the Research and Innovation department at Portsmouth Hospitals NHS Trust (PHT) and primary care, Jayne and Emily have been leading the delivery of a series of research projects aimed at improving the care pathway for patients living with respiratory conditions.

CURRENT CARE PATHWAY

Jayne explains: “The concept was to look at the current model of care for patients with long-term conditions. In particular, we looked at the journey for patients with poorly controlled asthma. Treatment optimisation can take up to two years for patients with severe disease. Our aim was to streamline the service between primary and secondary care, in order to provide an accurate diagnosis and comprehensive management plan for patients with respiratory conditions whilst ensuring patients remained the focus.”

Emily adds: “Patients currently face a number of challenges when accessing healthcare. Through the delivery of the MISSION ABC project, we identified and addressed a number of issues to improve the patient experience. Examples included ensuring patients could access the clinics in their local vicinity and improving communication between patients, their families and healthcare professionals in primary and secondary care.”

THE MISSION ABC STUDY

MISSION ABC was a new and novel way of delivering highly specialised care for patients with asthma, Chronic Obstructive Pulmonary Disease (COPD) or undiagnosed respiratory symptoms. Jayne describes the process of proactively identifying patients with undiagnosed respiratory symptoms or those with poorly controlled disease by using electronic GP patient registers.

Jayne says: “Patients were invited to attend a comprehensive medical assessment of their condition to help improve their disease control and quality of life within a GP practice local to them. The model has changed the way services for patients with respiratory conditions are currently delivered and is easily transferable to other long-term health conditions.”

Emily explains, “Initially, patients attended a rapid clinical review. They were reviewed by the multidisciplinary respiratory team using a carousel-style clinic process. Each patient was reviewed by a specialist respiratory nurse.”

“The model has changed the way services for patients with respiratory conditions are currently delivered and is easily transferable to other long-term health conditions.”
physiologist, physiotherapist and physician. All patients had their diagnosis confirmed, their treatments optimised and personalised management plans discussed. Families and friends were encouraged to attend the clinic for ongoing support and primary care staff were invited to partake in the study to ensure consistency of care.

Jayne adds, “Education for healthcare professionals and patients was a priority to ensure patients were empowered to take ownership of their health and to improve the confidence and knowledge of healthcare providers. Patients felt really privileged that a team of specialists wanted to spend time looking after them and felt better equipped to manage their symptoms in the future.”

Jayne says, “After their review, patients and healthcare professionals were overwhelmingly positive and we had some incredible plaudits. Many described how MISSION ABC had changed their lives for the better. One particular patient said, “It’s the best care that I’ve ever had and, having it all under one roof, it was just incredible.”

BENEFITS OF RESEARCH

Jayne explains, “Everybody should take part in research because, without research, how would we develop the NHS? People often think of research as taking part in a commercial study and that it can involve invasive procedures or taking new medications, but it’s not. The Research and Innovation team at PHT deliver a number of different studies in a variety of conditions, which may involve simply completing questionnaires, testing new technologies or taking part in quality improvement studies. Research doesn’t necessarily have to be in a hospital setting. It can be anywhere – in your GP practice, in a pharmacy or even at home. “Taking part in research can have a phenomenal impact. There are changes that you can make, not just for the NHS or for the future, but also for your own care.” Jayne adds, “Research has changed people’s lives for the better.”

MISSION ABC’S LEGACY

Emily concludes, “A key part of MISSION ABC was delivering sustainable respiratory education and leaving a legacy of understanding for both patients and healthcare providers. MISSION ABC’s success has inspired several sustainable projects nationally. These include the development of long-term condition hubs that are aimed at supporting patients with long-term conditions, based on the MISSION ABC model.” The results of MISSION ABC are expected later this year. In the meantime, the team have been busy developing a website to share what they have learnt. You can find out more about MISSION, including patient testimonials and video content, at https://missionabc.uk/.

“Patients felt really privileged that a team of specialists wanted to spend time looking after them and felt better equipped to manage their symptoms in the future.”
JOINING THE DOTS: 
MANAGING DIABETES & SCHIZOPHRENIA

CHALLENGING THE SYSTEM

Managing multimorbidities is an evolving challenge for the NHS, and something that we are having to adjust to rapidly in order to manage conditions and their impact on the healthcare system.

My role and training as a diabetes & endocrine registrar allows me to react to patients’ needs and manage their symptoms with what we have currently, but I decided to take three years out from clinical practice to pursue the opportunity to do research at Southern Health NHS Foundation Trust. It’s allowed me to explore the potential and possibilities of what we could do to improve and change the management of multimorbidities. This is a tantalising insight into what the world of the healthcare system could look like in the future.

We’ve been investigating the link between type 2 diabetes and schizophrenia for many years. We still cannot say definitively why the two conditions are closely linked but we are aware of the challenges that occur in managing both conditions simultaneously and the importance of therefore trying to prevent people with schizophrenia from developing type 2 diabetes.

Alongside a potential genetic link between the two illnesses, people who are diagnosed with schizophrenia tend to withdraw following their diagnosis. They can become apathetic, stop exercising, lose their jobs and begin eating foods that are higher in fat and less nutritious. This can have an impact on their weight, which can then lead to diabetes. The antipsychotic drugs they may be started on can also contribute to significant weight gain for some patients.

The Stepwise study looked at whether a lifestyle intervention could encourage people with schizophrenia to introduce lifestyle changes through advice and support to help them manage their weight effectively. Unfortunately, the study didn’t see any impact on the weight of the individuals taking part, so we wanted to explore more methods of supporting weight loss in individuals with schizophrenia.

“It’s recognising and acknowledging the need for mental healthcare and physical healthcare to be treated with equal importance and equipping staff with the skills to cope with patients with multiple health conditions.”

Currently, people with severe mental illness are often excluded from participating in medical trials for physical health drugs. This means that there is often a data gap when it comes to knowing whether or not certain drugs would have a positive impact on their health and clinicians may therefore be more reluctant to use them once they are licensed. We wanted to change this and begin to fill the gap so that we could establish a baseline with the potential to change lives.

LOSE WEIGHT STUDY

We established the LOSE Weight study to help us answer some of the unknown questions around managing schizophrenia and weight. We already had an understanding that current lifestyle interventions haven’t been successful in managing weight, so we wanted to explore a pharmacological option alongside lifestyle advice.

The drug Liraglutide has been used among people with diabetes and has been successful at reducing weight. It has also been approved for use in managing obesity but isn’t currently available on the NHS due to its cost. The drug has been approved for use in schizophrenia and weight. We already knew that it would present a challenge – traditionally retention in weight loss trials can be difficult to maintain. Adding a serious mental illness to the mix may also make it more difficult to retain participants and encourage them to sign up. The trial opened in July 2018 and will run until the end of October 2019 and we currently have 34 people in the trial, some on Liraglutide and some in a placebo group. Exceeding our expectations, we’ve only had five people drop out of the study so far.

The results won’t be analysed and released until April 2020, but we have seen a number of people on the trial losing weight. We can’t yet attribute this to Liraglutide, but we’ve already seen the improved quality of life this weight loss can have for the individuals involved.

What we’ve also discovered is that studies like these are incredibly important at breaking down barriers within healthcare and looking at patients holistically. It’s recognising and acknowledging the need for mental healthcare and physical healthcare to be treated with equal importance and equipping staff with the skills to cope with patients with multiple health conditions.

Managing multimorbidities is about looking at the long term.”
THE IMPORTANCE OF MANAGING MULTIMORBIDITIES

On average, people with schizophrenia and psychosis die 15-20 years earlier than the general population and not because of suicide. The biggest cause of death among people who have schizophrenia or psychosis is cardiovascular complications. This link between one health condition having an impact on another is hugely important for the future of the NHS.

We need to get better at understanding the links between health conditions and being able to communicate these effectively to our patients, the workforce and policy makers. There is a tendency to become short-sighted with healthcare, reacting to an immediate problem or looking for a short-term impact or saving. Managing multimorbidities is about looking at the long term.

It’s about preventing them from occurring in the first place, by offering interventions like the LOSE Weight study. And that’s a difficult balance to achieve. Many clinicians are reluctant to step away from clinical practice, so offering ways for them to become involved in research while still being able to practice is essential to gaining valuable insight and understanding of the research world.

Research and clinical practice need to find a common ground where we’re all working towards a longer term goal. As managing multiple long-term health conditions becomes the norm, the future of the NHS depends on it.

The LOSE Weight study, which is part of the NIHR CRN portfolio, is sponsored by Southern Health NHS Foundation Trust.

“...a difficult balance to achieve. Many clinicians are reluctant to step away from clinical practice, so offering ways for them to become involved in research...”

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THE IMPACT OF FRAILTY

As a population, we’re all getting older. It’s becoming more and more common that we’re seeing patients living with multiple long-term health conditions.

Frailty is now being seen more as a long term condition on its own. There are five frailty syndromes that are linked to frailty and can often be warning signs that immediate action is required. The frailty syndromes are falls, a recent decline in mobility, confusion or delirium, a sudden change in continence and a sensitivity to new medication.

It’s important that we recognise frailty and as healthcare providers we need to understand how to screen for frailty and assess the needs of the individual living with frailty. If we can identify frailty in the earlier stages, then we can help to ensure that the person living with the condition understands how best to stay well.

The link between multimorbidities and pressure on the NHS is well proven and frailty is a key focus for the NHS because of this. The care of people with long term health conditions accounts for 70% of expenditure on health and social care in England, so it’s vital we begin to do something about this and explore the ways in which we can reduce the pressure and improve our patients’ lives at the same time.

Giving patients knowledge and understanding about their condition can improve their decision making powers, allowing them to feel in control and more likely to take positive steps towards managing their health condition rather than reactively coping.

SUPPORTING GPs

I have just begun a forerunner project to see if early intervention can reduce admission to hospital for those triggering a frailty syndrome in primary care. Admission avoidance is an important way to reduce expenditure in the NHS but also an important way of making our patients happier. This is especially important for those living with frailty as we know that any period of reduced function can have a high impact on recovery. Given the choice, most patients would choose to be at home but the lack of awareness on how to manage their conditions effectively, and the lack of provision currently available to help them, impacts that.

Delivering this care for someone living with frailty is important because through early intervention we are hoping to reduce the impact of an unnecessary hospital stay. By providing an early intervention we can gain a clinical history and arrange diagnostics like blood samples and we will assess the individual taking a comprehensive geriatric approach that looks at physical and mental wellbeing, care needs and prescribing medication if necessary.

Performing a holistic consultation like this allows us to have vital conversations that we can follow up as part of this project. We visit the patient again and make decisions on whether we feel our recommendations and treatment are making a difference, all done at their home. It allows us to reassess them, keep them out of hospital if we can and be more proactive and positive in the way that we manage their health conditions.

ASSessing THE IMPACT

We share our clinical findings closely with our GP colleagues via a shared system, so we both have access to records and can
monitor and discuss progress. We also talk daily with GPs to ensure nothing is being missed. Initial feedback has been positive, we will be reviewing the trial at three months and then again upon its conclusion at six months.

Gathering patient experience data, as well as analysing admission avoidance statistics and GP experience of the service, will help us gauge how successful the trial has been and whether it could become a viable model for future local commissioning. There are a lot of important conversations to have around the service and what it would look like if it were to be commissioned. Who would we need? What would it look like? What is the impact on the workforce?

Projects like these are not just important for reducing admissions and achieving greater patient satisfaction, but they also help us to understand and shape our workforce for the future. As nurses, we hold so much clinical knowledge and experience that roles like mine are vital to the future of the NHS.

I’m currently involved in a three-year research project with the University of Southampton, assessing the dynamics of frailty in old people and how this will impact healthcare demands and inform planning and commissioning. Both this study and my own is giving nurses a vibrant voice within clinical research, and also paves the way for other nurses to do the same.

“Delivering this care for someone living with frailty is important because through early intervention we are hoping to reduce the impact of an unnecessary hospital stay.”

It’s essential for the NHS that nurses’ roles keep diversifying, without taking the emphasis away from their clinical capabilities. It’s also essential for the lives and health of our patients, who will benefit from our skills and insight. With the right support in place, nurses can begin to make a much larger impact on our healthcare system.

The NIHR has recently funded the 70@70 Senior Nurse and Midwife Research Leader Programme. This three-year programme hopes to raise the research voice for nurses and midwives and encourage those who are currently taking on research responsibilities to become research champions.

Encouraging and developing research among nurses and midwives across their organisations and promoting a research culture to improve healthcare will begin to pave the way for nursing-led research to become an everyday part of the NHS.

It is hoped that the programme will encourage more nurses and midwives to thrive in their careers but also grow our knowledge of patients and our understanding of treatment and provision for the future.

“Delivering this care for someone living with frailty is important because through early intervention we are hoping to reduce the impact of an unnecessary hospital stay.”

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Let researchers know you want to take part in their studies
Across Europe, around seven in ten people over the age of 65 experience either sight or hearing loss. Alongside this, over two-thirds of over 65s suffer from depression or other mental illnesses, including dementia.

Dementia is a general term used to describe a range of conditions that affect the brain and cause symptoms such as memory loss and changes in mood, judgement and movement. There are over 200 different subtypes of dementia, with Alzheimer’s disease and vascular dementia making up the majority of cases. When a person is affected by dementia in addition to hearing or vision impairment, the negative impact can severely affect their quality of life.

A new NIHR CRN portfolio study, funded by the European Commission and sponsored by the University of Manchester, is seeking to address the issues. Joanne Taylor, an older person’s mental health research nurse, led the delivery of the study for Solent, working alongside colleagues to form partnerships with local residential homes.

“We already had relationships with a number of local residential homes,” explains Jo. “My role was to make contact with all the residential homes in the region to ask them to be part of the study. I was organised in my approach and phoned, emailed and visited the residential homes to promote the benefits of participation in research. For example, if someone isn’t wearing their glasses and they fall over, it may be seen as being caused by their dementia rather than them not wearing their glasses. Or if they’re not wearing their hearing aid or it’s not on properly, again, it’s possible to think that it’s the dementia or hallucinations, when it could be simply that the hearing aid isn’t in or working properly.”

Current evidence shows that adults experiencing comorbid and sensory impairment are increasingly likely to feel disorientated and may have difficulties locating themselves. This can increase their distress, leading to an increased prevalence of hallucinations, delusions and depression. As a result, those affected can become more isolated and may find it difficult to participate in social activities and hobbies.

“The challenge faced by this group of patients,” explains Jo, “can be that they’re not always heard. They don’t always have capacity to consent which is an issue for research because it means that they’re not always included in studies. They’re very vulnerable and it can feel like they are forgotten about.”

Jo adds: “The results of this study are expected later this year. Depending on the outcome, it could lead to further studies or an intervention of some form. For example, if the surveys show knowledge gaps within the workforce, plans can be put in place to address this.”

I plan to share the study results with the staff, residents and families by producing a poster which can be displayed throughout the residential homes that took part. Now that the relationships with local residential homes are there, I think there’s potential for us to do further research together in the future.”

On the importance of continued research, Jo comments: “Research is so important. The more knowledge we have, the more power we have in terms of treating and eradicating. At Solent’s recent research conference, I heard a presentation from a researcher about how far we’ve come with our understanding of the causes of Alzheimer’s disease and how and why it develops. In 1985, research had identified one gene linked to immunity. I hope to be involved in further research including looking at immunity. I hope to be involved in further research which can improve outcomes for dementia patients and their families.”

The study, known as SENSE-Cog Knowledge, Attitude and Practice (KAP), is being delivered across Europe and internationally, including at five UK sites. Solent NHS Trust are the top recruiting UK site, exceeding their target of 40 to recruit 521 participants. Joanne Taylor, an older person’s mental health research nurse, led the delivery of the study for Solent, working alongside colleagues to form partnerships with local residential homes.

“We already had relationships with a number of local residential homes,” explains Jo. “My role was to make contact with all the residential homes in the region to ask them to be part of the study. I was organised in my approach and phoned, emailed and visited the residential homes to promote the benefits of participation in research. For example, if someone isn’t wearing their glasses and they fall over, it may be seen as being caused by their dementia rather than them not wearing their glasses. Or if they’re not wearing their hearing aid or it’s not on properly, again, it’s possible to think that it’s the dementia or hallucinations, when it could be simply that the hearing aid isn’t in or working properly.”

Current evidence shows that adults experiencing comorbid and sensory impairment are increasingly likely to feel disorientated and may have difficulties locating themselves. This can increase their distress, leading to an increased prevalence of hallucinations, delusions and depression. As a result, those affected can become more isolated and may find it difficult to participate in social activities and hobbies.

“The challenge faced by this group of patients,” explains Jo, “can be that they’re not always heard. They don’t always have capacity to consent which is an issue for research because it means that they’re not always included in studies. They’re very vulnerable and it can feel like they are forgotten about.”

Jo adds: “The results of this study are expected later this year. Depending on the outcome, it could lead to further studies or an intervention of some form. For example, if the surveys show knowledge gaps within the workforce, plans can be put in place to address this.”
BLENDING STORIES WITH SCIENCE

HOW COULD PALLIATIVE CARE IMPACT DIALYSIS PATIENTS?

People over the age of 65 have the fastest growing rate of chronic kidney disease, we are therefore seeing increasing numbers of older patients with poor function and greater comorbidity visiting our clinics. Other conditions like heart failure, depression and cognitive impairment are all common among this age group receiving dialysis, and this can result in an accelerated decline in their quality of life.

Treatments for end stage renal disease include haemodialysis, peritoneal dialysis, transplantation, or ‘non-dialysis’ conservative kidney management. Dialysis treatment has many inherent risks for older frailer patients with multiple comorbidities. In addition, the burdens of dialysis outweigh the benefits for some people. As a result, people may choose not to start dialysis and increasing numbers withdraw from dialysis before death.

In the UK, the emphasis has been on developing conservative management programmes for people who choose not to start dialysis. The focus of conservative kidney care is on detailed symptom assessment and management, advanced care and crisis planning and providing psychological, social and medical support. The practice and research developments in palliative nephrology have largely neglected the needs of people who choose to start dialysis and have a high symptom burden and comorbid illness. The emphasis is very much on disease and technologically focused care, making it difficult to change focus towards the end of life.

We wanted to know whether a palliative care approach would make an impact on patients living with chronic kidney disease and undergoing dialysis – would it improve their quality of life and facilitate person-centred decision making throughout the course of their illness? Current evidence shows that when a decision is made to discontinue dialysis, the average time from their last dialysis until death is seven to ten days. However, in patients with high comorbid illness this is likely to be even less. It is crucial that we identify people who may benefit from palliative care alongside their active dialysis treatment upstream in their illness trajectory in order to provide the best care.

”Developing different approaches to palliative care for patients with multimorbidity will help us to navigate the complex future of healthcare and the NHS.”

The current UK evidence base on dialysis withdrawal is very small and few studies have adopted a person-centred approach. I wanted to ask questions that will help us establish palliative care and dialysis withdrawal practice patterns. In addition, I wanted to examine variations in care, costs and outcomes for patients and families in relation to how they die.

QUALYCARE KIDNEY STUDY

The QUALYCARE KIDNEY study is designed to understand the patient experience in the last three months of life. We are exploring this using a mortality follow-back survey with bereaved relatives of dialysis patients that have died. Finding out the views of bereaved relatives is really important, it allows us to understand how they cope with their loss and grief and to get a population-based perspective on end of life care relating to a consistent time period close to the patient’s death.

We are discovering that relatives of patients want to help and share their experiences. By having difficult conversations around patients’ end of life experience and their care, which produces problems around grief and potentially causes distress. We spent considerable time deciding on the best design approaches that minimise the risks of distress and sensitive issues.

“Without this vital research we simply won’t know what we need to do to help our patients and their families to cope when facing end of life care.”

DR EMMA MURPHY

Lecturer, School of Health Sciences, University of Southampton and Advanced Nurse Practitioner, University Hospital Southampton NHS Foundation Trust. NIHR Clinical Lectureship award. The study has recently begun and will continue for six months. We are asking some difficult questions around patients’ end of life experience and their care, which produces problems around grief and potentially causes distress. We spent considerable time deciding on the best design approaches that minimise the risks of distress and sensitive issues.

The QUALYCARE KIDNEY study is funded by the NIHR and Health Education England (HEE) as a Clinical Lectureship award. The study has recently begun and will continue for six months. We are asking some difficult questions around patients’ end of life experience and their care, which produces problems around grief and potentially causes distress. We spent considerable time deciding on the best design approaches that minimise the risks of distress and sensitive issues.
As the NIHR Clinical Research Network Wessex, we provide the infrastructure that allows high quality health and social care research to take place within our area, for the benefit of patients and the public. We help to increase the opportunities for people to take part in research and ensure that studies are carried out efficiently. We are hosted by University Hospital Southampton NHS Foundation Trust. The Wessex region covers Hampshire, Dorset, Isle of Wight and south Wiltshire.

 SHAPE THE FUTURE

We hope that our data will help to grow an evidence base, which will then inform future service provision and national policy on end of life care for people living with chronic kidney disease and receiving dialysis. The study findings will form the basis of many discussions around costs, quality of care, preferences and palliative outcomes for dialysis patients – something which we simply don’t know right now. There are a handful of comparative observational studies that have shown that in patients over the age of 75 years there is a survival advantage with dialysis vs (non-dialysis) conservative kidney management, however, in patients with multiple comorbid illness this survival advantage disappears. This doesn’t mean these patients can’t choose to start dialysis but the approach should be very much palliative care alongside dialysis treatment to improve symptom burden, quality of life and facilitate decision making in line with patient preferences towards the end of life. A broader picture when managing long-term health conditions can only be a good thing. By blending clinical work and research we will be able to cross over services and the management of conditions, making it more convenient for patients and providing them with better care. Giving them greater options of treatments at home, for example, or giving them contact points for help will ease their worries or potential for distress during the last stages of their lives.

In order to manage patients with multiple illnesses I believe patients and families need someone to navigate their care. In addition, as a clinician I need to be able to navigate multiple health conditions and liaise with many different specialists and departments in order to provide the best person-centred care in line with the patient’s goals of treatment. Moving away from treating conditions in isolation from each other and developing different approaches to palliative care for patients with multimorbidity will help us to navigate the complex future of healthcare and the NHS.

 About NIHR CRN Wessex

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The QUALYCARE KIDNEY study is funded by an NIHR and Health Education England integrated clinical fellowship and is sponsored by the University of Southampton.

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local.nihr.ac.uk/1crn/wessex
studysupport.crnwessex@nihr.ac.uk
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Providing study support throughout Wessex

Our Study Support Service helps researchers and the life sciences industry plan, set up and deliver high quality research to time and target in the NHS and across the wider health and social care environment in Wessex.

We provide this service for all studies eligible for our support, regardless of location, study type, study size, therapy or research area. Whether your study is medical, diagnostic, pharmaceutical, bio-tech or is looking at healthy populations or people with social care needs, we can help.

In the last 12 months, we have:

- Trained 144 principal investigators
- Engaged with and supported more than 15 small and medium enterprises (SMEs)
- Supported local investigators to engage with industry
- Supported early engagement and the completion of the Schedule of Events Cost Attribution Template (SoECAT)
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