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The Journal of the Institute of Ageing and Health

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A note from the editor: Dr Bernie Keenan

In this edition of the journal, we are pleased to once again offer an eclectic range of multi-disciplinary contributors and of topics. These include Dr Martin Figgit & Dr Kashif Haq's work on the physiological impact of ageing on chronic wound care, Loren Bleaken & Claire Jones systematic review regarding best practice in physiotherapy rehabilitation techniques related to Parkinson's disease, Natalie Quinn-Walker's public health perspective on elderly victims of domestic abuse, and my own reflections on the complexities of undertaking research in the acute hospital setting.

I am particularly excited that this edition also reflects the service user perspective, with Dr Peter Mayer's very personal account of his experience of the challenges of working as a medical practitioner who has on-going mental health issues. Dr Catharine Jenkins & Claire J Roberts also offer a very moving account of the experiences of a family carer looking after a relative with dementia during the pandemic, which explores the issues of loneliness and isolation associated with the lockdown (O'Sullivan et al 2021), and the restrictions and disruption to services (Brooke 2022).

Editorial team: Dr Bernie Keenan (Editor) and Jeanette Lane (IAH Administrator)

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Or;

https://www.researchgate.net/publication/348565741_Comment_Will_the_pandemic_reframe_loneliness_and_social_isolation

Ageing and chronic wound care: The need for a new approach

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Abstract: Chronic wound infections are a major health problem with an increasing rate of 12 %, annually in the UK alone. This condition has huge impact upon the aging population and is linked to various underlying medical conditions such as diabetes. For these reasons it is important to better understand the wound repair process condition and how underlining health conditions impact upon wound micro-environment. Thus from these studies to develop more effective novel treatments, such as the use of bacteriophages.

Introduction:

In the UK, the prevalence of chronic wounds and non-healing wounds is increasing at a rate of 12% annually. This pathological condition has implications for an ageing population with various underlying medical conditions. The most common of these infections arise from diabetic foot infections, with a total healthcare expenditure estimated at billion pounds per year (Guest et al, 2020). The problem is further compounded by multi-drug resistant bacteria, such as methicillin resistant *S.aureus* (MRSA) infecting such wounds when patients are in a clinical setting, thus increasing lower limb amputations and mortality rates (Fridh et al.,2017).

Chronic wounds or hard to heal wounds are cutaneous wounds that fail to heal within 6 weeks (Tricco et al, 2016). There is a growing health care burden due to chronic wounds, it has been estimated in developed countries, that approximately 1-2% of population will experience difficult to heal wounds (Gottrup, 2004; Sen et al.,2019), increasing health care budgets between 2 - 4% (Frykberg and Banks, 2015). In the UK it is estimated, healthcare settings treated between 2.2 and 3.8 million chronic wound infections in one form or another 2018 (Guest et al. 2020).

There are several major causes of chronic wounds ranging from, vascular insufficiency also known as venous /arterial ulcers (VU/AU), diabetes mellitus, diabetic ulcers (DU) and local mechanical pressure ulcers (PU). Its estimated these aetiologies account for more than 90% of chronic wounds (Mustoe et al, 2006). Other systemic factors are involved in impaired healing, such as advanced age, malnutrition and underlying pathologies (Eming et al 2014). For example, Diabetes is an escalating global burden with 422 million diabetic patients worldwide (WHO,2016), it is estimated, upto 25% of individuals will suffer from impaired wound healing in the form of a diabetic foot ulcer (DFU) (Oliver and Mutluoglu 2019), it is difficult to treat (Amin and Doupia, 2016), and leading cause of lower leg amputations (Du et al., 2021).

Infection is believed to be the major cause of delayed healing, involving biofilm production, exacerbating the cascade of immune complexes and complements involved in cellular repair (Leaper, Assadian and Edmiston 2015). The rise of antimicrobial resistant infections further compounds the

issue (Negut, Grumezescu, and Grumezescu 2018), because of these complications it is of increasing importance to investigate and understand the inter-relationship between the infectious agents involved in chronic wound infections and the impaired wound repair process. with the aim of improving chronic wound treatment and outcomes.

Discussion:

Wound Repair Process

The wound repair process involves a series of phases; Hemostasis phase, Inflammation phase, proliferation phase and remodelling phase.- Hemostasis phase: immediately takes place after injury ,this involving platelet activation coagulation cascade, to produce a clot. Disrupted keratinocytes release interleukins eg IL 1, together with platelet secretions of platelet derived growth factor (PDGF), epidermal growth factor (EGF), cytokines CXCL1, CXCL5. These moecules attract neutrophils and monocytes /macrophages. Thus forming a scaffold upon which to start wound repair. The Inflammation phase- entails an early and late phase, whereby neutrophils and monocytes recruited to the wound site, fight infections through phagocytosis and secretion of various powerful enzyme (Selders et al., 2017). Towards the end of this phase neutrophils are induced to apoptose, together with secretion of growth factors (VEGF), β-TGF, to promote angiogenesis, re-epithelialization, fibroblast migration and matrix deposition. Therefore, preparing the injured site for the proliferation phase. The hallmark of this phase is re-epithelialisation, when the clot is replaced, involving fibroblasts and fibrocytes, which proliferate and produce new ECM. The final phase the remodelling, is when the wound is finally repaired by fibroblast degrading any remaining clot material (Wallace, Basehore and Zito 2021) and new collagen (types 1 and III), as shown in Figure 1.

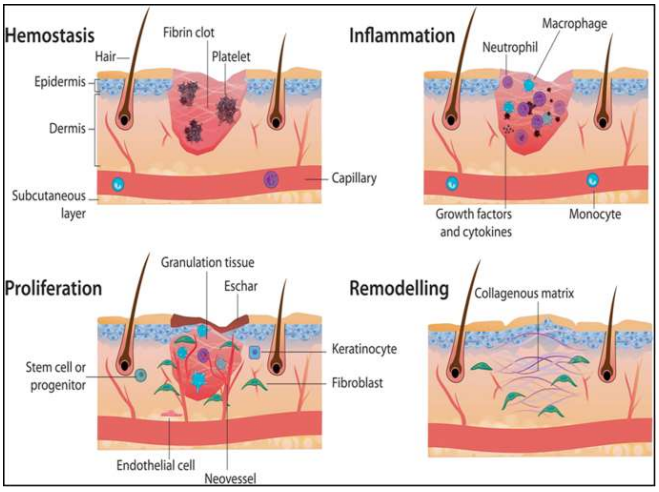

Figure 1: Stages of wound repair

Therefore, it can be determined that the skin and its components play a crucial role in the various stages of repair. Furthermore, a closer look at these components will help to put into perspective, of how different components contribute to the wound repair process and ultimately how they may be compromised in a chronic wound setting. Additionally, highlighting how these components are effected by ageing.

Skin structure and Ageing:

The gross structure of skin comprises of a complex outer stratified epidermal layer including appendages such as hair follicles. Underneath this layer lies the dermal layer, primarily comprising of fibroblasts and a collagen extracellular matrix (ECM). It is these fibroblasts that actively respond to physiological responses of the skin. The third component is the subcutaneous layer, development, maintenance of the skin and direct communication is thought to take place between the epidermal and dermal layers. Moreover, signalling from the dermal layer is vital for the correct functioning of epidermal progenitor cells (Rippa et al.,2019; Jahoda and Reynolds, 2001).

In generalised terms, the ageing process that, skin undergoes can be categorised as extrinsic and intrinsic. Extrinsic ageing is referring to external agents such a UV radiation or air pollutants. Whereas, intrinsic ageing is really chronological ageing or the process of time. But it should not be just considered that chronological ageing is due to time only, there are other factors involved such as nutrition, which have an impact upon skin structure and function. So the differences between these two phenomena is not just a matter of exposed or covered skin.

Of note, different UV wavelength do have distinct affects (Watson et al., 2014). The majority of damage detected in photo-aged skin is due to UVB exposure. UVB is the most energetic and because of its shorter wavelength only penetrates the epidermis. On the other hand UVA is less energetic, but a longer wavelength means it penetrates deeper into the dermis, causing profound alterations to the dermal connective tissue. Predominately this is linked to reactive oxygen species (ROS). ROS is a very powerful chemical species that can cause extensive DNA damage in particular to mitochondria DNA. Other effects of ROS involve cellular signal pathways that stimulates the production of various enzymes such as metalloproteinases (MMPs) and cytokines related to the inflammatory process (Nelson et al, 2018).

Intrinsic ageing or chronological ageing of skin is the skin ageing process, without the influences of extrinsic ageing factors such as UV radiation. Intrinsically aged skin does have marked differences to extrinsically aged skin, such as the progressive loss of skin tissue; thinning of the subcutaneous fat layer and dermis. The loss of the subcutaneous layer increases the sensitivity to hot and cold, whereas the ECM of the dermis becomes fragile and more prone to wounds (Waldera et al., 2015)

The skin matrix (Cells and fibres) ageing and wound repair

An essential perspective of skin ageing and its role in wound repair is to understand the cellular and molecular alterations and the interactions between the various components that comprise the skin undergoing the ageing process.

The dermis may be considered to have a central role in this, the dermis provides the structural and mechanical properties of the skin. As opposed to the epidermis which is comprised of densely packed keratinocytes. The dermis comprises largely of an acellular component, the ECM. The ECM comprises 75% of dry of collagen fibres, in human skin 80-90% is type I collagen, 8-12% is type III collagen, whilst type IV collagen comprises <5%. The collagen bundles generally get thicker upon traversing the dermis. Elastin is another component, giving skin the ability to return to shape after being stretched, other components include proteoglycans (PG) and glycosaminoglycans (GAGs), these are amorphous molecules that surround and embed the fibrous and cellular elements of the dermis. Although they

comprise only 0.2% of the dermis, they absorb 1000 times their volume in water and have roles in water regulation (Shin et al, 2019).

Fibroblasts form the cellular element of the dermis, differentiated from the mesenchymal stem cells. The fibroblasts are responsible for the synthesis and degradation of the ECM. Their function and interaction with the environment are important in understanding the molecular mechanisms of dermal ageing. Dermal fibroblasts (DF) deserve some special consideration when referring to skin ageing. Fibroblasts are not rapidly dividing cells compared to keratinocytes and thus create a post-mitotic tissue. It is the fibroblasts that are responsible for the composition of the ECM. Therefore DF should be considered a long lived cell population exposed to continued damage, with accumulation and adaptations resulting in characteristic features of dermal ageing as wrinkles (Shin et al, 2019). For these reasons, fibroblasts are the preferred model for studying both extrinsic and extrinsic ageing (Salman and Pardo,2021).

Numerous investigations have been undertaken to look at various aspects of fibroblast ageing, one study involved using parallel features of the "Hallmarks of ageing" (Lopez-Otin 2013), which includes DNA damage, telomere shortening, cellular senescence, proteostasis (protein balance) and mitochondrial dysfunction. Tigge's study (2014) has reviewed these ageing parameters in fibroblasts and compared them with observations in other human tissues and species. Revealing,majority of the hallmarks of aging were seen in cultured fibroblasts (Tigge et al 2014). Although some features such as stem exhaustion is not applicable in the culture situation. Another aspect to these findings is the reverse, some of the features observed in culture have not been investigated *in situ* in other words there are aspects that can be observed in laboratory condition that cannot be reproduce in animal and human models. It is interesting to note that the ability of fibroblast to migrate diminishes with ageing (Ashcroft et al, 2002), fibroblast migration is important in wound repair and creating new scar tissue. Therefore, ageing affects the ability of fibroblasts to contribute to the wound repair process with time, Furthermore, it is believed these intrinsic and extrinsic profiles are regulated through a complex cascade of gene expression (Lago and Puzzi 2021).

In young skin, the fibroblasts adhere to the surrounding ECM, mainly comprising of type I collagen (Shin et al, 2019). This arrangement allows the fibroblasts to exert the mechanical forces on the surrounding ECM and promote young skin characteristic properties. In aged skin there is an alteration in the fibroblast-ECM arrangements, namely the attachments of fibroblasts to ECM are impaired due to ECM degradation, resulting in reduced fibroblast size, collapsed morphology and reduce elongation (Fisher et al, 2016). This change in morphology is characteristic of senescence, linked to reduced ECM production and increase in mitochondrial ROS.

MMPs are a family of ubiquitous enzymes (MMP1-MMP-27) that degrade ECM proteins and can be divided in to five categories I) collagenases, II) gelatinaes, III) strimelysins, IV) matrilysins and V) membrane bound (Verna and Hansch, 2007) . Collagen types I and III are predominant in the skin and MMP-1 initiates the fragmentation of collagen followed by MMP-3 and 9. MMP production in the skin is mainly initiated by keratinocytes and dermal fibroblasts, of note, in aged skin, it has been revealed that a range of MMPs (1,2,3,9,10,11,13,17,26.27) are raised (Quan et al, 2013). It is interesting to note that while in aged skin there is rise in MMPs there is not a rise in the TIMP protein which regulates MMPs. TIMPs generally act to control MMPs to moderate excess activity. In ageing skin it appears TIMP1 levels are reduced, thus accelerating progressive collagen fragmentation in the dermis.

Reactive oxygen species (ROS) is a major driving force in the elevation of MMPs in aged skin (Shin et al, 2017), ROS is generated in both intrinsically and extrinsically aged skin. A cell signalling pathway involving the mitogen-activated protein kinase (MAPK) family, which in turn activates transcription factors and it is these that play a crucial role in the regulation of MMP1,3,9 and 12 (Shin et al, 2017). Another transcription factor nuclear factor-κB (NFκB) is activated by ROS, and is responsible for up regulation of MMPs, such as MMP1 and 3 in dermal fibroblasts. In general oxidative damage is more obvious in photo-aged skin.

Elastic fibres also undergo changes during ageing, these fibres originate from tropoelastin, which is cross linked by lysyl oxidase (LOX) (Weihermann et al, 2017). The elastic fibres include an array of microfibrils (fibrillin, fibrulin), together with microfibrillar-associated glyproteins (MAGPs), latent TGFβ binding proteins (LTGFP) and amorphous elastin. In young skin these fibres have a very ordered architecture, with perpendicular microfibers in the papillary dermis and large diameter elastin fibres in the reticular dermis. During the ageing process the elastin fibre system undergoes various structural changes. In the case of intrisincally aged skin fibrillin-rich microfibers are degraded. Fibulin5 is related to elastin remodelling in intrinsic aged skin (Langton, et al,2012), there is also evidence that although fibulin5 is localised on the elastin fibres throughout the dermis, however in aged skin this relationship is completely disappeared.

They may not be major structural elements of the ECM, however, proteoglycans and glycosaminoglycans (GAGs) play an important role in skin function and ECM regulations, but these too go through alteration during the ageing process. GAGs are a group of large linear polysaccharides, including chondroitin sulfate (CS),dermatan sulfate (DS), keratin sulfate (KS), heparin sulfate (HS), heparin (HP) and hyaluronic acid (HA). HA is not sulphated and as does not bind to proteins to produce proteoglycans. It does however, crosslink with ECM proteins such as collagen, resulting in network of fibres, which further stiffens the skin tissue (Anderegg et al, 2014). In the dermis HA is produced by fibroblasts, during intrinsic ageing HA binding proteins (HABP) are reduced, but the HA itself is not noticeably reduced (Shin et al, 2017). HABPs are known to be involved in several different signalling pathways regulating cell proliferation, migration and differentiation (Maytin, 2016). In photoaged skin, the opposite situation exists with significant raised levels of dermal HA, especially in areas of solar elastosis (Maytin, 2016). It is interesting to note that while UV irradiation activates HA synthase (HAS), the RNA levels of HAS are reduced in sun exposed skin as compared with sun protected skin, suggesting some unknown regulatory system (Lee, et al, 2016).

The proteoglycans (PG) are a family of conjugated GAGs that perform an essential role in the mechanical strength of skin (li et al, 2013). The most abundant PGs in the human are decorin, biglycan and versican. Investigations into PG and intrinsically aged skin have shown interesting and varying results depending upon site, age and gender (Lee et al, 2016). As it appears in photoaged skin, versican is increased, whereas biglycan remains the same and decorin disappears (Lee et al, 2016). There are complex mechanisms involving CAGs and PGs and there is a lot more to be revealed in term of their role in the ageing process.

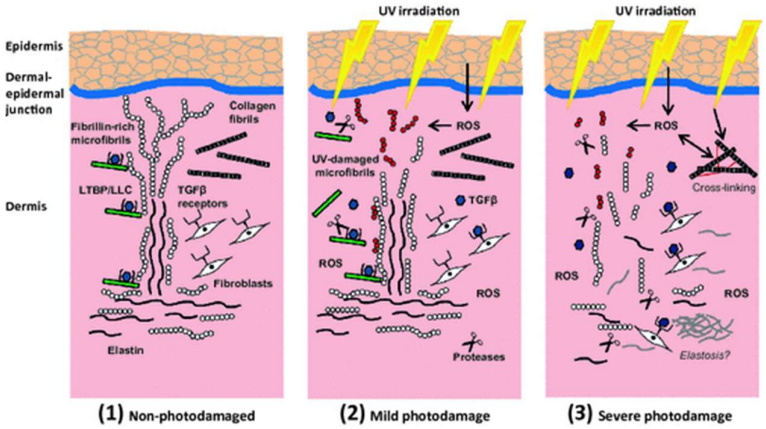

Figure 2 : Schematic diagram illustrating the physiological changes occurring with skin ageing

Hence we have an organ system in the skin that is exposed to both external and internal stresses, performing varied functions including defence, barrier and body regulation. All these functions can be effected by ageing and in particular the process of wound repair.

Types of chronic wounds

There are a group of specific wound types that are particularly associated with chronic wounds, these are important because of their underlying medical conditions, which impact upon normal tissue function and indeed have profound consequences upon healthcare in general.

Diabetic Foot Ulcers

Diabetic foot ulcers (DFU), are a frequent complication of type 1 and 2 diabetes (Del Core et al 2018; Oliveira et al., 2018), together with frequent hospitalization (*Uçkay 2015*), which often results in complex ischemia and neuropathy. Peripheral arterial disease results in diabetes-associated ischemia, which causes poor arterial inflow, results in a decreased blood supply to the ulcer, contributing to reduced levels of oxygenation and ulcer healing. Neuropathy occurs through a combination of extrinsic mechanical factors like excessive pressure on high planks and dryness of skin, which results in the breakdown of skin causing ulceration and bacterial colonization. Diabetic foot osteomyelitis develops in 68% of patients, in most cases infection is predominately characterized by multi drug resistance organisms (MDR) and the adverse microenvironment at the site of infection is the leading cause of amputations in such patients the site of infection is the leading cause of amputations in such patients (Lipsky et al., 2004, Van Asten et al., 2016).

Diabetes has profound effects over time on skin function and hence wound healing. In particular the process of glycation (addition of glucose molecule), due to high levels of glucose associated with diabetes there is corresponding increase in glycation to produce advanced glycated endproducts (AGEs). The result of this is more crosslinking between collagen fibres, causing increased stiffness, decreased solubility and less susceptibility to proteolysis. Another consequence of AGEs is the generation of ROS during UVA irradiation, hence increasing damage to photoaged skin. Some recent work has shown there is a link between senescence and diabetes and a possible therapeutic target in the case of diabetic related chronic wounds (Wilkinson and Harman,2020).

There is an estimated 30% chance of a patient developing DFU (Audit 2014) and a global impact of such infections of 6.3% (Zhang et al, 2017). It is interesting to note that Caucasian males are more prone to developing DFU, that those of Asian, Afro-Caribbean and female. A recent report commissioned by the NHS (2014-15), stated that £962, 000, 000, 0.8% of the NHS budget wound be spent on DFU treatment and secondary care (Kerr, 2017). Added to this a more recent estimated to costs of over 1 billion pounds (Kerr et al, 2019).). Lower limb amputations attributed to diabetes in the UK is estimated to be 7000 per year (Kerr et al., 2019; PHE. Diabetes), additionally mortality rates increase to 78% within five years of an amputation (Thorud et al., 2016). In the UK, diabetic foot management is correlated with NICE guidelines (nice.org.uk)

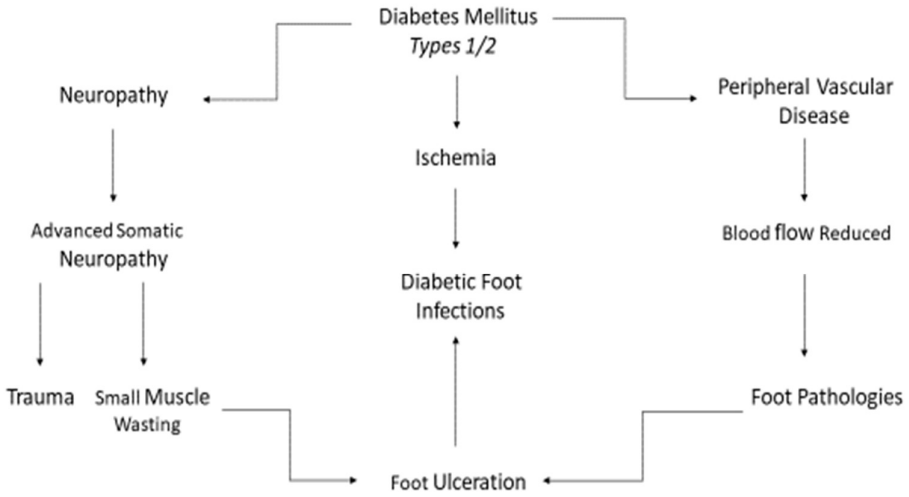

Figure 3 : Schematic of the pathophysiology of Diabetic Foot Ulceration

Pressure Ulcers

Pressure ulcer, also known as decubitus ulcers easily develop into chronic wounds, in long term care patients or those who are neurologically impaired and wheelchair patients. There are many factors, both extrinsic and intrinsic that interact to create skin and subcutaneous tissue damage. These include; chronic disease, genetics (intrinsic), whereas dryness/moisture, friction, excessive pressure (extrinsic), Figure 3 summarizes how these factors interact (Bouten et al, 2003). The damage occurs over boney prominences, where localised pressure easily rises above the capillary filling pressure (30-32 mm hg), this can occur over a short period of time or conversely low pressure over a long period of time, resulting in occluding of blood flow, and leading to ischemia, impaired lymphatic drainage and tissue death (Jaul et al, 2018). NICE pathways have been developed for pressure ulcer management (Pathways.nice.org.uk) however, a number of cross sectional studies in the UK have revealed that 4.6% of individuals suffer from pressure sores with an associated cost in the region of 1.4-2.1 billion pounds (Norman et al, 2016)

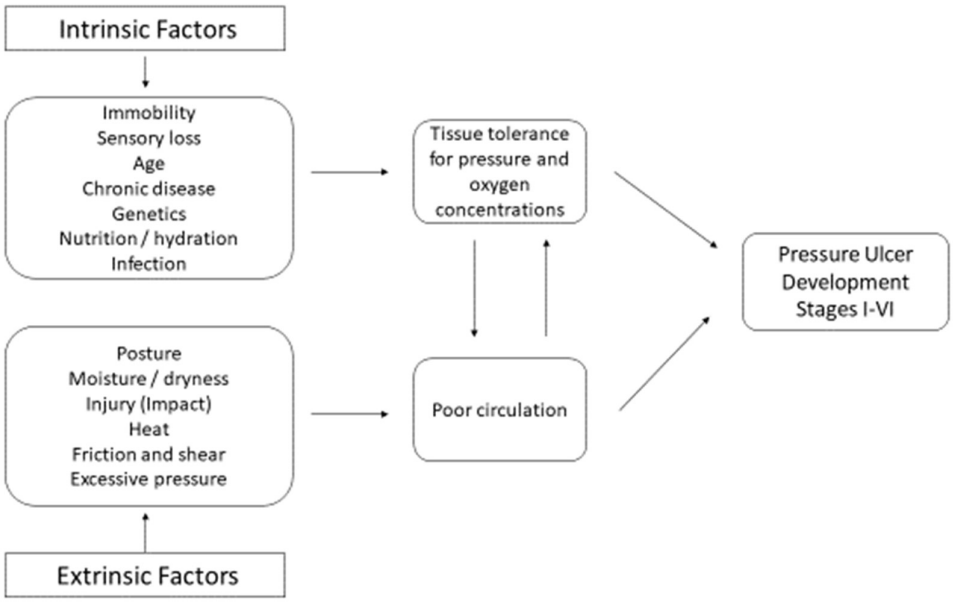

Figure 4: Pathogenesis of pressure sores

Chronic Leg Ulcers

Chronic leg ulcers (CLU) can be due to a range of causes including vascular and trauma, they usually effect the skin below the knee and can persist for up to 3 months. Adults over the age of 65 are predominately effected, with rates increasing for the over 85 age group (Mekkes et al, 2003). They occur in all socioeconomic groups but the rates of healing are longer together with a higher frequency of re-infections lower socioeconomic groups (SIGN 2010). Venous leg ulcers arise from prolonged hypertension resulting from venous insufficiency, due to either impaired calf muscle pump or lack of venous valve efficiency. This leads to a reflux of blood and if venous pressure remains high, eventually resulting in oedema, venous skin changes and finally ulceration of the skin and subcutaneous tissue (Franks *et al.*2016). The estimated cost to the NHS in treating CLU is between 500-900 million pounds per year (Guest, 2018).

Wound Bed Micro-Environment

Nearly all chronic wound and non-healing wounds have very similar pathophysiological features (Iqbal et al., 2017; Han and Ceilley 2017). Studies have shown there are a variety of biomarkers such as tumour necrosis factor (TNF-α) and interleukin-1 receptor antagonist (IL-1RA), which are found to be increased in pressure ulcers. Interestingly, the latter inhibits the production of pro-inflammatory cytokines, thus impeding cell repair. The concentration of macrophage inflammatory protein (MIPI-α) and interleukin 6 (IL-6) are reduces, the impact of these is a reduction of the immune response and tissue repair especially in the case reperfusion injuries (Moor et al, 2009; Krishnan et al, 2017).

In DFI inflammatory markers are also increased (Noor et al, 2017). Cellular proliferation and dermal repair are impaired, together with an increase proteases (Larazo-Marinez et al, 2020). Serine proteases for example human neutrophil elastase (NHE) plays a number of vital roles ranging from cell

migration and activating MMPs (Ferreira, 2017). In the equiliberated wound environment serine proteases are important in aiding healing (Gibson et al, 2009). Keratinocytes, fibroblasts and growth factors such as VEGF also stimulate MMPs, as well as stimulating protease expression involved in the pathways of cellular repair.

Diabetes has several associated complications encompassing neuropathy, hyperglycation and ischemic heart disease, which all impact upon the healing process. For example advanced glycation end-products (AGE), reduce neutrophil migration and increased oxidative stress (Volmer-Thole and Lobman, 2016). As the wound becomes hypoxic due to the increase in oxygen intake necessary for wound healing, this in turn causes the release of ROS. Which in turn results in the disruption of transcription factor, hypoxia induced factor (HIF), enhancing angiogenesis, further release of ROS, leading to ischemia-reperfusion injury (Nunn et al, 2014).

The wound can be seen as a complex environment involving many elements cellular and molecular, which interact and respond to the physiological demands of the healing process. Another facet which is integral in the chronic wound environment is the microbiome

Wound Microbiome

The wound micro-environment hosts a predominantly polymicrobial and a complex biological system, added to which each wound has a unique microbiota. The situation is further complicated by the presence and rise of multidrug resistant bacteria such as *K.pneumoniae, E.cloace,* MRSA and VRE. The complex biofilm structures created, severely reduce the ability of antibiotics to fully penetrate the biofilm, for example, concentration of antibiotics can be reduced by a 100-1000-fold of its original strength by the time it has diffused to the sessile cells (Mattheiu et al, 2019). Thus resulting in a poor prognosis and increasing resistance of the microbe. For these reasons it is imperative that treatments and new strategies can be developed to tackle such issues, one such idea is the use of phage therapy to target bacteria.

Phage Therapy

Bacteriophages are viruses that specifically infect bacteria, they were first discovered by Fredrick Twort in 1915 and confirmed by Felix d'Hevelle in 1917. They are ubiquitous, found all over the planet in soils and water, there are estimated to be 10^{31} present. In essence, there two types of phages temperate and lytic, figure 5 shows the life cycle of lytic phages. Lytic phages target and kill bacteria, by injecting their nucleic acids, allowing replication to take place. Temperate phages are lysogenic, meaning they do not cause lysis of the bacteria cell. Instead they incorporate their genome in to host cells to produce prophages. A consequence of the temperate replicative life cycle is that resistant elements can be inserted into the bacterial genome. One of the key features of lytic phages is their ability to target and destroy bacteria and so can be characterised that local microflora is not destroyed, in addition there is no known receptor on eukaryotic cell e.g. human cells. Food producing animals have been treated with phages to reduce intestinal colonization of pathogens such as *Campylobacter jejuni* and *Salmenella ssp.,* reducing the need for agricultural antibiotics (Carvalho et al, et al, 2010). Moreover, a number of phages have been employed in other areas of the food industry including phages Phi 88 and 35 to prevent *S.aureus* colonization and the release of endotoxin a (causative agent

of vomiting and diarrhoea) in UHT production. Other phages (Sj2 and A511) have been used in cheese production to eliminate *Salmonella enteritis* and *Listeria monocytogenes,* known to cause meningitis in food related outbreaks and is dangerous to pregnant women and the unborn.

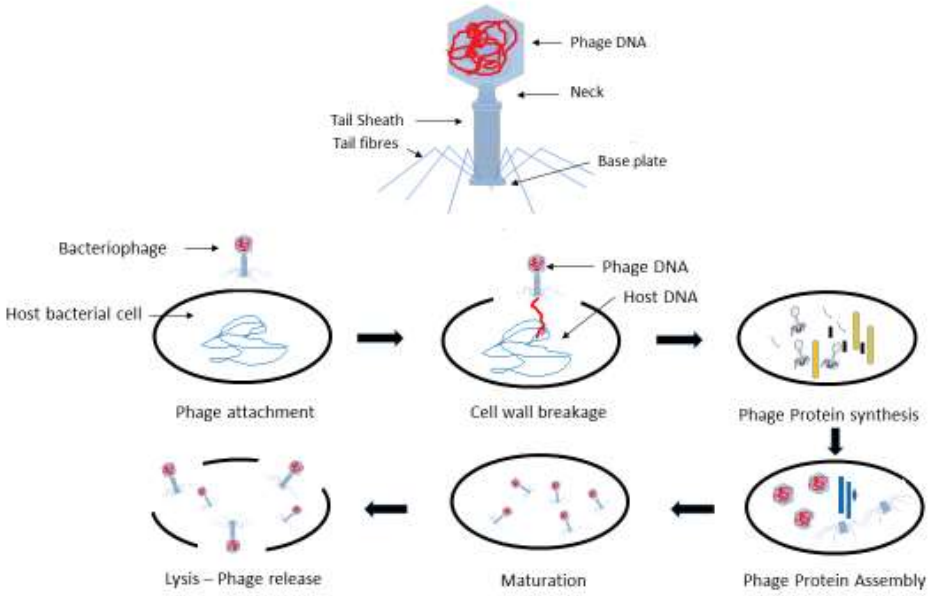

Figure 5: Diagram illustrating bacteriophage life cycle

There have also been some limited human studies, encompassing topical phage application in combating skin and otitis media infections with *P aeruginosa* and *S aureus* (Morozova et al, 2018a, 2018b). Another study has used oral administration of phages to prevent and treat lung injury (Hoyle et al, 2018). As well as reducing *P. mirabilis* biofilms are associated with urine catheter infections (Lu et al, 2007). Research has also shown that phage treatment does not cause any tissue damage or any elevation of any inflammation markers or ROS (Hwang et al, 2016), suggesting phage therapy may also induce a positive immunomodulatory effect (Gorski et al., 2020). Furthermore trails using phage and antibiotic combinations (phage AB-PAOI + antibiotic) to reduce infection and healing time of skin infections, together with respiratory infections involving multidrug resistant *P.aeruginosa* have shown promising results. (Aslam et al, 2019).

Chronic Wound Model

With the increasing pressures on health care services, together with the difficulties and complexity of investigating chronic wound micro-environment and treatments. There is an urgent need to create and use a more efficient *in-vitro* model that more closely resembles the wound micro-environment encountered in a patient and a system that efficiently evaluates antimicrobial treatments.

In pursuit of this aim we have instigated research in the isolation and characterizations of bacteriophages, as well as chronic wound microflora, together with establishing a wound bed model using various types of collagen matrices.

Summary

Chronic wound healing is major problem for healthcare and is particularly associated with several medical conditions and ageing. There is complex interplay between the different components (cellular and molecular) involved in the healing process and mechanism that may impede that process, together with interactions of the infectious agents and wound bed. For these reasons there is an urgent need to develop better wound models to investigate the wound micro-environment and develop better treatments.

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Systematic Review: Is supervised exercise a superior method of rehabilitation for improving balance in individuals with Parkinson's disease?

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Abstract

Background

The motor and cognitive disturbances caused by Parkinsons disease (PD) result in progressive disability, with balance impairments being highlighted as having an incapacitating impact. Exercise has shown to be a fundamental aspect of managing PD but questions remain about optimal delivery of exercise. Limited research has been conducted on the benefits of supervision of exercise in patients with PD.

Aim

Conduct a systematic review to critically appraise and evaluate findings from available literature on the impact of supervised exercise on balance outcomes in patients with PD.

Methods

Searches using key terms were conducted on electronic databases (CINAHL, MEDLINE, and AMED) which yielded 148 articles, nine of which were included in the review. The author independently extracted data, and no meta-analysis was completed.

Results

Four studies reported significant improvement of supervised exercise on balance-related outcomes. Two studies found no improvement. Two studies found no difference between supervised and unsupervised groups. One study found supervised exercise was significant in improving balance outcomes compared to unsupervised.

Conclusion

Balance improved following intervention within eight of the trials suggesting that supervised exercise has benefit to people with mild to moderate PD. Although findings from this study should be considered with caution due to the low quality of studies used within the review.

Introduction

PD is a progressive neurodegenerative disorder which impacts motor and non-motor functions leading to impairments in quality of life, independence, and function (Koui et al 2018). PD symptoms differ significantly from patient to patient. Due to the death of dopaminergic cells, common symptoms include impaired balance, gait disturbance, tremor, bradykinesia, and muscle rigidity (Jankovic 2008). Other non-motor symptoms include fatigue, anxiety, depression, cognitive and memory disturbances (Tysnes & Storstein 2017). The mean age of onset ranges between 58-62 years, however early onset (<40) has been identified with a prevalence of 3.6% in a community-based study (Wickremaratchi 2009). Several studies following patients with PD over the course of their illness and have estimated 60-80% will develop dementia at some stage throughout the disease (Hobson and Meara 2015, Noyce et al2012, Hely et al 2008). Risk factors of PD related dementia (PDD) include older age and severity of motor

symptoms and cognitive impairment (Yarnall et al 2013). Several cohort studies in different regions found the PDD prevalence among the general population is approximately 38.7 to 112.5 per 1000 persons over a year (Aarsland and Kurz 2010, Hobson and Meara 2004). In the UK PDD accounts for roughly 2% of all cases of dementia and it has been found the patients with PD have an above average risk of developing PDD (Alzheimer's Society 2021).

Motor disturbances experienced in PD has been shown to cause progressive and fluctuating disability in patients despite the effectiveness of symptomatic therapy (Tolosa et al 2021, Chapuis et al 2005). Balance instability has been alleged to have the most incapacitating impact on PD patient's independence, activity levels and quality of life (Petzinger et al 2010). Multiple clinical studies have demonstrated the advantages of exercise on motor symptoms such as balance, muscle strength, walking and functional tasks in patients with mild to moderate PD (Allen et al 2012, De Carvalho 2018, Morris et al 2009). Physiotherapy interventions and exercise have become fundamental aspects of managing of PD with high quality reviews and randomised control trials (RCT) demonstrating the effectiveness of therapy input (Shein et al 2016, Morris et al 2015, Tomlinson et al 2013).

Prescribed exercise for PD varies a considerable amount within research. Several questions remain around the optimal delivery of exercise therapy including the amount of supervision required, ideal location, intensity, and duration (Allen 2012). For example, home-based exercise may be more sustainable and practical for PD patients as studies have shown improvement in motor function from home-based unsupervised rehabilitation programs (Nocera 2009, Caglar 2005). Other research has suggested that patients completing their own rehabilitation exercises unsupervised creates an active role in the management of their care which can help self-efficacy and belief in their ability to perform certain activities (Grosset & Grosset 2005).

However, studies have also suggested that due to complications of additional comorbidities, a supervised program would be best to prevent patient decline (Gillespie et al 2012, Gitlin et al 2006). Although this research should be interpreted with caution as it was not based on patients with PD. Due to the high likelihood of patients developing PDD (Hobson and Meara 2015), supervised exercise therapy could ensure patients stay on track with rehabilitation whereas without supervision they may experience negative impacts on their rehabilitation due to cognitive decline. This is supported by a study which conducted eight months of personal training for PD patients and reported that patients required guidance throughout training on exercises due to the impact of fluctuating energy levels and cognitive deficits (Morberg et al 2014). Research has also indicated that patients with PD may overestimate their perceived ability and measures of daily living tasks and exercises, therefore, suggesting the importance of some form of supervision throughout exercise (Sitek et al 2011).

Due to the progressive nature of PD, which is compounded by age-associated functional and cognitive decline, the need for supervised therapy could be suggested to help maintain essential motor function and activity levels. Previous research has insinuated decreased function and activity level if left to the individual alone (Mak et al 2017). No recent reviews have been conducted on the impact of supervision compared to non-supervised exercise in relation to balance instability in PD patients. Therefore, the main aim of this review is to answer the question; is supervised exercise a superior method of rehabilitation for improving balance in individuals with PD?

Aim and objectives

The aim of the systematic review is to critically appraise and interpret existing literature surrounding the benefit of supervised exercise on balance function in patients with PD. The primary objective is to identify current best practice for physiotherapists for level of supervision of exercise and impact on improving balance function. Studies with different levels of supervision will be included to provide a range of literature to review the impact on balance function. A subsequent aim of the review was to establish the quality of existing literature and highlight areas for future research.

Methods

Search strategy

A comprehensive literature search was conducted on databases including CINAHL, MEDLINE, AMED which indexes the top allied health, life sciences and peer reviewed literature (EBSCO Information Services 2021). Specific search terms used below related to supervised and non-supervised exercise for motor functions in patients with PD and due to the limited research around the chosen idea, a variety of terms were used for broader searching. There were no date restrictions in the search to increase the body of literature available and only English written studies were screened. Inclusion and exclusion criteria were employed when selecting relevant articles.

Search terms

Within each search, key terms were combined with 'OR'. Searches 1-4 were connected using 'AND'.

- **Search 1:** Parkinson's disease
- **Search 2:** Supervised exercises, group exercise, physiotherapy rehabilitation, balance training
- **Search 3:** Unsupervised exercise, individual exercise, home-based exercise
- **Search 4:** Motor symptoms, balance, postural balance, functional balance

Inclusion/exclusion criteria

The literature search was generated using the PICOS model as shown in Table 1, which has been supported by Methley et al (2014), who declares the effectiveness of using the PICOS tool for literature searches within systematic reviews on the chosen databases discussed earlier.

Table 1. *Inclusion and exclusion criteria*

Inclusion/exclusion criteria	**Inclusion**	**Justification**
Participants	Adults (18<)	Links to purpose of the study
	Participants with diagnosed PD	Links with aims of study, Parkinsons disease being a main factor
Intervention / Outcome	Focus on rehabilitation/exercise	Links to the objectives of the study

	Impact on motor function (balance) Outcome measures for targeted balance exercises	Links to the aims of the study focusing on motor function – specifically balance
Comparison	Supervised and/or unsupervised exercise Intervention and control	Links to the aims of the study
Study type	Peer reviewed	Good quality evidence, providing a reliable source
	English language	Unable to translate to English. Time consuming
	Primary data collection	Primary data provides a better link to conclusion

Data extraction

Articles were included with samples focusing on people with PD at any stage of disease severity (Hoehn and Yahr 1998); all studies involving other neurological disorders were excluded. Trials were included if the intervention focused on supervised or unsupervised exercise or rehabilitation with impact on balance-related outcomes. Home-based and group-based exercise were also included due to the lack of studies specifically noting supervision in the titles; the unsupervised nature of home-based exercise and the supervision of group-based exercise gives reason for inclusion. Focus on non-motor functions alone were also excluded due the lack of motor function improvement. Full details are shown in Table 2.

Outcome measures

The primary focus of interventions in the review were specifically related to balance function. Due to the variety of balance-related outcomes, an analysis of measures was undertaken to create a pool of the most comprehensive and frequently used measures. The analysis identified the following outcome measures: Berg Balance Scale (BBS) (Qutubuddin et al 2005), Mini-BESTest (Godi et al 2013), Activity Balance Confidence (ABC) (Lohnes, and Earhart, 2010), Functional Reach Test (FRT); Sit to Stand (STS), Unilateral Stance (US), Timed Up and Go (TUG) (Morris et al 2001), Physical Function Test (PPT) (Reuben and Siu 1990). Similar analyses of mobility and balance outcomes have been used in previous systematic reviews reporting outcomes in PD (Flynn et al 2019, Shen et al 2016). Other secondary outcome measures designed for motor function such as the Unified PD Rating Scale Motor and Active Daily Living (UPDRS-ADL/motor) (Siderowf 2002), and Continuous Scale – Physical unction Performance (CS-PFP) were used (Schenkman 2002). Quality-of-Life (QOL) and function measures using the PD questionnaire (PDQ-39) were also included (Peto et al 1995).

Risk of Bias (RoB)

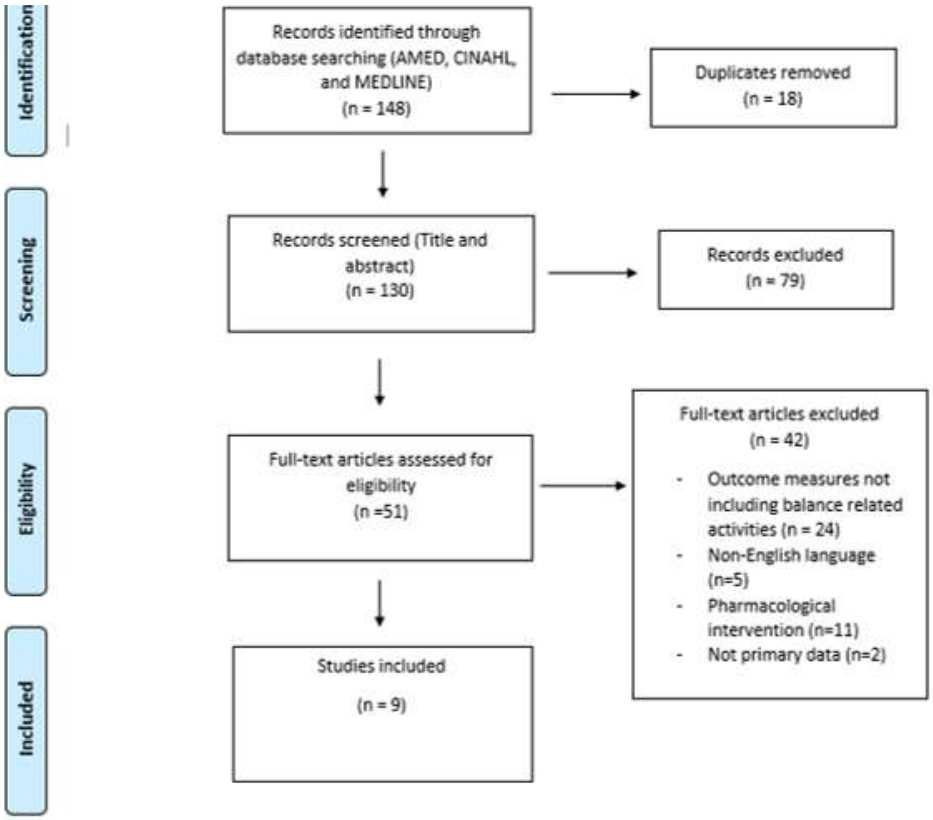
The Cochrane RoB2 tool (Sterne et al 2019) was used to evaluate RCT's as research demonstrates that it is the most appropriate tool to assess the risk of a study due to its reflection on current understanding of how the causes of bias can have an influence on study results (Higgins et al 2011). ROBINS-I RoB tool (Sterne et al 2016) was used for the non-randomised control trials (NRCT) as research provides useful accounts of the comprehensive and organised approach to assessing RoB in NRCTs. Both Cochrane RoB tools include three ratings of bias: low, high and some concerns. Due to the limited amount of research, low quality studies were not excluded from this review. Critical Appraisal Skills Programme (CASP) tool (Critical Appraisal Skills Programme 2018) was used to assess the quality of the cohort studies focusing on three broad issues appraising the validity of methodology, generalisability, and usefulness of the results (Ma et al 2020).

Results

Study selection

Database searches using AMED, CINAHL and MEDLINE identified 148 articles. After articles were fully screened by the author, nine studies (King et al 2019, Atterbury & Welman 2017, Schenkman et al 2012, Gandolfi et al 2017, Lun et al 2005, Kara et al 2012, O'Shea & Blake 2017, Combs et al 2013, Mehta & Kapoor 2020) met the inclusion and exclusion criteria which has been outlined in Figure 1.

Figure 1. *Prisma flowchart (Page et al 2021)*



Study characteristics

The search strategy yielded a total of nine studies. Five studies were RCTs from USA (King et al 2019, Schenkman et al 2012, Combs et al 2013), South Africa (Atterbury & Welman 2017), Italy (Gandolfi et al 2017), two were cohort studies from Ireland (O'Shea and Blake 2017) and India (Mehta & Kapoor 2020), and two were NRCTs from Turkey (Kara et al 2012) and Canada (Lun et al 2005). Sample sizes range from 9-121 with a mean participant age of 68 years an d 90% of studies included patients with PD in mild to moderate stage of the disease (Hoehn & Yahr 1998).

Interventions

Study interventions ranged between four weeks and 16 months (King et al., 2019, Atterbury & Welman 2017, Schenkman et al 2012, Gandolfi et al 2017, Lun et al 2005, Kara et al 2012, O'Shea & Blake 2017, Combs et al 2013, Mehta & Kapoor 2020). Four studies completed intervention on three days a week (King et al 2019, Atterbury & Welman 2017, Schenkman et al 2012, Gandolfi et al 2017), one completed exercise twice a week (Lun et al 2005), and two completed exercises once a week (Kara et al 2012, O'Shea & Blake 2017). Two studies did not document the number of sessions per week (Combs et al 2013, Mehta & Kapoor 2020). Exercises varied between studies involving either or a combination of balance, functional, aerobic, agility, circuit class, strengthening, stretching, coordination, or boxing exercises. Six studies specifically investigated the effect of supervised exercise and balance (Schenkman et al 2012, Gandolfi et al 2017, Kara et al 2012, O'Shea & Blake 2017, Combs et al 2013, Mehta & Kapoor.2020), and three studies compared supervised and unsupervised exercise and the result on balance outcomes (King et al 2019, Atterbury & Welman 2017, Lun et al 2005). Interventions varied between studies with mixed levels of supervision including group supervision, un-supervised, and physiotherapy supervised exercise. Six studies reported participants performed exercises and testing in the 'on' phase, where their normal PD medication was working most optimally (King et al 2019, Atterbury & Welman 2017, Schenkman et al 2012, Gandolfi et al 2017, Lun et al 2005, Kara et al 2012, Combs et al 2013).

Risk of bias

The chosen studies were evaluated using three RoB tools, Cochrane RoB2 tool (Sterne et al 2019), ROBINS-I tool (Sterne et al 2016), and the CASP tool (Critical Appraisal Skills Programme 2018). From the RCT's, four studies were considered to have some concerns of RoB and one was considered high RoB. Out of the two NRCT's and two cohort studies, one study proved high RoB and the other three presented with some concerns (Lun et al 2005, Kara et al 2012, O'Shea & Blake 2017, Mehta & Kapoor 2020).

Supervision and balance outcomes

Four studies (Gandolfi et al 2017, O'Shea & Blake 2017, Combs et al 2013, Mehta & Kapoor 2020) assessed supervised interventions which was shown to provide a statistically significant improvement on balance-related outcomes including one or a combination of the BBS, TUG, and ABC ($p<0.001$). One study found a significant change pre and post intervention of supervised exercise on static unilateral balance and one dynamic balance test ($p<0.05$), however no differences were detected in STS and other dynamic balance tests ($p>0.05$) (Kara et al 2012). One study compared different levels of supervision and found no differences between any of the groups in FRT scores (Schenkman et al 2012).

One of the more supervised groups (FBF) showed greater improvements in overall functionality (CS-PFP) than the less supervised control group at four months (mean difference 4.3, 95% CI= 1.2 to 7.3). In addition, once the supervision of the FBF group had decreased to the same level between both groups, the significant improvement scores were not maintained.

Three studies compared supervised and unsupervised exercise on balance related outcomes. King et al (2019) detected that the individually supervised group improved in PPT ($p<0.004$) and MiniBEST ($p<0.001$). The unsupervised group presented as the least effective in outcome measures compared to the supervised programs. Atterbury & Welman (2017) found that groups did not differ significantly ($p<0.05$) pre or post intervention dynamic balance. Both groups had a significant improvement in the TUG but more significant in supervised group ($p<0.001$). The supervised group slightly improved in balance confidence ($p<0.051$) whereas the unsupervised group made no improvements. Lun et al (2005) found no change in scores in either groups for BBS, ABC and TUG during the intervention. Additionally, UPDRS-motor scores improved significantly in supervised group ($p<0.009$) compared to unsupervised ($p<0.022$).

Table 2. *Summary of key characteristics and findings*

Author, location, and study	**Participants and disease severity (DS)** (Hoehn and Yahr scale)	**Intervention**	**Comparison** (N = number)	**Outcome measures assessed**	**Primary findings**
Atterbury & Welman (2017) **South Africa** **RCT**	40 participants M: 29 F:11 **Average age:** 65 years **DS:** 1 to 3	**Duration:** Eight weeks **Intervention:** **Supervised (therapy led) and unsupervised (DVD led) groups:** 3x/week 40–60 minutes balance sessions Participants were in the medication ON phase	Pre-test baseline **VS** post-test **Supervised group** (N = 23) VS **Unsupervised group** (N= 16)	**Primary outcomes (PO):** TUG, ABC	- Supervised group significantly improved in all outcome measures (p<0.001) compared to unsupervised group. - Supervised group had a larger group size compared to unsupervised group
King et al (2019) **Oregon, USA** **RCT**	58 participants M:41 F:17 **Average age:** 63.9 years **DS:** mean 2.5	**Duration:** 4 weeks **Intervention:** Agility Boot Camp exercise program Exercises: Tai Chi, boxing, lunges, kayaking, agility course and Pilates **Unsupervised home exercise program:** exercise handouts provided 3x/week **Supervised individual exercise program:** 3x/week **Supervised group class program:** 3x/week	Pre-test **VS** post-test **Unsupervised home exercise program** (n=17) VS **Supervised individual physical therapy** (n=21) **VS supervised group class**	**PO:** PPT, Mini-BESTest, TUG, ABC **Secondary:**, PDQ-39, UPDRS-motor/ADL	- Significant improvements in PPT and Mini-BESTest in individual group (p<0.004/p<0.001) - Significant improvements in ABC scores in supervised group (p<0.001) - Unsupervised home group was least effective

		Participants were in the medication ON phase	**intervention** (n=20)		
O'Shea & Blake (2017) **Ireland** **Cohort**	15 participants M:11 F:4 **Average age:** 72 years **DS**: mean 2.5	**Duration:** 8 weeks **Intervention:** Supervised circuit-based group exercise class 1x/week 60minutes 2x45 mins educational component. Exercises: strength, balance and coordination Home-exercise booklet provided: 3xweekly for 15-20 mins.	Pre-test baseline **VS** post-test and 3month follow up test	**PO:** BBS, TUG, FRT, PDQ-39	- Significant improvements ($p<0.001$) between pre and post-test and three months follow up were reported in BBS, FRT and PDQ-39 - TUG was not found to have significant change throughout the study.
Combs et al (2013) **Indianapolis, USA** **RCT**	31 participants M:21 F:10 **Average age:** 67 years **DS:** 2	**Duration:** 12 weeks **Intervention:** Supervised Boxing training group (BOX) and traditional exercise group (EX). 24–36 sessions, 90 minutes each. EX exercises: strengthening, endurance training, and balance. BOX = Boxing specific activities Participants were in the medication ON phase	Pre-test baseline **VS** post-test	**PO:** BBS, ABC, TUG, PDQ-39	- Significant improvements in both supervised groups for BBS ($p<0.005$), TUG ($p<0.021$) and PDQ-39 ($p<0.022$) - EX group improved significantly in ABC ($p<0.022$).
Lun et al (2005) **Canada** **NRCT**	19 participants M:13 F:6 **Average age:** 65 years **DS:** 2 to 3	**Duration:** 8 weeks **Intervention:** **Supervised group:** 2x1hour/week. **Unsupervised group:** 2x1 hour program familiarisation session, continue exercises as often as they wanted	**Unsupervised home group** (n=8) VS **Physiotherapy -supervised group** (n=11)	**PO:** BBS, TUG, ABC **Secondary:** UPDRS-motor	self-supervised exercise program was found to have similar effectiveness as a physiotherapist-supervised exercise program in improving motor symptoms in PD patients - Both unsupervised ($p<0.021$) and supervised ($p<0.009$) groups improved significantly in UPRDS-motor scores

		Exercises: balance, core and extremity strengthening Participants were in the medication ON phase			- No other significant outcomes found between programs
Kara et al (2012) **Turkey** **NRCT**	17 participants M:11 F:6 **Average age** 65 years **DS:** 3	**Duration:** 12 weeks **Intervention:** Two supervised exercise groups 1x/week 50–60 minutes – using Balance Master protocol Exercises: balance, stretching, strengthening and coordination. Participants were in the medication ON phase	Pre-test baseline **VS** post-test	**PO:** Outcomes were based on the Balance Master protocol. Dynamic and static balance tests: STS, US	- No significant difference in STS and other dynamic balance tests between groups ($p>0.05$) - Significant change was noted in static balance (US) ($p<0.05$)
Schenkman et al (2012) **Colorado, USA** **RCT**	121 participants M:76 F: 45 Average age: 64.5 years **DS:** 1 to 3	**Duration:** 16 months **Intervention:** **AE program**: Supervised aerobic exercise 3x/week for 4months, 1x/month onwards **FBF program:** Supervised individualised flexibility, balance/functional exercise 3x/week for 4months, 1x/month onwards **Control group:** 1x/month supervised group session - national Parkinsons foundation fitness counts program Participants were in the medication ON phase	Comparisons: 4 months, 10 months and 16months **AE group** (n=41) VS **FBF group** (n=39) VS **Control group** (n=41)	**PO:** FRT **Secondary:** CS-PFP, UPDRS motor/ADL, PDQ-39	- No differences between groups in FRT, PDQ-39 and UPDRS-motor scores. - Supervised FBF group improved most in CS-PFP at 4 months (mean difference = 4.3, 95% CI = 1.2-7.3) - No differences were observed in CS-PFP scores at 10 and 16 months

Mehta & Kapoor (2005) **India** **Cohort**	44 participants M:32 F: 12 **Average age** 75.18 years **DS:** not measured	**Duration:** 74.2 days (mean sessions 66.8) **Intervention:** Individual supervised exercise (45-60minutes) Exercises: balance, gait, stretching, active exercises, and strengthening.	Pre-test baseline **VS** post-test score.	**Primary outcome:** BBS	- Greater improvements in BBS scores found in 70-79year age group with less duration of treatment - Significant change between initial and final values of BBS scores ($p<0.001$) with a mean difference of 6.09
Gandolfi et al (2017) **Italy** **RCT**	76 patients M: 51 F: 25 **Average age:** 68 years **DS:** 2.5 to 3	**Duration:** 7 weeks **Intervention:** 21 supervised sessions (50 minutes), 3 days/week **Telewii group:** at home supervised via skype balance and coordination exercises **SIBT group:** supervised clinic rehab - dynamic balance exercises	Pre-baseline **VS** post-test and one month follow up **TeleWii group** (n=36) VS **SIBT group** (n=34)	**PO:** BBS, ABC	- Both supervised groups significantly improved in BBS, ABC and PDQ-39 scores at post-test and follow up ($p<0.001$)

Discussion

PD symptoms can be managed with a variety of physiotherapy methods. Previous reviews have focused on exercise type, location, and outcome measures (Choi et al 2020, King et al 2013). This review draws together all evidence from studies by evaluating the effectiveness of supervised exercise on balance function in patients with PD, with an indirect comparison between level of supervision and different interventions used.

Evidence from this review suggests that supervised exercise aids short term (<4months) balance-related functions in individuals with mild to moderate PD (King et al 2019, Atterbury & Welman 2017, Schenkman et al 2012, Gandolfi et al 2017, Lun et al 2005, Kara et al 2012, O'Shea & Blake 2017, Combs et al 2013, Mehta & Kapoor 2020). This is reinforced by research that considers the effects of supervision on balance and muscle power in healthy adults which found supervised exercise is superior to unsupervised (Lacroix et al 2016). Although research was not conducted on individuals with PD, the results still demonstrate evidence of supervised methods having a beneficial impact on balance performance.

In the current review, five studies (Schenkman et al 2012, Gandolfi et al 2017, Kara et al 2012, Combs et al 2013, Mehta & Kapoor.2020) found short-term improvement in balance related outcomes with supervised exercise and one study identified long-term improvements three months post intervention (O'Shea & Blake 2017). Varying levels of supervision and intervention methods were used within studies, including one study which used supervised virtual reality in the intervention, which ultimately proved to be a beneficial method (Gandolfi et al 2017). This is supported by a review which suggested virtual reality-based rehabilitation has shown encouraging results for patients diagnosed with PD or a stroke (Amirthalingam et al 2021). However, the study may not be suitable for people with PD with cognitive difficulties and therefore, results are not generalisable. Two studies showed significant improvement in balance-related outcomes from supervised exercise with additional unsupervised sessions (Kara et al 2012, O'Shea & Blake 2017). This suggests the benefits in combining supervised with unsupervised exercise for improvement in balance function. One study had two supervised interventions, including one unconventional exercise group using boxing training which demonstrated significant improvements (Combs et al 2013). The number of dropouts in the study were high and pre-test scores were still compared with participants who completed the whole intervention; therefore, the results should be referred to with caution, due to the high RoB of the study. One study compared two highly supervised group with a minimally supervised group and significant improvements in balance were noted at over 4months in the highly supervised groups (Schenkman et al 2012). However, when the levels of supervision decreased to the same as the minimally supervised group for the remainder of the intervention, significance was not maintained (Schenkman et al 2012).

In the three comparison studies (King et al 2015, Atterbury & Welman 2017, Lun et al 2005) only one study identified a significant improvement in supervised compared to unsupervised exercise (King et al 2015). This is supported by other research that suggests supervised exercise groups provide greater benefits to individuals with PD, although the focus was on QOL and not balance (Dereli & Yaliman 2010). In this review, improvements in QOL were noted in group studies using the PDQ-39, whereas individual supervised sessions were not. Therefore, it is impossible for this study to make comparisons between

group and individual sessions on function and QOL together. From the two other comparison studies (Atterbury & Welman 2017, Lun et al.2005), one reported no difference from baseline balance measurements in supervised or unsupervised (Lun et al 2005). Patients were able to self-select their preferred intervention and supervision ceased eight weeks into the study, which could have created a bias in the results and therefore, the results from this study should be interpreted with caution (Lun et al 2005). The results from other comparison study displayed significant improvements in both supervised and unsupervised exercise groups, although the biggest improvements were made by the supervised group (Atterbury & Welman 2017). This supports previously mentioned studies (Kara et al 2012, O'Shea & Blake 2017) which suggest an approach for incorporating a combination of supervised and unsupervised sessions, to improve balance in people with PD.

Limitations/Quality assessment of studies

RoB assessments were performed to assess the quality studies included in the review (Sterne et al 2019, Sterne et al 2016, Critical Appraisal Skills Programme 2018). The reporting of adherence and drop-outs to the interventions also should be considered as this caused bias in most studies used. Unequal sample sizing between intervention groups was highlighted as an issue due to the impact on effect size of results, which should be taken into consideration from this review. The quality of 80% of RCTs identified some concerns in at least one of the domains due to the strategy of the interventions which impacted non-adherence, deviations from the intervention and created confounding bias. Three studies accounted for non-adherence by providing appropriate analysis of the estimated effect (King et al 2015, Schenkman et al 2012, Gandolfi et al 2017). One study identified high RoB in two domains resulting in overall low-quality rating due to missing data and deviations from the intervention which were likely to negatively impact on the results (Combs et al 2013).

Both NRCT's reported low intervention, deviation, and selection of reported result bias (Lun et al 2005, Kara et al 2012). However, overall RoB of the study by Kara et al (2012) was deemed unclear due to concerns with confounding, selection and missing data which impacts both internal and external validity. High RoB was identified in Lun et al (2005) due to participants self-selecting group allocation and self-reporting outcomes in one of the studies resulting in a considerable bias. The two cohort studies produced concerns of RoB between them for intervention, sampling, exposure, reporting of results and confounding factors (O'Shea & Blake 2017, Mehta & Kapoor 2020).

Implications of results for practice

Limitations of the review

Non-English studies were excluded from the review which could have contained high quality evidence to help support the review. Many studies had small sample sizes and none were conducted in the UK, therefore, the generalisability of the results cannot be applied to UK based patients with PD (King et al 2015, Atterbury & Welman 2017, Lun et al 2005, Kara et al 2012, O'Shea & Blake 2017, Combs et al 2013, Mehta & Kapoor 2020). Due to variations of balance-related outcome measures within the review, better consistency in outcome measures used could facilitate future research. Most studies did not conduct post-intervention follow ups meaning the effectiveness of long-term interventions cannot be considered, and therefore, implications can only be made short-term.

Conclusion

The balance of individuals with PD improved following intervention in eight of the trials suggesting that supervised exercise can benefit those with mild to moderate PD. Although the evidence holds low methodological quality and a low percentage of follow up testing, the recurring themes could provide some clinical value for improving physiotherapy rehabilitation methods for people with PD. Improving the management of motor symptoms such as balance for individuals with PD is essential throughout disease progression to help reduce impacts on patients, carers, families, and the NHS (Alzheimer's Society 2021). Future research should consider conducting studies in the UK with larger sample sizes and looking into levels of supervised exercise and its impact on improving balance in people with PD.

Conflict of Interest Statement

The Author declares that there is no conflict of interest.

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Elderly Victims of Domestic Abuse

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Although the UK government definition of domestic abuse recognises anyone over the age of 16 years as a victim, Age UK (2020a) demanded that the government ensure older abuse victims are not left unheard, calling for more inclusive legislation addressing this abusive pandemic. As SafeLives (2016) explained, although elderly abuse is included under the branches of domestic abuse policies, there has been no tailored response to elderly victims. The UK Government responded with the further inclusion of older people defining elderly abuse as "Elder abuse is a single or repeated act, or lack of appropriate action, occurring within any relationship where there is an expectation of trust, which causes harm or distress to an older person" (House of Lords Library, 2021). However, this is arguably not enough, as reports of the abuse, although increasing, do not show the true nature of the pandemic of abuse. Yon et al. (2017) have expressed concern that an estimated one in six people over 60 will experience abuse within their community. Yon et al. (2017) concern is further raised as out of these cases, an estimated 1 in 24 is reported.

The Office for National Statistics (2019) states that in 2019, 280,000 people aged between 60 – and 74 years old reported experiencing domestic abuse in the UK. Older victims of domestic abuse often face further challenges in reporting their experiences, as in many cases, their only window to the outside world is through their perpetrator. Thus, these figures do not accurately represent the elderly

abuse occurring across the country. One of the key findings from Hoegar et al. (2022) report showed that between 23rd March 2020 and 21st March 2021, they recorded 145 adult abuse deaths, with 40 of these being classified as a family homicide, with the reminding 105 as intimate partner homicide. One in four of these classes is a victim aged over 65 years old in the UK. Furthermore, Hoegar et al. (2022) reported that 63% of adult family abuse victims were over 55 years old, with abuse increasing as their age increased.

Band-Winterstein (2015) defines elderly abuse as ageing in the shadow of violence. The experience of abuse differs from younger victims, where family traditions, values and the fear of reporting a loved one are instilled into the victim. SafeLives (2016) report stated that older people over 61 years old were 44% more likely to experience abuse from an adult family member. Furthermore, SafeLives (2016) reported that they are 48% more likely to be living with a disability, with just over a third (34%) living with a physical disability, thus, increasing their vulnerability.

More specifically, The National Institute on Aging (2022) and Aceirno et al. (2010a) summarise neglect as one of the most common forms of elderly abuse, where abusers willingly do not meet older adults' needs, leaving them to suffer. Like any victim of abuse, elderly individuals could experience financial, physical, emotional, coercive control, economic abuse or sexual abuse and violence towards them. During the Covid-19 pandemic in the UK, Age UK (2020b) received an increase of calls to 655 on their advice line seeking support for victims of elderly abuse.

Furthermore, Aceirno et al. (2019) state that financial mistreatment, including withholding finances and improper use of an older adult's money, property, and assets, is becoming increasingly common. Hafemesiter (2013) explains that financial abuse can leave the older adult traumatised and unable to trust anyone, leaving lasting psychological stress. Often the perpetrator will gaslight their victim, tricking them into signing over assets or trick/manipulating them into thinking they had spent their funds (Home Office, 2022). The World Health Organisation (2008, in Adams, 2014) defines financial elderly abuse as the improper and illegal exploitation of funds, including forcing changing of wills, accessing finances without consent, and abusing a power of attorney. In addition, Wilson et al. (2009, in Bagshaw et al. 2013) suggest that families may have a keen interest in their elderly relative's assets, as though they are attempting to ensure they protect their future inheritances.

Older adults also experience sexual abuse and violence. However, there is a limited exploration into this area. Lea et al. (2011) challenge the concept that rape victims are positioned as young women attacked by strangers, thus excluding the imagery that

older men and women could be victims. As an extension, Aceirno et al. (2010) research reported that out of 5777 participants, 0.6% (34) had experienced sexual abuse by a family member within the last year. Elderly victims are more hesitant to report sexual abuse by a family member, as often, the preparators are their children. Therefore, these numbers do not accurately represent the experiences of elderly abuse. One of the concerns raised from the findings of the Crime Survey for England and Wales survey is the age capping of data collection, which is halted at 74 years old (Shepperd, 2021). Age UK (2020c) further raise their concerns, as the Crime Survey for England and Wales survey does report that 180,000 women and 98,000 men aged 60 to 74 were victim-survivors of domestic abuse in England and Wales. Shepperd (2021) explains that this results in victims over 75 years old experiencing partner or family abuse not being captured. Thus, illustrating only a fraction of the public health issue.

There is emerging is new evidence that older men are becoming prime targets of domestic abuse due to their dependence on their partners (Respect, 2013). In response, Respect (2013) explains that their increasing vulnerability of being unable to retaliate due to their lack of physical strength results in them being overpowered quickly. Older adults bruise, and their bones break easily due to the fragility of their bones and skin; they will require more hospital submissions, which could become a red flag in the system. Although they may not declare these injuries as domestic abuse, the healthcare professionals may presume these are due to their age and ability. Although, Respect (2013) has suggested that some older male victims of abuse may have been abusers in their youthful days, and due to their increased vulnerability, their victims may retaliate.

Roberto et al. (2013) explain that older women are more likely to be abused by their spouses, partners or adult sons. Abuse against the elderly is rising, especially by their offspring (Bows, 2019). Holt (2017) explains that men in their fifties and women in their seventies are at a higher risk of being attacked or murdered by their sons or daughters. Thus showcasing the violence between parents and children. Bows (2019) research focused on UK domestic homicides and showed that of the 221 recorded between 2010 and 2015, 43% of these were older people.

Due to the nature of ageing, there is an expectation that older adults will become more dependent on others to assist with their daily living, increasing the risk of abuse. SafeLives (2016) explains that victims are often hidden; victims fear that if they speak out, they will either experience further abuse or experience neglect. Due to an increase in the proportion of older people in the population, there is an associated increase in the number of family members providing care (Adib et al

2019). Elderly abuse has been associated with caregiver burnout or burden (Arai, et al., 2017).

Domestic abuse has always been defined as a hidden crime; with elderly victims, it is no different; however, it is less likely that an older adult will report their abuser. Adib et al. (2019) explain that victims may recognise the abuse as family conflict, with the desire to remain in-house due to the sense of shame it could bring if exposed. Age UK (2020c) expands on this, suggesting that older abuse victims are less likely to have access to professional support provisions, limiting their opportunity to raise this. This further instils the social image that abuse does not happen to older adults by their family members.

Regarding perpetrators of elderly abuse, society often refers to a healthcare professional or carer being the aggressor (World Health Organisation, 2021). Thus, neglecting the idea that the abuser could be an older adult's son, daughter, partner, or relative. Additionally, Tyrell et al. (2016) study reported that partners of people living with cognitive decline, including those living with dementia, often displayed aggressive behaviour toward their partner when they experienced a lack of support or felt vulnerable caring for their loved one. Therefore it could be challenging to recognise, as the victim may feel they are to blame or feel it is just due to frustration, rather than view it as abuse. Isham et al. (2017) research also report similar findings, suggesting that as family relationships decline, there is an increased risk of violence and abuse. Elderly abusers use their dependence against them, increasing the challenge of reporting their experiences. A cycle of abuse is formed, with their loved one continuously abusing them with promises of it not occurring again.

When elderly abuse is mentioned in society, the thought trail focuses on professionals being the abuser or neglecters (Age UK, 2020c). However, it is becoming a phenomenon internationally that older adults are experiencing abuse by their family members (Age UK, 2020c). Without further research and insight into recognising this matter, many more older adults will suffer at the hands of their loved ones. Furthermore, Age UK (2020a) is calling for a new law to further protect older abuse victims, including introducing more substantial penalties for these serious crimes. There needs to be an elimination of the perception that domestic abuse ends at a certain age and that people over sixty years old do not experience this. The abuse devastates the victim, leaving a lasting emotional trauma and impacting the victim's self-esteem and self-worth. This report showcases that elderly abuse by family is on the increase, and further awareness and support provisions are needed. Elderly victims need to be provided with the tools to seek support, thus, no longer being hidden in society.

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Reflections on the complexities of undertaking research in the hospital milieu

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Introduction

A fundamental part of the reason for the persistence of poor care practices can be seen to lie in the failure to translate knowledge to practice, which is a particular and continuing cause of concern within health care environments (Lomas 2000, Lomas 2007, Dopson & Fitzgerald 2005, Nicolini et al 2007, Kontos & Poland 2009, Oborn et al 2010, Pentland et al 2011, National Institute for Health Research 2017).Kitson et al (1998) advocate the use of the Promoting Action on Research Implementation in Health Services (PARiHS) framework as one model that represents the complexity of processes involved in utilising research into practice. They identify some key elements; the effect that contextual factors have upon implementation of evidence, the importance of facilitators in this process to provide support for change and the need to combine different evidence types for clinicians.

This analysis of change as a process aligns well to the action research perspective, part of a family of related investigative approaches under the umbrella of 'Action inquiry' (Morley 1991). One element of this paradigm is the concept of Praxis; acting upon existing conditions in order to change them, with knowledge derived from practice and practice informed by knowledge in an on-going process (Lather 1986). I used the Praxis approach in some recent research comparing a standard medical ward with two others who had been adapted to reflect a more dementia friendly environment (Keenan 2022) and feel that my reflections on how this contributed to overcoming issues might be of value to others.

B**ackground**

Undertaking research and attempting to change practice in the NHS hospital environment requires a fundamental awareness of the culture and the sometimes-quixotic nature of that setting. Some of the difficulties that I encountered echo that of other recent research in NHS hospitals, for example, Godfrey et al (2018) emphasise the instability and turbulence of the acute hospital environment. Their longitudinal study of 10 wards in 5 acute NHS Trusts used a comparative study design to evaluate the impact of using the Patient Interaction and Engagement (P.I.E.) programme in the care of people with dementia on acute wards. However, 4 of the 10 wards in the study were closed at short notice for organisational reasons and

the P.I.E. process adopted in only 2 of the remaining 4 wards, so that they lost 80% of their total sample population. They cite organisational factors as being fundamental to improving care or acting as restraints to those improvements and conclude that changing practice in such complex organisations requires a more in-depth understanding of the contextual factors that impact on the capacity to absorb and embed new practice. I sought to address these organisational factors in my approach to the present studresearch by utilising the inherently collaborative and pragmatic working of the Praxis framework (Lather 1986).

The complexity and instability in health care settings is not of course exclusive to hospital environments and there are further examples from residential care settings. Towers et al (2016) also encountered difficulties in their project to inform practice in care homes using the Adult Social Care Outcomes Toolkit (A.S.C.O.T.). The original sample population consisted of four care homes but during the course of the project one of the nursing homes in the study experienced a complete change in senior management and then unexpectedly transferred its ownership to another provider and had to withdraw from the project completely.

Reflections on my own experiences

Some of the issues I encountered in conducting my study illustrate the complexities of this process. For example, my field notes detail that although the NHS ethical approval process had progressed within the expected timeframe, the Trust clinical governance process had taken an unexpectedly protracted period of 6 months due to a cumbersome bureaucratic process, the absence of key decision makers, and quandaries about costs associated with the research. Governance approval was finally given only after the direct intervention of senior nurses and medical staff within the Trust, and without which that process would have been even lengthier rendering the study unfeasible. Had I not been working in close collaboration with clinical colleagues over an extensive period I would not have been able to access the support I was given, and I doubt that this situation would have been resolved in time to complete the study.

Upon discussing this with nursing colleagues I discovered that this type of delay was a not uncommon experience and would seem to proffer at least part of the reason that nurses are not more involved in research (Pentland et al 2011). In the light of this experience, it could be concluded that the clinical governance research process currently inhibits the potential of nurses to conduct high quality relevant research that relates to practice. To address these deficiencies, I would suggest that the process needs to be simpler, more transparent, and quicker to negotiate.

My field notes highlight my frustration and powerlessness in another instance, when at the point of data collection on the standard medical ward I discovered that the functions of almost all the medical wards had completely changed in the preceding two months due to a management reconfiguration for pragmatic/business rather than clinical reasons. Thus, in one example, staff who had a genuine interest in dementia and who had consequently attended all the courses that they could access were no longer caring for this type of patient but were now caring for a younger cohort of working age patients who had been adversely affected by the new range of so called 'zombie' drugs.

Consequently the previously designated ward in my sample had to be abandoned as inappropriate to the study and a new one selected carefully to ensure that the patient population was both appropriate and was homogenous in terms of the population in the preceding 12 months, as this would have impinged upon the study both in terms of staff ideology/attitudes and also in the significance of retrospective data- as the data might not be comparing like with like on the same ward. This situation may not have been salvageable for the study had I not been working within a Praxis paradigm of close collaboration and cooperation with clinical colleagues who 'rescued' me from such situations of organisational impasse on many occasions. The state of flux within which the environment of care is set also has important implications for staff training, fundamentally training in caring for people with confusion must be more global in nature rather than targeted at specific wards geared for that purpose at any one time.

The data collection on the first dementia friendly ward in the sample had also proved problematic. My field notes detail that I encountered an apparent reluctance on the part of ward staff to let me approach any of the patients or even consider that people with early dementia or mild cognitive impairment could be considered for the study, they seemed to be overly suspicious of my presence and very averse to cooperating in the study. When this was explored with the Senior Nurse who was supervising the researcher the 'real politick' of the situation became apparent. It emerged that the ward staff had very recently been through a very harrowing period following criticisms about care.

The traumatised trained nursing staff on the ward were understandably very fraught and almost paranoid about making any mistakes, and my presence was merely adding to their unease. It was agreed that this was not the most propitious choice for inclusion in the study and another more suitable venue selected. Upon reflection it would have been difficult for me to have

foreseen this situation and must be seen as part of the constantly evolving state of flux that constitutes the acute general hospital and accepted as part of understanding the nature of that setting. Once again, the close collaboration and cooperation of clinical colleagues that is an essential element of the Praxis process, facilitated alterations to the sampling at very short notice.

Understanding the complexities of the care environment is also a crucial element in interpreting the results of the research, for example, the issue of staffing on the three wards. Unlike Scotland there is currently no legislation to ensure safe staffing levels in England despite the evidence of significant negative patient outcomes associated with lower registered nursing numbers (Royal College of Nursing (R.C.N.) 2019). These include issues surrounding; mortality, care quality, missed care, and adverse events such as falls and the development of pressure ulcers (Royal College of Nursing (R.C.N.) 2019).

In this study the staff/patient ratios did not vary greatly between the three wards which would imply an equivalence between the settings regarding care delivery, and an adherence to safe staffing guidelines (R.C.N. 2019). However separate trained and untrained staff: patient ratios differed, with a more diluted skill mix on one of the adapted wards. The staff: patient ratios also do not reflect the practical impact of the actual numbers. Because the more dementia friendly wards were smaller than the standard medical ward and contained less beds there were less nurses per se present to deal with difficult situations or any crisis that might arise. In addition, any staff shortages due to sickness or absence would have a proportionally greater impact on the smaller wards. So, although the Trust guidelines for staffing levels per patient had been met the nature of safe staffing proved to be far more complex than the formulaic strategy would suggest.

Another example of the complexity of the methodological issues relates to the findings on rates of falls on the three wards. Despite previous research findings that the incidence of falls was reduced in dementia friendly ward environments (Sprinks 2012; Bray et al 2015), in this study regression analysis of the Trust falls data for the three ward environments in the period during the study elicited no evidence of any significant differences between them in terms of the incidence of falls. However, the relationship between intervention and risk of falls is much more complex than has previously been acknowledged (Public Health England 2019), with a recent Cochrane systematic review on interventions for preventing falls in older people in care facilities and hospitals, (Cameron et al 2018), suggesting that there is less certainty as to the effectiveness of multifactorial interventions due to the quality of the available evidence.

It was not possible in this study to track the incidence of falls in the specific sample population as the overall figures accessed for the number of falls on the wards may not have reflected differences between the wards in the fall rates specifically of older people with cognitive impairment, and the effect that the different environments had on this, so were not a reliable source of data from which to generalise. Also, only information on the total number of falls per ward was specified in the IRAS ethical approval document, which resulted in data which gave no detail as to the circumstances of the fall, such as time of day or exact location on the ward, etc. Consequently, issues such as lighting on wards or in toilet areas and how that might have contributed to falls could not be explored. To capture such data a further contemporaneous longitudinal study would have been required but this was not a practical option in view of resource and ethical approval restrictions. This had negative consequences for the use of this data as a source of evidence for triangulation (Wilson & Hutchinson 1991; Morse 1991; Bryman 2006; Rinaldi Carpenter 2007). Had I collaborated more closely with colleagues at the point of writing the IRAS ethical approval document I could have accessed their more expert knowledge about this data and avoided the situation entirely.

Conclusions

The issues I encountered in undertaking my research are not uncommon in such a multi-faceted and complex clinical setting (Godfrey et al 2018, Towers et al 2016). They emphasise the key elements identified by Kitson et al (1998) for addressing the research/practice divide: the importance of facilitators to provide support and the need for blended approaches. The Praxis model incorporated both these elements, without the support and collaboration of clinical colleagues this study would have stalled on many occasions, and further collaboration and blended approaches on my part would have overcome methodological issues much more effectively.

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No Excuses. Or the story of my Black Suit: ***An update of an article published in 2008***

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I was born during the Second World War in Nottingham and moved to Birmingham aged four my father, having just left the army, buying a house near the airport without a prior viewing. My horoscope said I would be a sickly child, but become stronger as I got older, but I'm not sure that this was very accurate; I was certainly a neurotic child and had many fears including the dark, heights, and authority.

Although I only just got into to a grammar school, after the first couple of years I did well and eventually qualified to go to Oxford University to read medicine. Whilst at Oxford I lived in "digs" with four other people and spent most of my time in the university science library, at parties and graduating with a degree in animal physiology before entering clinical studies.

During my second year, people started throwing peppermints at me in the library, (due to my coughing) and eventually I saw a general practitioner, who decided I was neurotic until a self-referred chest x-ray at the Radcliffe Infirmary confirmed that I had pulmonary tuberculosis. I was sent home by train to tell my parents. I was then admitted to the sanatorium called the Sunnyside Convalescent Home where I was isolated, as they had found I was highly infectious. Although the nurses used to come to smoke in my cubicle, I was soon allowed freedom of the site. I could not use the internal telephone as I was infectious, but I was allowed to use a public telephone outside the hospital gates. It makes today's infection-control seem quite draconian!

I did my first major exams, while an inpatient and was amused that other patients tried to help by describing the box, which came for my practical exam. I came top in the University in Physiology, which they thought was due to my fever, rather than my intelligence. I was told that up to 5% of medical students were, at that time, expected to get tuberculosis, although my lifestyle living with two other people with TB may have been relevant!

On discharge I lived in the newly built St. Catherine's College, completed an unexpected First Class Degree and transferred to UCH London for clinical studies and though the top entrance scholar discovered life, including drawing at the Slade School of Art which gave me a lifelong interest in other people's images. Maybe the highlight of my final exams was the prescription for amphetamines from the GP. Never used again.

After my first House job at UCH I returned to Birmingham as my wife to be lived there. We married in 1969. I trained in renal medicine and obtained my specialist qualification (MRCP) at first attempt and started research, but my health deteriorated and I resigned and after some locums, became a principle in General Practice in Wolverhampton. However, following a severe episode of depression, I was admitted to the York Clinic in London under a famous Psychiatrist Dr Stafford Clarke. It was only after Electro-convulsive Therapy that I improved. This has left me with the loss of a lot of childhood memories.

Before that admission my wife had been told I had a personality disorder and would never manage to sustain a medical career. It became clear that I had had problems from my teens onward and was eventually diagnosed as bipolar. I lost an agreed

appointment in Southampton because of my mental health problems.

I had as a general practitioner, become irritated by psychiatrists and geriatricians vying with each other to avoid elderly patients with confusional states. This motivated me so that when I returned to work, I took a locum job in geriatrics at the local hospital. I was eventually ejected for undermining the consultant's authority. Others thought I had promise and Dr Ronald Cape appointed me as a Supernumerary Registrar at Selly Oak Hospital then substantive Senior Registrar at East Birmingham Hospital; becoming Professor Isaacs first lecturer and then returning to the NHS as a Consultant in South Birmingham to stay till I retired in 2007

The title of this piece referring to my black suit was based on staff who saw me arriving who would tell the ward what mood I would be in that day based on what I was wearing. I equated this with Churchill's "black dog", but his having depression has now been challenged (Vale & Scadding 2020)

I was fortunate that lithium, for approximately 30 years prevented serious relapse but since I stopped taking medication, I unfortunately had several relapses which started 15 years after the last episode but due to the care given by my present and second wife, I have never required re-admission. I can only imagine the difficulties my first wife had as well as our having four children and our marriage ended after 21 years. I met my second wife when we had both become Churchill fellows, a travel award which is offered annually for personal development.

I worked as a fitness to practise assessor for the General Medical Council (now MPTS) for the maximum 10 years retiring in 2016.This is made me realise how fortunate I was, as for many medics bipolar illness is a career ending diagnosis. In many people's eyes I have had a successful career. My colleagues said I was safe as I recognised when I was becoming unwell.

I have before and since retirement had several serious physical conditions. Following vascular surgery for popliteal aneurysms and compartment syndrome, while on a GMC panel high dose opiates provided vivid hallucinations -including the hospital car park becoming the Manchester ship canal and the adjacent building a larger oil tanker. In an earlier episode at Selly oak hospital, I thought I had to get out of bed to vote and tore out my drip but did get to the toilet for the first time.

Retirement brings us new opportunities to remain active and for me these had to be where I could be of service. Despite two recent episodes of depression controlled by long term medication, probably for the rest of my life, I remain active and involved in a number of activities. Since I retired in 2007, I have remained active including working for the GMC and as lead governor the Birmingham community healthcare trust from which I retire in September 2022. I retire as a public governor in 2024

I would say to anyone told by their medical adviser that they would never be able to maintain a full-time job due to their mental health problems (but not Stafford Clarke), listen, but follow your "nose" to do something you want to do and you will have a good chance of succeeding. They also told my wife to handle all finances, which she refused, and hopefully that was the right decision?

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Exploring the experience of a family carer looking after her father with dementia during the pandemic

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Introduction

Claire is the daughter of a man who is living with dementia. She has supported her parents and brothers through the different stages of his illness. The purpose of this article is to share Claire's experiences in the hope they will give practitioners deeper understanding of the caring role and carer's experiences. Claire's father's dementia worsened during the time of the covid pandemic, meaning that she has a distinct experience to report on, which nevertheless shares similarities with experiences of others pre-covid and during this time.

Dementia is an umbrella term for a range of conditions, including Alzheimer's disease, that lead to poor short-term memory, language and communication problems, difficulties with judgement, motivation and managing emotions (Sandilyan and Dening 2019) which together lead to problems in managing the skills required in everyday life and increasing need for support from others. The caring role involves adapting a relationship to keep the cared-for person safe, happy, healthy and socially included (Jenkins et al 2016). This adaptation requires significant effort. For example, communication skills to respond warmly and calmly to repetitive conversations, to anxious prompts for reassurance and in providing clear, brief explanations to aid orientation. Carers also manage the environment so that the person can maintain independence safely. As the condition progresses, the person living with it may need assistance with activities of daily living including preparing food, using the toilet, finding their way, even in familiar environments and eventually with eating and drinking, washing, and walking (Jenkins et al 2016).

Dementia is a gendered condition. Most people living with dementia are female (65%) and most carers (60-70%) are female, either spouses or daughters (Alzheimers Research UK 2015, Kokorelias et al 2021). Older women who develop dementia may previously have cared for their father, husband or both. They in turn

are more likely to be cared for by a female relative. In this respect Claire reflects the demographics of caring in the UK and globally. Yet her personal experiences also shed further light on how the caring experience is mitigated by factors including her family's social and economic circumstances, her professional insight and professionals' attitudes and behaviour.

Lifestyle factors can increase and decrease risk of development of dementia. Protective factors include higher levels of education, a healthy diet, regular exercise, social connections and engagement with activities that require thought or effort (Akyol et al 2020). When a person does have these protective elements in place, the risk arising from genetic factors and poor physical health (family history of dementia, circulatory issues, diabetes, hypertension) is mitigated. In Claire's father's case, his risks related to these factors (his mother also had dementia) could have been offset by his educational level and professional and social activities. When a person participates in activities that build 'cognitive reserve' this can postpone development of dementia (Zhu, Bao and Swaab 2019), although the person's deterioration may later seem to condense into a shorter but steeper decline. Claire describes this as *'like a steam train.*'

The course of progression of dementia is often written about as if it happens in stages (for example Siafarikas et al 2018), but although there may be a general pattern of deterioration, the process is very individual. It reflects not only the changes in a person's brain, but also factors such as their opportunities to stay socially involved, have a healthy lifestyle and have people around who can promote self-esteem through sensitive communication and who can enable them to live with as much independence and autonomy as possible (Jenkins et al 2016). In this article we share an example of how the family of a person living with dementia experienced this process. While it is a personal account, the illustrations may correlate with those of many other families whose loved ones come into our services.

Recognising problems, getting a diagnosis

There is no cure or effective medical treatment for dementia (Vernooij-Dassen et al 2021). As a former GP, Claire's father may have been aware of this. Claire's father did not pursue a diagnosis, despite recognising his poor memory:

'He had my granny living with them who had dementia. We did have conversations about it, and he used to joke 'I'm losing my marbles''

The family noticed his forgetfulness but did not initially frame this as dementia. However, with time more issues arose, some of which were risky:

'Well, to begin with, just his medication …. so he was usually very capable of taking his meds. He was really on it and then gradually there was a realization that actually (he was) always taking double doses or he would wander off into the study where the stash of drugs were, so to speak, rather than the organised stuff. And he would take another dose … because he's forgotten that he's taken … and obviously because of the cocktail of medication he was on it was quite dangerous really'.

A diagnosis may not have resulted in treatment, but nevertheless there are many reasons to have one. A person who is aware of their diagnosis can tell their family and friends, thus potentially enabling others to adjust interactions and so promote social inclusion. The person can plan ahead, share their wishes for the future, including preferences for care interventions (Jenkins et al 2016). Under the Mental Capacity Act (2005) this can be formalised through advance statements and decisions, and by appointing trusted friend or family as 'Lasting Power of Attorney' the person with dementia can ensure that if they are unable to do so themselves, decisions about them are made in their best interest by someone who understands their values.

Claire described the family gradually realising that her father could not be left alone, without ever really discussing the underlying reason for this. However, in retrospect, she questions why none of the professionals noticed the issues:

'I struggle that any professionals didn't notice that my dad had some kind of symptoms and didn't broach it with him. My dad had 18 tablets in total per day – morning and the evening. So, yes he was under the care of health. Why didn't any of them pick up on subtle changes?'

The lack of diagnosis for Claire's father reflects that of around 40% of the population with dementia in the UK (Alzheimers Research UK 2022). Diagnosis rates are currently 62%, so still below that of the aim of two-thirds in the Prime Minister's Challenge on Dementia 2020 (Department of Health 2015). The Covid 19 epidemic had a catastrophic impact on diagnosis rates due to minimal availability of face-to-face appointments with GPs and memory assessment services, while informal recognition (e.g., by hospital nurses) followed by assessment fell too because of the extreme high pressures on services (Allen 2022). Claire's father's memory problems began 15-20 years before the pandemic, but his significant deterioration took place alongside it. This may have reflected the natural progress of his condition, or perhaps the sudden isolation, lack of stimulating activities and opportunities to exercise that resulted from the restrictions hastened his decline. In any case, the lack of diagnosis at this stage and time may not have made much difference, as Claire says:

'It is good to get a label. When it means you can get the help, yes, it opens the doors, but in a lockdown it wouldn't have opened so many doors anyway'

Coping with problems

Caring happens in the context of existing norms and relationships. In describing her family response as '*just dealing with it. Old school, everything's fine…*' Claire seems to indicate they were calmly compensating for a disability without ever naming it. Culturally, it was normal for Claire's father, and many others of his generation and background (Welsh) to be looked after in old age, as they were when working and their wife was home raising the family.

'Difficult to say in terms of activities of daily living because my mum actually did a lot for my dad in terms of cooking, cleaning, very traditional household. In that respect she was a housewife and he was the worker. So he did have a lot of stuff already done for him like his ironing and things like that. So yeah, he never had to do that anyway. No so he didn't need any help with reminding to go to the toilet or eating or anything like that.'

For many carers, symptoms become difficult when the person they look after breaks a cultural norm (Bunting and Jenkins 2016). For Claire's Mum, this arose when his self-care and personal hygiene deteriorated,

'he was not getting dressed and I remember Mum being really infuriated by the fact that there was this gentleman that used to religiously get up in the morning shower and shave, get dressed. He just lost interest in that'

Fortunately for Claire's father, he never seemed to be distressed by his condition. This was despite various problems that arose, especially in noisy, busy or unfamiliar environments,

'He couldn't keep up with the speed at which people have narrative with each other and that was hard. And then there was one time I was watching the rugby with him and it was in lockdown. We called some friends on FaceTime, so we have an iPad with the telephone. And watching the Six Nations and he got up, he said well, should we go home now and he thought we were in the pub'

Technology was a lifeline to social contact for many people throughout the pandemic (Siette et al 2020) but would be difficult to navigate for a person with dementia if they were not accustomed to its use.

Dementia can affect proprioception, gait and balance (Jenkins et al 2016), meaning that those affected can find it difficult to move their body around a space. This happened to Claire's father,

'he started falling off the sofa, just onto the floor, he couldn't physically get back up. So we got called quite a lot of times to pick him up

because he fallen off it. But significance of this was, he was an able-bodied man. Although yeah…'

'Dad fell once in the bathroom and it was a complete mess. They said you need to come over, you need to help. Even my brother found it difficult.'

Emotions and relationships

The caring role is often experienced as exhausting, challenging and thankless, with financial, social, psychological and physical consequences for caregivers (Dempsey et al 2020, Francis and Hanna 2022). People with dementia may be frightened, lonely, disorientated and anxious and act accordingly (Jenkins et al 2016). However, this was not the case for Claire and her family. In the following example, a difficult situation could have been exacerbated by tension related to misunderstanding, embarrassment or shame. But Claire's father remained appreciative:

'He was the easiest person to look after because he was so grateful. I remember moisturizing his legs once, so 'you're very good at this Claire'. Putting some moisturizer on made him feel a bit better, you know, after having a shower because he soiled himself … he always used to just be really grateful for anything. Yeah, never moaned, never got agitated or anxious'

While much of the literature focuses on carer stress and distress (Francis and Hanna 2022) there is also evidence to suggest that carers can gain emotionally and spiritually and that relationships sometimes strengthen (Dempsey et al 2020). This is more likely with adult child carers than spouses (Kokorelias et al 2021) and happened for Claire,

'100% you know. Yeah, definitely, he relied on me and we had a bit of a laugh'

For Claire, the caring role seemed to offer a chance to reconnect with her parents after years of living far away from them. Her parents came to live in the West Midlands and she and her family spent more time together, her children became closer to their grandparents and later they too could offer practical support. While the arrangement suited the family others had mixed reactions. Some people implied that the role was inappropriate for a daughter or that Claire was taking on too much:

'Other people, I think, looked at me doing it, going well, you can't do that. I'm alright with it and he's alright with it, so that's fine'.

Sometimes the concern was couched within praise:

' 'you're amazing what you do for your Dad'. Well, yeah, but it's great. Why would you ever not want to do it, and I'm lucky enough I could do it because I was here. I guess it is physically being closer to your parents. It's the original relationships. Going to make a difference as well isn't it?'

Claire's father gradually became more dependent and less able to communicate. She observed that '*he's not the dad that he was because he's not the same'*. But in the following anecdote, Claire and her son were able to recognise that her father was still the same person he had always been:

*'we raised the bed up so we didn't hurt our backs and then put the bed down and the bed broke halfway. And my Dad was like floating in the air and then went: 'Ohh you ***** the bed up'. Yes, just like my Dad would have said, you know and previous to that he'd been talking about what I don't know, but a bit of a confusing conversation. But at that pure moment, it was like a moment of lucidity'*

The nature of dementia and its long progression means that it is often likened to a journey. Other metaphors are used which can have the effect of dehumanising the person. For example, they may be compared to a 'shell', or having a 'living death' or being 'no longer there'. Examples like this show carers that their family member may have changed, but at core their real self remains. Respecting this quality, sometimes called 'Personhood' (Kitwood 1997) guides practitioners and family carers in providing care that promotes a sense of identity and enables emotional needs to be met.

Navigating the system

Knowing how to access and interact with professional support is often very difficult for families, who report a lack of information about services, difficulties obtaining a diagnosis, and problems accessing support for the person they acre for and for themselves (Francis and Hanna 2022). Even though Claire is a healthcare professional she too found it very hard, perhaps because there was never an official diagnosis:

'Not knowing is hard…. you know, I'm not an expert in this. Not really any professional help that you could get because we didn't have a diagnosis ……and with not having a diagnosis is really, really difficult ……really, really hard. If you don't get that label…'

The role of carer can be all-consuming. Carers need a person as a point of contact to guide them through. The dementia navigator role (Merrilees et al 2020, Agewell Sandwell 2020) should work like this, but access to help is limited without a diagnosis (Hanna and Francis 2022).

'Actually, when you're living and breathing it, you don't know what you need. You need somebody to you……I needed someone to tell me, right? Because sometimes when you're embroiled in a situation you don't see it all. You can't see the whole picture. Hmm, it's hard'.

The lack of support meant Claire and her family had to plan and provide care between

themselves. Even as a person with a high degree of 'health literacy' within an informed community (Muscat et al 2021) Claire was not able to identify any source of support. This may be hard for professionals to imagine, but poor health literacy in the public is something to bear in mind when designing services and signposting between them (McGrath et al 2016).

During the most stringent lockdown periods Claire could not contribute, but at other times she and her husband provided extensive personal care and emotional support. Gradually her father's condition worsened, and the family came to the decision to arrange a care home for him. Claire explains what happened and her thought process:

'I could manage the catheter to a certain degree, I can't, you know, not prepared to re-catheterise my Dad.. And then with his dementia he started doing things like cutting the catheter off, you know? Walking, he started really wandering around the house. Luckily he never went out of the house so it was just wandering around the house and the only reason that we started to use a home is because he was up all night. Lost all sense of day and night and up and down, up and down, up and down … just he couldn't sleep and I got to the point, physically said I can't do this anymore too. You know I'm working full time and looking after Daddy and I'm staying awake because I was scared of my ability to safeguard him, I couldn't. I couldn't keep safe anymore and I realized that, that was heart-breaking'.

For many carers, there is a trigger that determines they can no longer continue in the role. For Claire it was keeping someone safe, but the factors include risk to the carer, no longer recognising them, or becoming abusive or aggressive (Fekonja et al 2021). Claire's father now lives in a care home. Contact with care home staff was the first professional support they received and was 'brilliant' from first assessment to the current everyday care. Her observations though around communication could be useful for others providing care for older people. The care home workers seemed unaware of how the family perceive contact,

'So when they ring I'm on tenterhooks because it's always because there's been an incident or something happens they're telling me about something negative about my Dad'.

Claire's mother too has been affected by communication with the home staff:

'I think they expect us to make a lot of effort to call and ring, whereas my mum hasn't got that energy. I think they forget she's potentially grieving, for she is. She has been grieving for her husband. She looks past my Dad's chair. He's not sat in the chair. She starts to learn to cook for herself and not him and her. Those kind of simple things'.

The transition to no longer being a carer can be very difficult for family carers, who may feel sadness and guilt (Fekonja et al 2021) and the need to monitor standards of care perhaps to compensate for no longer doing the role themselves or because of concerns over the quality of care (Midtbust et al 2021). It was not possible for Claire and her mother to monitor care, because her father was admitted during lockdown. Since the restrictions have eased, the family are able to visit, although not freely.

'When I go, I slip into this carer mode. I could feel myself doing it. Looking at him, I can see myself assessing him, does he need this, does he need that… I went with my son the other day. He is a carer and he shaved him and we sorted it out as he looked a little bit dishevelled. And my son actually said to me, sit down and relax and I found it really difficult'.

Dementia in the pandemic

Evidence on the impact of the pandemic on people living with dementia is just emerging. There were many factors which led to huge emotional distress and significant mental health problems across the population (Usher, Durkin and Bullar 2020). For people with dementia, the impact was further complicated because of not being able to remember the reason for lack of family contact, not being able to articulate distress or its causes, not having the option to walk freely and so manage stress through exercise, and of course missing loved ones (Roach et al 2021). People with dementia retain the ability to sense emotions (Jenkins et al 2016) and would have picked up on the extreme tension when they were able to interact with others. The restrictions also took a toll on family members, the more so because it was not possible to explain what was happening in a way that a person with dementia could make sense of. Claire describes an incident that illustrates some of these factors:

'it must have been in a period where we were able to come around. I didn't see him at all, right? We were really strict because my mum's very vulnerable and they both were technically, so I never used to come into the house and that was when we first noticed because actually, he used to say, come in, come in so we used to have to reiterate the rules about COVID and lockdowns, and 'we're not allowed in Daddy. We're not allowed to come in and see you'. We would literally drop in essentials, you know, and that was really hard. And you know what, in hindsight, I wished I'd broken the rules because it didn't do him any favours. Social isolation did not do my Dad any favours whatsoever. No mental health perspective - tragically, you know, we lost a year and a half of his life. That we'll never get back'.

Conclusions

Claire's story is the story of her experience of negotiating how to live with dementia during a pandemic. In some respects it is the same as the stories of thousands of other families. The

needs of people with dementia revolve around connections with other people. It is other people who support their sense of identity and who provide not only practical care, but importantly the interactions that enable needs of comfort, attachment, inclusion and occupation to be met and promote psychological well-being. Kitwood (1997) summarises this in one need, that for love. Claire's account conveys how despite all the challenges, though isolation and lack of professional input, it was love that kept them going. But not all our service users have people who love them; many are alone. Claire reflects on this below, with a request to readers who may be involved in providing care:

'My Dad was really lucky because he did have a lot of people around him, but what about all the people that haven't got anybody? It must be so hard for people to navigate now. To get the right support in place, I do feel for people. And if anybody's reading this and thinking what's this all about, just help people ask these awkward questions. People don't know what they need'

In the midst of being a carer, people may not recognise what they need or be able to articulate this. However, people with dementia themselves (Dementia Action Alliance 2017) and family carers (Hanna and Francis 2022) have reported extensively on their needs. In the 'We' statements, they identified that they need control over their own lives and decision-making, a timely accurate diagnosis, high-quality well-funded care and treatment, to be partners in care, to be socially included and to be supported in taking part in research relevant to their needs (Dementia Action Alliance 2017). They also need accurate, accessible and personalised information, individualised psychological and emotional support, education about caring skills, strategies for balancing care while meeting their own needs and access to flexible tailored care when needed (Bresson, Visintini and Palese 2020). Claire's particular experience highlights the need for greater health literacy among the public and awareness of this lack among professionals. More research is required to explore this. By sharing experiences, people like Claire can guide professionals in developing and providing services that support other families who are living with dementia.

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Chapters in books

Mountain G. (2010) *Assessment and dementia* In Downs M and Bowers B (eds) Excellence in

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