CHAPTER 4

Emotional well-being

Fiona Murphy

Trinity College Dublin, Dublin, Ireland

Learning Outcomes

- To outline the emotional challenges that individuals may present with whilst living with chronic kidney disease and kidney replacement therapy.
- To explore the importance of emotional well-being for individuals living with chronic kidney disease and kidney replacement therapy.
- To identify means of support for individuals and their partners, families, and caregivers.
- To understand the management strategies that may assist individuals and their partners, families, and caregivers to cope and adapt to this long-term condition.

Introduction

Chronic kidney disease (CKD) impacts substantially on morbidity and mortality with an international incidence of 9.1%. It is the 12th leading cause of death globally (Bikbov et al. 2020) and is anticipated to be the 5th leading cause of premature death by 2040 (Foreman et al. 2018). The incidence of CKD and kidney replacement therapy (KRT) continues to grow. CKD-associated mortality has not observed sustained progress that other long-term conditions have including cardiovascular or respiratory diseases (Bikbov et al. 2020). Persons living with a long-term illness are more than just their disease with emotional concerns just as relevant as physical. It is well documented that there are a variety of emotional challenges faced by individuals when living with CKD and whilst preparing for and undertaking KRT. This chapter aims to address the importance of emotional well-being for individuals and their partners, families and caregivers when living with this long-term condition. It will also address how well individuals manage these emotional challenges through these life changing events of CKD and KRT. The role of the multidisciplinary team will be highlighted together with management strategies which may assist individuals and their partners, families, and caregivers to cope and adapt with the various facets of treatment modalities for kidney disease (KD).

Persons living with KD experience not just physical but emotional challenges regardless of whether they are receiving dialysis, are transplanted, or not yet requiring KRT. They can struggle with uncertainty about their future and can experience fatigue, emotional stress, mental health concerns, sexual difficulties, fluid, and dietary restrictions, discomfort, and pain, along with a high medication burden. Furthermore, there are serious effects on quality of life (QoL), day to day activities, work, and participation in the social life of their partners, families, and caregivers (Vanholder et al. 2021; 2022).

Living with KD is life changing. There is no cure and treatments can be extremely burdensome; for example, attending multiple hospital appointments. Dialysis treatment is often arduous and typically necessitates individuals to spend four hours plus in hospital three times weekly thereby reducing their capabilities to work and socialise (Kidney Research UK, 2022). Psychological distress such as depression, anxiety and stress are experienced by individuals receiving dialysis (Maharjan, 2022). Those individuals requiring a kidney transplant (KT) can wait an extensive timeframe (on average 2 to 3 years) before receiving a donor kidney with no assurances. They can have successful surgery; however, they live with the understanding that on average their transplant from a decreased donor

lasts 15-20 years and a transplant from a living donor about 20-25 years. The longevity of these transplants is impacted by several factors such as age, health, and additional multi-morbid risk factors such as diabetes and cardiovascular complications (Kidney Research UK 2019; Kidney Care UK and the National Psychosocial Working Group 2022). These uncertainties can take a toll on the mental health of persons living with KD (Kidney Research UK, 2022) and can have a substantial influence in the longer term on kidney outcomes. Therefore, both psychological and psychiatric care is essential throughout the patient's journey (Kidney Care UK and the National Psychosocial Working Group, 2022).

Banks et al. (2020) on behalf of the Centre for Mental Health and Kidney Research UK (2020) issued a statement of intent concerning the importance of mental health with KD which was endorsed by both the UK Kidney Association (UKKA) and the British Renal Society (BRS). They identified the need to collaborate to better comprehend the association between mental health and KD and to produce evidence of how treatment can be improved for those in need, as well as promoting this evidence to ensure the mental health needs of individuals with KD are also addressed by others key stakeholders within the kidney community and beyond.

Sarah Green, a patient advisor and one of the authors of this report outlined in her own words what it is like to live with KD:
"Once you're a kidney patient, you are a kidney patient for life... Every time you are admitted or have a procedure you go into that carrying all the trauma from previous procedures. Trauma that has had time to grow and solidify in your head. Then you are made to feel like you are overreacting. This often leads to you feeling even worse. Shame, self-doubt, and criticism all mix in with the trauma and make de-escalating your reaction harder and harder. Is it any wonder those with long term health conditions are more likely to have a mental illness? I think all too often the medical professionals hugely underestimate the burden that we carry and minimise the psychological effects of this burden" (Banks et al. 2020: 1).

Kidney Research UK (2022) is continually campaigning for improved access to specialist mental health support as part of routine kidney care. They conducted a survey of 1000 adults living with all stages of KD with 68% identified that they had not been offered any mental health support; 67% acknowledged since kidney diagnosis they had endured symptoms of depression whilst 27% disclosed that they had contemplated self-harm or suicide. This survey highlighted additional critical significances, with 36% identifying their poor mental health indicated they were not able to completely look after their physical health. It is therefore not surprising that 53% of adults surveyed acknowledged finding it difficult to speak out about their mental health. A subsequent series of kidney conversations with individuals, emphasise the struggles that they often endure with their mental health because of their kidney condition (Kidney Research UK, 2022).

Cogley et al. (2023a) established that the levels of psychological distress, mental health diagnoses and suicide attempts was high with individuals living with CKD in Ireland. The participants self-reported their mental health histories using the Hospital Anxiety and Depression scale (HADS) and the Short-Form (SF)-12 to assess health-related quality of life (HRQoL). Recruitment was completed (n= 268) via the Irish Kidney Association social media pages and three large Irish hospitals. Depression rates were marginally higher for those individuals receiving haemodialysis (HD) compared to those with a KT and individuals not receiving KRT. A lower HRQoL was associated with depression, anxiety and having a mental health diagnosis. There is a necessity for routine screening to be applied in clinical practice for psychological distress, mental health difficulties and suicide risk along with a prioritisation of access to effective mental health services for individuals living with CKD. Similarly, to the recommendations by Kidney Care UK and the National Psychosocial Working Group (2022) there is a need for kidney care

teams to be sufficiently resourced with mental health care professionals including social workers, psychologists, and psychiatrists (Cogley et al. 2023).

It is vital that the emotional perspectives of individuals with KD are not underestimated. It was in 2012 that Jonathon Hope a patient advocate living with CKD in the UK identified the need for more action to support the reduction of mental health problems for those living with long-term conditions following the report from the UK Department of Health (2011) *'No health without mental health'*. There was further identification of the need for a robust campaign to highlight more awareness among renal healthcare providers, individuals impacted and carers of the cause, prevalence, and frequency of KRT and its complications, including depression, anxiety, and poor coping mechanisms that individuals with KD can face along with a necessary recognition of the interrelationship between mental and physical health (Hope, 2012). This report was subsequently protected into UK law in 2012 with positivity moving forward; so why then over 10 years later is there still a delay for parity that was assured with the need for mental health to be given the same significance as physical health? This must be a priority for all to develop services to meet the psychosocial needs of individuals living with KD (Arday, 2022).

There are many organisations and associations worldwide that advocate on behalf of people living with KD and their partners, families, and caregivers at local, national, and international levels to enhance their voice, to promote prevention and initial detection and to recognise the heavy burden of KD and its impact on QoL along with improving life conditions. This includes for example the Irish Kidney Association, the Northern Ireland Kidney Patients Association, Kidney Care UK, European Kidney Health Alliance (EKHA), European Kidney Patients' Federation, the American Association of Kidney Patients (AAKP), the Kidney Foundation of Canada and Kidney Health Australia.

The AAKP (2019) launched the Decade of the Kidney (2020-2030) as a global initiative to generate increased awareness and establish demands for those persons living with KD for long delayed innovations in kidney care with their insights, experiences, and engagement along with their care choice crucial to these changes. The EKHA is working with the AAKP on this global initiative at a European Union (EU) level to devise a stepwise progressive method including a structural recognition of CKD in EU programmes and strategies, the advancement of an EU code for prevention and screening of CKD, enhancement of disease management along with promotion of transplantation and home therapies. Furthermore, the importance of engaging with EU policy makers to enhance the quality of care for persons living with the burden of KD is paramount. Adults living with KD must be actively engaged in kidney health policy and become successful partners in the perseverance of their care (AAKP, 2019; Vanholder et al, 2021; 2022). Concurrently in the UK, people living with KD have contributed to a campaign for enhanced mental health provision by petitioning their political representatives (Kidney Research UK, 2022) again highlighting the relevance of recognition by policy makers of KD and its impact on individuals' QoL.

There is a necessity for further research to examine KD amongst those with mental health problems and the impacts of KD on mental health (Kidney Research UK, 2019). Kidney Research UK (2023) issued the most widespread review of the health economics of KD in the UK for more than ten years. One of several evidence gaps highlighted when developing this report was the need for UK studies on the association between KD and mental health incorporating the influence of poor mental health on adherence to treatment.

In 2020 Kidney Care UK together with expert voices from various professional groups that provide psychological, social, and counselling services to persons with KD, formed a National Psychosocial Working Group. There was a recognition of the wide divergence in service delivery both anecdotally

and evidence based. It was established that the development of this working group would be a positive and progressive step in inducing change and enhancing quality and access to these services throughout the UK (Loud, 2022).

Kidney Care UK and the National Psychosocial Working Group (2022) released the report: '*Caring for people with kidney disease: psychosocial health - a manifesto for action'* in 2022. This manifesto is a nationwide call to action for individuals living with KD, their families, friends, and healthcare teams to unite and insist upon equal access to the highest quality, timely and renal specialist psychosocial care. The term psychosocial used throughout this document indicates the complete span of psychological, psychiatric, and social care needs. Psychosocial care is regarded within this manifesto as a key component of person-centred care. It depicts the relevance of considering the broad array of determinants impacting emotional well-being (integrating biological, psychological, social and environmental feature) and that there are a variety of useful interventions that are provided by a diversity of professionals comprising clinical, health and counselling psychologists, counsellors, psychotherapists, mental health nurses, psychiatrist and social workers (Kidney Care UK and the National Psychosocial Working Group, 2022, Coyne and Fretwell, 2022).

This report makes the following 10 key recommendations for change so that people living with KD live their lives with the greatest possible mental and physical health.

1. The psychosocial care needs of every person with KD must be assessed by renal specialists (co-located psychology, psychiatry, and social care professionals) using validated processes. These assessments should be conducted when the person is initially diagnosed; as their treatment changes or transitions, as they advance through the various stages of CKD; during times of distress and yearly screening. This should include psychosocial distress and cognitive impairment (dementia). Standard distress and cognitive screening should be included to recognise those who require additional support.
2. The appropriate psychosocial care should be provided for every person with KD and should completely support their level of need, as part of their regular National Health Service (NHS) care delivery.
3. A person's level of need should dictate the psychosocial interventions required. The use of a traffic light system should be contemplated where there is standardisation in the level of a person's psychosocial care and these levels of care escalate in intensity in tandem with their needs. Some examples include if the person's disease is not currently advancing, or if they so far do not require dialysis, transplantation, or end of life care they could be referred for general counselling such as Improving Access to Psychological Therapies (IAPT). Enhanced or specialised renal specialist psychosocial care should be extended to specific groups of individuals.
4. There should be an integration of psychosocial care needs for care plans with persons living with KD (which are generated by their hospital kidney team) which should include simply understandable information concerning their condition, what to anticipate from their diagnosis, symptoms to watch out for and how to avail of interventions and support. These care plans should be co-produced between kidney teams and mental health teams for persons with severe mental illness (SMI), dementia or learning disability. They should signpost external resources that are applicable to the individual's cultural or ethnic background and relevant to their local community. Outreach should be available for at-risk groups, especially for those from diverse ethnic, cultural, and socioeconomic backgrounds to comprehend more about their specific needs.

5. The psychosocial care needs of people with KD along with their physical health can be supported better through the new NHS integrated care systems. This will ensure various parts of this system are better combined. There is a need for enhanced associations amid renal specialist psychosocial services and NHS IAPT services, secondary mental health and social care services, primary care services and the third sector.
6. Within other diseases including diabetes, cancer, and cystic fibrosis there are multidisciplinary team (MDT) clinics that organise annual reviews wherein physical and psychosocial issues are considered equally. Renal MDTs should combine renal specialist psychology, counselling, psychiatry, and social work to guarantee persons with KD have access to all the support they require to assist them manage their condition and the multifaceted connections between mental and physical health.
7. To support access and equality to psychosocial care, staffing levels should be monitored.
8. The importance of education for all renal staff concerning the mental health needs of persons with KD so that they know who and where to refer them and act as "first responders". Whilst mental health staff should receive education concerning screening for KD and management for individuals living with dementia and SMI. Specialist nurses are educated to deliver lower-level psychosocial provision alongside specialist supervision in both diabetes and cancer services. Whilst there are many accredited diabetes educational programmes in the UK that deliver psychosocial modules.
9. There is considerable disparity nationally in accessing integrated psychosocial care. Hence there is a need to introduce and monitor minimum nationwide standards of psychosocial care so that there is equality in terms of access to care for every person living with KD irrespective of geographical location.
10. The success of psychosocial services in enhancing the health of persons with KD can be monitored through the creation of a dashboard. This is available with other long-term conditions within the NHS such as the Diabetes Transformation programme in London, wherein mental health screening is available on its dashboard. It must be determined by the national renal and mental health teams the number of individuals who are on both the renal and the SMI registers (Kidney Care UK and the National Psychosocial Working Group, 2022).

The Centre for Mental Health and Kidney Research UK (2023) report "*addressing the mental health challenges of life with kidney disease: The case for change"* recommended that the NHS needs to invest in expanded and enhanced psychosocial support for individuals with CKD (and other long-term conditions). There should be a stepped care model of psychosocial support regularly accessible to everybody of all ages living with CKD in Integrated Care Boards in England and Health Boards in Scotland and Wales. Healthcare providers for renal therapy services should ensure that all their staff are: 1) trained, supported, and supervised to recognise the psychosocial needs of individuals with KD; 2) practice through psychologically informed means and 3) provide low-level support and refer rapidly onward when more intensive support is necessitated. The psychosocial health of individuals with KD should be regularly assessed by renal services including these services asking patients routinely about the quality of psychosocial support they provide. There is a necessity for more investment from government into research on KD and mental health to advance comprehension and support the continual development of services.

COVID-19

Coronavirus-2019 (COVID-19) pandemic impacted healthcare globally (Divyaveer and Jha, 2021). People with some pre-existing medical conditions were identified as being an increased risk of COVID-19 (Antoun et al. 2021) especially for individuals with pre-existing KD (Divyaveer and Jha, 2021). A containment strategy was therefore developed early in COVID-19 (Antoun et al. 2021) to minimise potential exposure. In the UK for example 70,000 persons with KD were regarded as

clinically extremely vulnerable to COVID-19 and were subsequently recommended to "*shield*" at home for consecutive months from the outside world. However, those that required in-center haemodialysis (ICHD) had no option but to travel to their local dialysis unit 3 times per week which was likely to have been a harrowing experience (Kidney Care UK and the National Psychosocial Working Group, 2022). Sharp and Loud (2020) discussed the outcome of a patient survey (n=1200) conducted by Kidney Care UK throughout the first wave of COVID-19. It established that over 4 out of 10 adults considered their mental health had been affected by COVID-19. Loud (2022) highlighted that COVID-19 and the applicable shielding advice exacerbated prevailing anxieties and made everything more difficult for those living with KD.

Antoun et al. (2021) conducted a qualitative study in the UK to examine how the influence of early COVID-19 shielding restrictions impacted individuals' physical activity (PA), well-being and QoL whilst conducting home haemodialysis (HHD) (n=10) or accessing ICHD (n=10). It also examined these individuals experience of an enhanced dependence on telemedicine within clinical care. The results indicated irrespective of dialysis modality (HHD or ICHD) that PA, well-being and QoL along with medical care were all impacted throughout this period. Negative consequences to PA, well-being, QoL and medical care was reported by individuals attending ICHD. Whilst those individuals receiving HHD mainly reported feelings of minimal change or a positive effect on their daily lives. There was an overall support by individuals receiving both dialysis modalities for the use of telemedicine and an increased use of digital health technologies within clinical care. Some of the HHD participants were already aware of MyRenalCare® and were more familiar to remote medicine and feedback then those individuals receiving ICHD. The recommendations identify the necessity for more proactive care if individuals are requested to shield again, along with an enhanced awareness of both safe and suitable PA to assist with home-based PA and emotional wellbeing for example the use of the Kidney Beam platform (Mayes et al. 2022) which will be discussed later within this section on COVID-19.

McKeaveney et al. (2021) completed a mixed method study aimed at comprehending the effect of COVID-19 in individuals with kidney failure (KF) accessing HD (n= 44) through assessment of features of mental health distress and decreased well-being. The findings highlighted the psychological, social, and emotional distress faced by individuals throughout the pandemic. It identified an initial comprehension of the distinctive experiences within the UK of this patient population. Similar findings were established by Lee et al (2020) in the United States (US) who outlined the psychosocial challenges of individuals living with KF and HD during COVID-19. Hao et al. (2021) cross -sectional survey highlighted that the occurrence of anxiety and depression symptoms increased throughout the pandemic amid individuals receiving maintenance HD (n= 321). This study recommended additional concentration on patients' psychology with an initiation of targeted interventions to ameliorate their anxiety and further enhance their QoL.

Overwhelmingly there should be global health methods engaged to address psychosocial tension especially for those receiving long-term HD and people with other long-term illnesses (Hao et al, 2021). Another cross-sectional survey (n= 300) in the US examined chronic conditions (CCs) (including that of CKD, cancer, chronic obstructive pulmonary disease (COPD), drug abuse/ substance abuse and stroke) and the role of COVID-19 on patient activation and health locus of control (HLOC). More than 50% of the respondents identified COVID-19 associated anxiety or distress concerning managing their CCs. These respondents had lower patient activation and external HLOC in contrast to those respondents not impacted by COVID-19 associated anxiety or distress. The findings identified a necessity throughout the COVID-19 pandemic to provide additional support for those individuals confronting challenges in managing their CCs (Imeri et al, 2021). Interestingly a Dutch study (n= 177 with 75% of participants on ICHD; remainder accessing home dialysis or home therapies highlighted that COVID-19 did not appear to affect their mental health.

Suggestions put forward include these individuals may be better able to adapt to the pandemic as they have high resilience and are not as impacted by social distancing processes (Bonenkamp et al. 2021).

Porteny et al. (2022) conducted interviews with older individuals with advanced CKD (n=39), their care partners (n=17), nephrologists (n=17) and physician assistants (n=3) from 4 kidney centres throughout the US. This qualitative study wished to comprehend how shared decision making for kidney treatment decisions was affected by the uncertainty of COVID-19 pandemic and how this can provide insights for sustaining shared decision making throughout COVID-19 and future public health emergencies. The findings identify that shared decision making was impacted by the vulnerability of older adults to COVID-19. Clinicians should promote and encourage conversations with individuals who wish to talk about COVID-19 with a priority on safety and QoL, including the hazards of COVID-19 and its impact on therapy options. These conversations should address all options including that of conservative management (CM) and integrate advanced care planning. Telemedicine was recognised by the participants as a convenient form of care and provided care partners the capacity to partake in clinical engagements when in-person care was limited. The openness identified towards telemedicine may also indicate a readiness to participate with other virtual tools such as web-based decision aids that could enable ensuing shared decision-making conversations for older adults with CKD. Clinicians could offer a pre-visit impartial description of therapy options with applicable advantages and disadvantages for example impact upon prognosis and the role of the older adult's preferences and therapy choices (Porteny et al. 2022; Ladin et al. 2021). There is a need however moving forward for both investment in technology and telehealth training for populations who require it the most including that of older adults (Ladin et al. 2021).

Long COVID refers to the disability and disease experienced by many individuals who survived the acute phase of COVID-19. There remain no systems that facilitate the assessment of the toll of long COVID and its myriad complications, including KD following the COVID-19 pandemic. This disparity needs to be urgently addressed and thus governments and health systems must develop adequate data systems that can encapsulate this missing information. These data will be fundamental to inform health system planning for post-COVID-19 care (Al-Aly et al. 2023). Goodman et al. (2023) conducted a survey to identify associations between self-reported Long COVID and worse mental health within a population-based sample (n=9500) in the US. Long COVID was described as reporting any present symptom that developed within 3 months of a confirmed positive COVID-19 test that could not be clarified by another diagnosis. The questionnaire encompassed multiple items associated with symptomatic experience of COVID-19, daily functional challenges post COVID-19 diagnosis, mental health, and socio-economic factors. This study highlighted that individuals with Long COVID describe worse mental health outcomes – including higher depression, anxiety, post-traumatic stress disorder (PTSD), suicide ideation and lower life satisfaction, Further research is recommended in this area (Goodman et al. 2023).

There is an increased recognition of the strengthening of negative consequences on the kidney community in the aftermath of the COVID-19 pandemic. The burden on the health and well-being of those impacted by KD has been incalculable as the degree of natural disasters and other overwhelming events instigated by human activities intensifies. It has become internationally vital that there is readiness amid health systems which includes establishing a robust system that can dispense with the health needs of complete community throughout periods of unforeseen disturbances to standard care. The multifaceted medical needs of those who have KD are not gathered by systems handling catastrophes itself. They are heightened usually by an acute escalation in burden via new patients because of the crisis itself. Disturbances in kidney care because of unforeseen consequences are becoming more predominant and expected to intensify in the years to

come. Thus, it is only fitting that the World Kidney Day (WKD) theme in 2023 concentrate on *Kidney Health for All: preparedness for the unexpected in supporting the vulnerable* (Hsaio et al. 2023, on behalf of the WKD Steering Committee).

The EKHA (2021) led a call to action which recommends several areas to be addressed in view of the COVID-19 pandemic. It highlights the heavy burden of CKD in Europe and advocates the necessity for urgent action including to enhance efforts on CKD prevention such as cohesive approaches and targeted investments at both national and EU levels to eliminate core lifestyle-associated risk factors for major CCs including CKD. There needs to be a cohesive approach to address the considerable lack of equivalent and supportable data on chronic disease frequency in the EU. KT should be promoted whenever feasible and suitable as it remains the best therapy option for KF. There were missed opportunities for KT because of COVID-19 with a reduction in donation and transplant activities (EKHA, 2021).

The use of telehealth has altered the practice of healthcare throughout COVID-19 (Lew et al. 2021). A paradigm shift is urgently required towards home therapies and telehealth to better react to individuals living with KD in both the short and long term. The use of home dialysis modalities should be promoted which has shown to enhance the QoL of individuals, along with reducing their necessity to visit hospitals thereby minimising exposure to COVID-19 and maintaining care. COVID-19 highlighted that there are extensive choices for "*healthcare from a distance*" specifically individuals living with peritoneal dialysis (PD) (EKHA, 2021). The uptake of digital technology and 'eHealth' interventions should be promoted which could provide areas of standard and improved CKD care (Mayes et al. 2022) This includes the use of remote management for individuals which can enhance patient empowerment. Other digital tools include telemedicine consultation, artificial intelligence assistants and mhealth apps (EKHA, 2021).

A 6-month prospective feasibility project supported by Kidney Research UK was conducted to allow rapid design, delivery, and evaluation of Kidney Beam during the COVID-19 pandemic. The Kidney Beam programme (https://beamfeelgood.com/home) is context specific, theory-informed intervention that was constructed to promote digitally delivered PA and emotional well-being self-management in adults living with CKD, as directed by the Behaviour Change Wheel (Michie et al. 2014). The use of social media promoted this platform with no extra technical or clinical support presented. The multidimensional digital intervention bundle was composed of online live and on-demand exercise training videos, careful meticulous selection of health care professionals (HCPs) and patient champions, use of email feedback and action planning, and online educational videos and blogs. Overall, 959 adults signed up to utilise the platform within the 6-month time frame; 276 participants completed the voluntary survey at baseline whilst 85 participants at 6 months completed the follow-up survey. 96% of participants surveyed would recommend Kidney Beam, with the major reported benefit being that the intervention was kidney-specific and provided by specialist kidney HCPs. Although there are recognised challenges around digital and health literacy, this digital self-management programme appealed to 736 participants living with CKD to sign up to the platform. A randomised controlled wait-list trial is in progress to evaluate the feasibility, clinical value and cost-effectiveness of the Kidney Beam programme delivered as part of kidney care (Mayes et al. 2022).

Health inequalities in kidney disease

The theme for WKD 2020 concentrated on preventative measures in CKD along with highlighting inequalities in kidney care delivery worldwide (Li et al, 2020). COVID-19 highlighted the health impacts of long-lasting social inequalities and that susceptibility to disease is shaped by conditions such as labour market structures and absence of social protection; for example, adults working in

adversative conditions have inadequate access to sick leave and healthcare services and usually low earnings (BMJ, 2021). This results in inability to manage to pay for adequate quality food, water, sanitation, and housing. Individuals may be reluctant to quarantine when they have COVID-19 because they cannot afford to lose wages and cannot work from home (BMJ, 2021). These conditions interconnect with numerous factors comprising ethnicity, migrant status, class, and gender, to impact which population clusters are most compromised to COVID-19 infection (BMJ, 2021). The inequities gap in kidney care widened even more because of COVID-19 in low and lower-middle−income countries (LLMICs) which demonstrated an essential need for a global approach to care (Tannor et al. 2022). The International Society of Nephrology and the Dialysis Outcome and Practice Pattern (ISN-DOPPS) survey emphasised the significant inequalities in both screening and diagnosis of COVID-19 in individuals receiving HD in LLMICs throughout COVID-19 which related to a higher increased mortality (Tannor et al, 2021). The COVID-19 pandemic highlighted the many challenges that people living with KD faced. It must be acknowledged that a paucity of social and mental health care as well as a high necessity for these services remain a facet in kidney care. These pre-existing inequalities remain post the COVID-19 pandemic (Kidney Care UK and the National Psychosocial Working Group, 2022).

Social deprivation

CKD has a profound impact on the lives of individuals, their partners and families, and their financial stability with inadequate access to dialysis and a much less possibility of KT in lower income countries (Vanholder et al. 2021, 2022). Persons with KD may have to give up their work and receive benefits because of mounting frailty along with lengthy hospital appointments numerous times per week possibly forcing them into poverty (Neukirchinger et al. 2018). They may rely on family members and caregivers or could have caring remits themselves. They could need home care as their housing may not be suitable any longer. Therefore, they depend upon social care services to address their needs for example domestic and personal care home support, assistance with taking medications, home therapies support, available transport systems, benefit and housing support, assistance with kidney diet and exercise schedules (Neukirchinger et al. 2018).

Kidney Care UK (2022a) conducted an online survey with 1042 participants (32% receiving dialysis; 32% transplanted; 25% had earlier stage KD and 11% had KF but not receiving dialysis) to examine the cost-of-living crisis in the UK. The influence of cost of living escalates on mental and physical health is overwhelming. Nearly all the individuals surveyed (98%) are concerned about the increasing cost of living with the majority (60%) continually anxious about this. 87% of respondents expressed these rises are influencing their mental health, with 15% highlighted that it is affecting them daily. The cost-of-living increases were also identified by 87% of adults as effecting their physical health, with 15% highlighted that it is also affecting them daily. It was identified the extra costs that derive with having a long-term condition with 87% of participants described that having CKD augmented their costs even prior to the cost-of-living crisis. These extra costs include 1) the necessity for additional heating as many individuals living with CKD can find it difficult to stay warm. 2) the expenses of a specialised diet necessary for many living with CKD. 3) Transportation to and from numerous medical appointments; for individuals receiving ICHD this is a 3 times per week round trips. 4) Those individuals receiving home therapies; the expenditure of operating medical equipment in the home can add over £1,000 yearly to energy bills (Kidney Care UK, 2022a).

Home dialysis regardless of region often results in at least some cost burden being transferred to individuals and their family members. Some countries (Australia, Canada, and New Zealand) provide local reimbursement policies to individuals receiving home dialysis for electricity, water, and waste disposal to balance these costs (Perl et al. 2023). There are reimbursement policies in some parts of the UK for dialysis travel and home dialysis costs. Unfortunately, there are variations in access to this

repayment necessitates many individuals are subsidising some or all these expenses themselves (Kidney Care UK, 2022a). Kidney Care UK (2023a) conducted another online survey with 1005 participants concerning their experiences of reimbursement. It was established that 37% of participants on HHD advised that they are not receiving any reimbursement for energy expenses from their applicable NHS trust. These reimbursement payments vary greatly even amongst those conducting the same amount of dialysis. 80% of individuals receiving home dialysis believe that the reimbursement amounts do not support all the expenditure their treatment incurs. Nearly 73% of individuals on HHD have been anxious about the expenses this Winter with individuals (43%) on HHD considered returning to ICHD (Kidney Care UK, 2023a).

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CKD is one of many long-term conditions now established as diseases of social disadvantage (Norton and Eggers, 2020). The probability for developing CKD and KF or end stage kidney disease (ESKD) is compounded amid persons of lower socioeconomic status (SES). This increased threat is interceded by adverse social determinants of health for example limited access to healthy foods and transportation, unsafe areas to exercise, poor health literacy and numeracy, discrimination, reduced social support, inadequate housing quality and stability, insufficient paid sick leave, and absence of health insurance (Norton and Eggers, 2020). These adverse social determinants generate impediments to health-promoting behaviours and lifestyles and minimise healthcare access, increase environmental exposure, increase stress and allostatic load. Allostatic load is the capacity of the body to sustain physiologic homeostasis in reaction to physical and psychological needs of stress through suitably coordinated reactions in the endocrine, cardiovascular, metabolic, immune, and autonomic systems in the body. These factors additionally may escalate allostatic load -recurrent stress responses or increased activity of systems to sustain allostasis depending upon the individuals' ability to cope with the stressors (Norton and Eggers, 2020).

These adverse social determinants additionally could have lifetime or even multigenerational effects, through means of developmental programming or by stimulating epigenetic changes. These processes add to inadequate kidney outcomes directly and indirectly, through enhanced risk of underlying (for example diabetes, hypertension, and HIV) and complicating (for example depression) diseases (Norton and Eggers, 2020). Smoking, obesity, and alcohol consumption are all lifestyle-associated risk factors that are also linked with socioeconomic deprivation (Guthrie and Bell, 2019). These are some examples of lifestyle related risk factors that can all impact on kidney health and nurses play a vital role to both educate and empower adults to make informed choices concerning their well-being (Murphy and Byrne, 2022a).

In developed countries like Australia despite universal access to healthcare, the prevalence of ESKD is considerably higher in less advantaged populations with a low SES and has a negative impact on younger dialysis patients' survival rates (Krishnasamy and Gray, 2018). Nelson et al. (2020) suggests that the findings of the study by Krishnasamy and Gray (2018) outline a subtle interaction between the existence of nature as opposed to nurture factors. The social determinants of health play a pivotal role in the management of CKD not unlike environmental and genetic factors. It is necessary therefore to identify these factors in individuals and comprehend how they could be diminished to avoid the impediment of suitable disease management (Nelson et al. 2020).

Caskey et al. (2018) identified in their kidney health inequalities report (on behalf of Kidney Care UK) that health inequalities occur amongst people requiring KRT. Health inequalities are allied with variances in choice of or access to KRT modality for example social deprivation persists in being a risk factor for decreased use of home dialysis (such as the space needed to store dialysis supplies and equipment). These findings are consistent with a retrospective French study by Beaumier et al. (2022) which measured the association between social deprivation projected by the European

Deprivation Index (EDI) and PD uptake to determine the possible mediators of this association. The data was collected using the Renal Epidemiology and Information Network (REIN) registry (n= 9588 with n= 1116 on PD). It established that social deprivation, measured with the EDI, was associated with lower prospects of PD 3 months post initiation of KRT. There was also an indirect outcome of the haemoglobin level at the start of dialysis, a proxy of pre-dialysis care, along with urgent start on PD uptake 3 months after the start of dialysis. This highlights that despite a universal health care system in France there are concerns around socially deprived individuals accessing healthcare services (Beaumier et al. 2022).

A person's age, ethnicity, sex, body mass index (BMI), SES along with comorbidities are all regarded as inequalities as well as where the individual lives in terms of size and type of accommodation, the geographical location along with the renal unit facilities which influences the KRT modalities. It has not been established if there is a causal relationship between inequalities and outcomes (including patient survival). There is a necessity for further research to address these issues and guarantee equitable outcomes for individuals living in the UK with ESKD (Caskey et al. 2018).

Kidney Research UK (2019) in their summary report upon "*Kidney health inequalities in the UK – an agenda for change"* outlined that individuals from socially deprived groups usually have poorer outcomes including higher mortality rates along with decreased levels of health literacy and education. They have associated risk factors for CKD including, obesity, hypertension, and diabetes and because of their debility may tumble down, so to speak, the socioeconomic scale. There is a multifaceted interface between ethnicity and SES with individuals from Black, Asian and minority ethnic backgrounds who are more likely to experience comorbidities associated with CKD and advance quicker towards KF as well as waiting longer for a KT. There is an increased prevalence of CKD in areas of higher social deprivation. Women are more likely to present with CKD and men are more likely to commence dialysis, however older persons are less likely to receive a KT. It can also be difficult to access dialysis services when living in rural settings (Kidney Research UK, 2019).

The Chronic Renal Insufficiency Cohort (CRIC) study (currently 3,140 participants) is a continuing multicenter, observational study of diverse adults with moderate to severe CKD in the US. It established those individuals who depended upon emergency department (ED) / urgent care as typical source of care were a vulnerable group in terms of reduced SES with a disproportionate number of persons from racial ethnic/ minority group with considerably lesser educational attainment and yearly income. They also had advanced comorbid condition burden and weaker blood pressure and glycaemic control. There was an association of an increased risk for hospitalisations and mortality in patients with CKD whose typical care is that of ED/ urgent care. There is a necessity therefore to better comprehend barriers to care and enable access to care for this high-risk group with the aim to enhance health outcomes and diminish costs (Toth-Manikowski et al. 2022).

Food and Fuel Banks

Individuals who are encouraged to adhere to a healthy renal diet may have trouble following diet recommendations if recommended foods are not physically or economically accessible (Puchulu et al. 2023). Kidney Care UK and the National Psychosocial Working Group (2022) highlighted that some individuals living with KD who have lost their jobs subsequently have insufficient and unattainable welfare support are therefore depending upon food banks. However, with the ever-increasing costs in living crisis resulting in food insecurity, more people are turning to the use of social and community alternatives along with food and fuel banks. Social and community shopping is a term used to describe local schemes that can help a persons' money go further when food shopping. These vary from nearby run supermarkets that provide surplus food, to community clubs that

provide low-priced memberships in exchange for discounted food. There is a necessity for referral to food banks with individuals encouraged to get information of what is available to access in their locality. They should contact Kidney Care UK advocacy teams or local councils, health care workers, social workers, GP surgeries, local schools, and/ or local faith groups (Kidney Care UK, 2022b). Kidney Care UK (2022b) have collaborated with the Renal Nutrition Group of the British Dietetic Association and have established a list of foodbank foods which are well suited to meet the dietary requirements of individuals living with KD. Individuals living with KD are also encouraged to contact their dieticians from their local kidney units if they are unsure of any of the foods provided at their local food banks. Within Europe, the European Food Banks Federation (2023) is a network of 351 food banks in 30 communities, reducing food insecurity and preventing food waste.

There are numerous people living in the UK (and beyond) who receive a limited income or are surviving on fixed state benefits who are confronted with a choice between feeding themselves (and their families) or heating their property. The concept of fuel banks work in a similar format to foodbanks; unfortunately, they are usually only accessible to those with a prepaid meter; local charitable support and charitable energy trusts are accessible for those who do not have a prepayment meter (Kidney Care UK, 2022b).

Stable housing

Individuals who are homeless are likely to have more multifaceted health and social needs and numerous long-term physical and mental health conditions (Omerov et al. 2020). Stable housing is a basic human right, and unstable housing has a serious impact on human health, wellbeing, purpose, and output. The term unstable housing incorporates homelessness and housing insecurity. Housing insecurity represents housing that is of elevated cost, overcrowded or hazardous. Housing along with other health-connected social needs may interrelate with recognised associations amongst poverty and structural inequalities that proliferate racial and ethnic disparities in KD. Unstable housing has been correlated with mortality, communicable and non-communicable diseases, acute care utilisation, an increased risk and progression of KD. The relationship between housing and KD is possibly a multifaceted interaction between individual and structural factors (Novick et al. 2022).

Henderson et al. (2022) conducted a qualitative descriptive study to depict the perceptions of adult men (n=16) who were homeless related to their heath and experiences accessing care. The findings identified three themes: 1) men that are homeless experience prejudice all through their healthcare and interpersonal interactions; 2) person-centred is the best care and 3) the priorities of men who are homeless and care management are insufficient. The housing requirements of individuals that are homeless are best considered by their health and social care needs. Their priorities must be taken on board to advance culturally congruent services that are suitable and effective care for this community (Henderson et al. 2022).

The conversations with individuals with KD concerning housing issues are achieved best using a non-judgemental and empathetic approach wherein the health care team previously has a positive relationship with the individual concerned. There are several screening tools that can be used, and the correct care plan should be initiated that contains aspects that are relevant for clinical care such as where medications are kept, access to a freezer, access to healthy foods, access to bathrooms, exposure to weather extremes and physical welfare. Issues like using a short acting diuretic may not be ideal in terms of ability to access bathrooms therefore a review of substitutes should be prescribed. A reduction of medications should be considered for example using longer-acting drugs is better over agents that necessitate multiple doses daily as there are challenges travelling and accessing pharmacies as well as storage of the applicable drugs. There should be close collaboration with different agencies to address impediments to care including early intervention from social care

and housing including the use of flexible transportation to and from dialysis (as applicable) and emphasise patient safety. It is vital that there is an avoidance of the use of possibly stigmatising language in adults' care records (for example "*non-compliant*") because of unstable housing which could influence their dialysis placement or transplant candidature. Education should be provided to minimise environmental harm to those that are on dialysis in terms of protecting their vascular access and delivering medications throughout dialysis where feasible (Novick et al. 2022).

Health literacy

Langham et al. (2022) on behalf of the WKD Steering Committee outlined the continuing high burden of KD and continuing global inequalities concerning kidney care. The theme of WKD in 2022 was that of advocating *Kidney Health for All,* the difficult concept of bridging the well-established gap in the global comprehension of KD and its health literacy. Centers for Disease Control and Prevention (CDC) (2020) identifies health literacy (HL) as both personal health literacy and organisational health literacy. HL is regarded as the degree to which individuals and organisations have – or equally facilitate individuals to have the capacity to discover, comprehend, and use information and services to impart health-related decisions and actions for themselves and others. These revised definitions highlight individuals' capacity to use health information rather than just comprehend same. It concentrates on the capacity to make "*well-informed*" choices instead of "*appropriate*" ones. It recognises the responsibility that organisations must address HL. It integrates a public health perspective acknowledging within the organisational definition that HL is associated to health equity which is achievement of the maximum level of health for all individuals (CDC, 2020).

HL should not be regarded as an individuals' deficit, instead enhancing HL rests mainly with health care providers communicating and educating successfully in co-developed collaboration with those with KD. HL provides the essential for kidney policy makers to change organisations to a culture that positions the individual at the focus of health care. The advancing capacity of and access to technology allows new opportunities to improve education and recognition of KD for every stakeholder. The developments in telecommunication, including social media platforms used to improve both individuals' and health care providers' education. Kidney communities endeavour to avert KD and facilitate living well with KD through engagement and supporting kidney health-focussed policy making, community health planning and HL approaches for all (Langham et al. 2022).

Unfortunately, the characteristics' of individuals who tend to have lower digital literacy and access are similar as those who are marginalised by established health inequalities namely lower SES, advancing age, minority ethnic background and lesser educational accomplishment. To develop and apply digital health interventions effectively it is vital not to ignore the necessity to develop eHealth literacy to enhance access for marginalised groups additionally to advancing tools to facilitate access for those with established health inequalities. This is particularly significant for older individuals with CKD and those from minority backgrounds (Graham-Brown et al. 2023).

Around 25% of individuals with KD have low HL particularly among those with low SES and non-white ethnicity (Taylor et al. 2017). It estimated also that 14-32% of individuals receiving dialysis have low HL (Cavanaugh et al. 2010). HL is specifically important for individuals with KD because of intricacy of self-care. Lameire and Vanholder (2020) discussed the impact of lower HL on the spectrum of kidney care (CKD, dialysis, and transplantation) with reduced medical and therapeutic adherence consequently. In CKD lower HL is also associated with additional cardiovascular complications and a hastier progression of KF; whilst in dialysis it is related to additional uncontrolled hypervolaemia and lesser uptake of home therapies or home dialysis. There is less pre-emptive/ live donation in transplantation also because of lower HL (Lameire and Vanholder, 2020).

Boonstra et al. (2021) conducted a systematic review to distinguish favourable intervention targets and strategies for HL problems in individuals with KD. Individuals with lower HL have decreased knowledge or lesser capacity to modify behaviour. There is a necessity for customised interventions specially to support the KT process and smoking cessation to enhance the outcomes of individuals with lower HL. This review identified a limited amount of well-controlled studies on the influence of HL in Europe on the consequence of care in adults with non-dialysed CKD. Most studies originated from the US. It also highlighted studies on the influence of the assorted European healthcare systems on the level of HL in KD as paralleled with other regions. Interventions that target the capabilities of healthcare professionals were totally lacking. There is a need for more support of individuals by healthcare organisations with lower HL to prevent adverse health outcomes. Although the best intervention strategies remain underexplored, the use of web-based education was hopeful for enhancing knowledge and behaviours. (Boonstra et al. 2021; Lameire and Vanholder, 2020).

CKD and mental illness

There is a three directional association with CKD, mental illness, and its impact. CKD can influence an individual's mental health, whilst mental illness, or pre prevailing trauma, can lead circuitously to KF. There are poorer outcomes with KD for those with co-prevailing mental illness, dementia, or learning disabilities or intellectual disabilities (ID) and/or neurodevelopmental conditions (Gerogianni and Babatsikou, 2013; Turþin, 2018; Seekles et al. 2020 Van Alphen et al. 2021; Whitney et al. 2020; Kidney Care UK and the National Psychosocial Working Group, 2022, Zisman-Ilani et al. 2022). Persons with a learning disability are at enhanced risk of mental illness with some studies indicate the degree of mental health difficulties is up to twice that of the general population (Mencap, 2022). Individuals with learning disabilities or ID and/or neurodevelopmental conditions often contend with mental health professionals who receive minimal training concerning the needs of this population and related options for treatment and support. Greater emphasis should be provided for early and accurate diagnosis and nonpharmacological interventions to promote mental health among this population (Zisman-Ilani et al. 2022). There has been an association with higher rates of developing KD for those individuals with pre-established trauma or mental illness with increased rates of mortality than the general population. Examples include adults who have experienced adversative childhood incorporating emotional abandonment, sexual abuse and residing with a caregiver with mental illness (Ozieh et al, 2020).

CKD and severe mental illness

Iwagami et al. (2018) maintains that there is a high prevalence of SMI (including schizophrenia, bipolar disorder, and other nonorganic psychotic illnesses) amid persons with CKD and those receiving dialysis. In the US, Wilk et al. (2022) identified that individuals with SMI encompass over 7% of everyone with KD but this figure is not entirely measured in the UK. There are a multitude of complex rationales as to why persons with SMI have a reduced life expectancy around 15 years as compared to the general population such as misdiagnosis and diminished access to care (Chang et al, 2011). Whilst Siddiqi et al. (2017) identify that persons living with SMI face elevated rates of long-term conditions and unfortunately can die 15-20 years earlier than persons who do not have SMI. This occurrence is known as the mortality gap. The indicators of various mental illnesses could impact the individuals' capacity to self-manage, comprehend, or even consider the necessity for the therapy for example an individual with delusions may refuse dialysis as they trust they can treat themselves without the need for medical involvement (Turþin, 2018).

Van Alphen et al. (2021) outlined that certain psychiatric drugs used for the treatment of bipolar affective disorder (lithium) and schizophrenia (antipsychotics) could lead to diabetes and/ or KD. It was established in the UK primary care that individuals with SMI had a greater incidence of CKD compared to the general population. This was marked in adults with a history of lithium prescription.

However, there was also an increase in likelihood of CKD even with adults at no time prescribed lithium and following modification for variances in established risk factors for CKD. Individuals with SMI additionally had an increased incidence of KRT and were more likely to be receiving HD as their modality than persons without SMI on KRT (Iwagami et al. 2018).

Cogley et al. (2022) identified in their literature review concerning SMI and CKD that there is a deficit of published evidence concerning the rates of SMI in individuals with CKD as compared to the high documented prevalence of mental health problems such as depression and anxiety in the CKD population. There are additionally adverse health outcomes including increased mortality rates and increased rates of hospitalisations for adults living with SMI and CKD. This review indicated that individuals with SMI access substandard kidney care, less appointments with kidney care specialists and reduced likelihood in obtaining a KT. The suggestions proposed identified the relevance of education for kidney health care teams concerning the needs of individuals with SMI through close collaboration with psychiatry. There is a necessity for additional research examining the incidences of SMI in individuals with CKD along with the impediments and facilitators to efficient care within this population. It is essential to enhance health outcomes for those living with SMI and CKD (Cogley et al. 2022).

Carswell et al. (2023) conducted a scoping review with available evidence highlighted that there is an increased risk of CKD amid individuals who have SMI, that individuals with SMI have worse clinical outcomes from CKD and that they are not obtaining specialist kidney care to the same extent as individuals without SMI. This scoping review also identified a lack of high-quality research concentrating on co-existing SMI and CKD**.** There is specifically a major gap in qualitative research. This is prevalent in addressing the related care pathways for individuals with SMI and CKD and how this is observed and administered in primary or secondary care mental health services along with how this compares to other long-term conditions related with SMI like diabetes, chronic obstructive pulmonary disease, and CVD. There is a necessity to conduct further research and close the mortality gap (Carswell et al. 2023).

A recent Irish qualitative study using semi structured interviews was conducted to explore the barriers and facilitators to effective kidney care for adults with severe mental health difficulties (SMHDs) and how care may be enhanced for this cohort. The participants were recruited through the Irish Kidney Association and 3 Dublin-based hospitals with (n=8) mental and (n=14) physical HCPs; all had expertise working with adults with KD and co-existing SMHDs. The results indicate that many individuals with SMHDs need further support to access kidney care because of challenges with their mental state, difficulties with motivation and organisation, cognitive difficulties, or anxiety and suspicion of the healthcare system. The participants narratives identified that it is challenging to support the additional needs of individuals with SMHDs because of the division of physical and mental healthcare, merged with under-resourcing and understaffing. The lack of mental health training for renal HCPs influences their confidence in their capacity to deliver care to individuals with SMHDs. The findings also suggest that system-wide stigma to adults with SMHDs in healthcare adds to poorer outcomes for this community. This can often make it challenging for renal healthcare settings to meet the comprehensive range of needs of individuals with SMHDs and KD (Cogley et al. 2023b).

This study by Cogley et al (2023b) highlighted that despite these recognised barriers that with sufficient social, community and hospital support that adults with SMHDs and KD can have positive outcomes even in the setting of substantial impairments and intricate presentations. There were a number of suggestions for enhancement in care for adults with SMHDs including cohesive physical and mental health care; assuming a "*whole person"* individualised approach to addressing the

interface between mental health and KD. There should be MDT team-based care encompassing clinical nurse specialists, social work, psychology, and psychiatry within renal healthcare departments. There needs to be both communication and coordination amid renal and mental healthcare providers to enable safe and effective kidney care for adults with SMHDs. There is a need for further research in this area to inform the provision of care for this community. This study did not explore the perspectives of individuals with SMHDs and KD and their families and caregivers but concentrated solely on the perspectives of HCPs (Cogley et al. 2023b).

Cognitive impairment

Cognitive impairment is independently related to KD and increases in incidence with deteriorating kidney function. It is up to three times more prevalent and can appear at a younger age at the point wherein KRT needed. Cognitive interfaces of KD are not a new concept with long established historical descriptions of uraemic encephalopathy and professed "*dialysis dementia*" to the current identification of cognitive impairment in those undertaking KRT. There are a multitude of suggested processes influence this burden including advanced vascular aging, substantial multi-morbidity, mood, and sleep disorders are frequent along with disease-specific consequences of uraemic toxins, chronic inflammation, and the impact of dialysis itself (Crowe et al, 2021). Both dementia and KD have shared risk factors such as diabetes, hypertension, and hypercholesterolemia hence another rationale for increased rates of dementia in individuals with KD (Iyasere et al. 2017).

The influence of cognitive impairment on people living with KD is immense extending from escalated hospitalisation and mortality to reduced QoL and altered decision making (Crowe et al. 2021). A meta-analysis aimed to evaluate cognitive function in PD as opposed to individuals living with HD outlined that persons receiving PD are less likely to have a reduced decline in cognitive function contrasted to those who are receiving HD (Ali et al. 2021). There needs to be additional research such as the use of randomised control trials (RCTs) into the management decisions for persons where cognitive screening of KRT populations would bring to attention the considerable number of individuals with undetected cognitive impairment. There should be additional deliberation of processes considered to conserve native kidney function and whether this can influence the natural history of cognitive decline. The effect of pharmacological therapy used for dementia in the general population and for affective disorders which can influence cognitive function also needs to be established in the KRT population. There is a requirement to develop comparable study endpoints for cognitive impairment and a necessity for enhanced detection and recognition of cognitive impairment in individuals needing KRT as well as further research that involves patient derived outcome measures (Crowe et al. 2021).

Lesbian, gay, bisexual, transgender, and queer (LGBTQ +) communities

Individuals from the lesbian, gay, bisexual, transgender, and queer (LGBTQ +) communities experience social, economic, legal, health, and health care–associated disparities (Mohottige and Lunn, 2019). LGBTQ + individuals are at disparate risk of KD. They may not seek medical care due to the cost, refusal of care, job loss, concerns of discrimination, and harassment (National Kidney Foundation, 2021). There can be considerable unbalanced barriers to obtaining, high-quality healthcare such as screening for diabetes and hypertension which could intensify risk of KD. There can be a fear of discrimination that could inhibit LGBTQ + individuals from reviewing their social supports and possible donors involving same gender partners in evaluation of kidney transplantation (Mohottige and Lunn, 2019). Leeies et al (2023) conducted a scoping review to explore inequalities in organ and tissue donation and transplantation (OTDT) for sexual orientation and gender identity (SOGI) diverse persons globally. This scoping review established that this diverse population experienced discrimination globally with no published benefits of their identities in the OTDT

systems. There were recommendations proposed to advance equality for SOGI diverse persons along with recognised disparities that can function as targets for activity moving into the future.

Mohottige and Lunn (2020) recommends that kidney care teams should instigate the following measures to improve care in LGBTQ + including when talking with individuals to use affirming language as well as promote tools to enhance care for LGBTQ + individuals across all clinical backgrounds. There is a need to advance inclusive engagement of individuals for example in research as well as advocacy for and the application of nondiscrimination policies that specifically embrace gender identity, sex, and sexual orientation to safeguard all individuals. Collister et al. (2021) in a narrative review deliberated on the care of transgender individuals with CKD and what HCPs should be cognisant of when delivering their care. Adverse outcomes are prevalent in individuals who are transgender including mental health, cardiovascular disease (CVD), malignancy, and mortality. There is a need for additional research including the effect of being transgender on outcomes in individuals with KD.

QoL and living well with kidney disease

There is a need to target what is relevant to individuals across the age divide, by concentrating on their QoL, including both physical and mental health. This could be targeted to individuals where it is relevant in their lives when they are not receiving direct care. There is a need to prioritise treatment modalities such as self-care in satellite units, HHD, continuous ambulatory peritoneal dialysis (CAPD), automated peritoneal dialysis (APD) and pre-emptive transplantation, which provides individuals with improved control over their lives and enhances overall QoL, along with mental and physical well-being. There is a need to recognise that KF is a family concern as it can affect family members' and caregivers' mental health, along with individuals with KD. It is important that everyone concerned are all supported (Hope 2012). Raoofi et al (2021) conducted a systematic review and meta-analysis examining the HRQoL and the determinants across adults who underwent HD and PD. There were useful strategies for HCPs recommended from the studies conducted concerning an extensive range of physical, mental, and environmental factors. This could enable HCPs to recognise the actual requirements of individuals undergoing dialysis and meet them in a suitable way. It also provided evidence-based information concerning the impacts of factors including age, BMI, length of illness, type of dialysis and geographical area of residence on individuals' QoL which can be used to plan an effective treatment strategy for individuals undergoing dialysis. The evaluation of QoL in individuals receiving dialysis can also impart appropriate information to confirm the efficiency of clinical interventions, evaluate the mental and emotional difficulties of the illness and recognise the influence of a particular treatment strategy on an individual through evaluating the quality of care (Raoofi et al. 2021).

The overall and domain specific QoL (pain, self-care, activity, mobility, anxiety/depression) was measured using the EuroQoL (5 dimension, 3 level) (EQ-5D-3L) tool with data accessed from a prospective multinational study (n=1696) within 11 centers from Australia, New Zealand, Spain, and Canada. The participants were from across the spectrum of CKD from stages 3 to 5 (n = 787), dialysis (n= 415; 69.9% on HD and 30.1% on PD), as well as transplant recipients (n= 494) (Krishnan et al. 2020). This study found overall a significant decrement in QoL across all spectrums of CKD. The most frequently affected 3 main domains were pain, anxiety/ depression, and mobility. Individuals receiving dialysis identified more difficulties in nearly all domains compared with individuals at CKD stages 3 to 5. A lower educational status, coexisting comorbidities (such as diabetes and CVD) and an absence of a partner were associated with decreased QoL in nearly all dimensions. The importance of comprehending these triad of factors will deliver beneficial ways of detecting those who are most at risk of poor QoL and outlining innovative social and medical interventions along with the resources to support them, which are of significance to this group of adults (Krishnan et al. 2020).

McKeaveney et al. (2023) conducted a cross-sectional study to examine QoL and other functional outcomes in individuals with advanced CKD using the Kidney Disease Quality of Life (KDQoL-36) tool. The participants consisted of two samples of older persons (> 60 years) either having CM, (n=263; CKD stage 4 n=188; CKD stage 5 n=75) or receiving ICHD (n=74). The findings indicated that there was significant impact on QoL for individuals with CKD stage 5 receiving CM. However, there was also significant impact on QoL for those receiving ICHD because of the burden of therapy. The evidence would suggest from this study that the use of QoL tools could assist with clinical prognosis in advanced CKD along with ensuring specialist support is accessible for suitable management of individuals with CKD (McKeaveney et al. (2023).

Tong et al. (2020) highlighted the need to develop and use patient-centred terminology for kidney health to improve patient autonomy, satisfaction, and outcomes. When feasible an example of this could be to use the term '*kidney*' instead of '*renal*' (Levey et al. 2021). Clearly, common nomenclatures could improve communications at all stages of treatment, encouraging greater comprehension of the burden of disease and patients' feelings concerning this. This could lead to more successful communication amid all key stakeholders (Levey et al. 2021). The National Institute for Health and Care Excellence (NICE) (2021) identifies the need to clarify any technical and medical terminology when communicating with patients throughout any consultations with HCPs and ideally use common, jargon-free language.

Despite the burden of living with CKD and its associated disruption and confinement with daily living and impacting on treatment satisfaction and clinical outcomes, there does appear to be limited enhancement in QoL over the past several decades for individuals living with CKD. There is growing acceptance of the necessity to recognise and focus upon patient priorities, principles, and goals to progress research, practice, and policy (Tong et al. 2018). There is an increased use of patient-reported outcome measures (PROMs) as a vital means of measuring treatment results in the perspective of what is meaningful for individuals living with KD, including QoL (Locatelli and Del Vecchio, 2023). The Standardised Outcomes in Nephrology (SONG) is an independent and global initiative that brings collectively patients, care providers, and HCPs in collaboration to determine core outcome domains and outcome measures across the range of KD for clinical trials and other types of research. The outcomes will be established based on the collective priorities of all relevant stakeholders. This will assist in ensuring that researchers convey outcomes that are significant and applicable to individuals with KD, their families and caregivers, their HCPs; and consequently, support decisions concerning treatment. Each SONG initiative is founded on the target group of patients which is determined by the appropriate stage of CKD/ therapy stage (1-5): SONG-CKD, SONG-HD, SONG-PD, SONG-Tx (kidney transplantation), children and adolescents (SONG-Kids) or diagnosis e.g., polycystic kidney disease SONG-PKD, glomerular disease SONG-GD (SONG, 2017, 2023).

Life participation

The concept of life participation (LP) is more precise than the wider construct of QoL. It positions life priorities and values of those impacted by CKD and their families at the core of decision making (Kalantar-Zadeh et al. 2021). LP is described "*as the ability to engage in meaningful activities of life, including but not limited to work, study, family responsibilities, travel, sport, social, and recreational activities*" (Tong et al. 2018; Carter et al. 2020).

SONG studies within excess of 9000 patients from all spectrums of KD from over 70 countries along with family members and HCPs, identified both children and adult participants assigned greater priority to symptoms and impact of KD on their lives whereas HCPs assigned greater priority to

mortality and hospitalisation (Carter et al. 2020; Hanson et al. 2020; Tong et al. 2018). These studies highlight how LP signifies the ability to live well with KD (Gonzalez et al. 2020). The participant priorities from these studies are identified in **Figure 1** within the conceptual framework of living well with KD. Individuals no matter what type of KD or stage of treatment they are at, wish to be able to live a normal life as possible, to live well, sustain their role and social function along with having a perception of control over their health and well-being (Kalantar-Zadeh et al. 2021).

"Living well with KD" was the theme for WKD 2021. The conception behind this theme was enhancing cognisance and education with the main aim of empowering persons with KD to oversee their treatment and continue active partakers in life (Kalantar-Zadeh et al. 2021; Rhee et al. 2022). There is a necessity for developing and implementing validated PROMs that may be used to assess and address aspects of LP in standard care. A conceptual framework was developed which concentrated on patient centredness with a prominence on competent symptom management and LP **(see Figure 1).** There are various self-care themes within this framework that are applicable to individuals living with KD include patient activation, self-management, patient empowerment, patient engagement, patient-centred care, LP, and the use of a strengths-based approach to build resilience (Kalantar-Zadeh et al. 2021).

HCPs through an LP measure could comprehend and establish if adults with KD are on course to accomplishing individualised goals and can provide the necessary resources to support their patients achieve them. There should be an LP measure available to manage right through the numerous transitions that individuals living with KD endure on their journey with KD. These transitions impart difficulties, distress, and challenges to confound before adjusting to the new changes in life. Thus, measuring LP is crucial to provide patient-centred quality care. The days of same kidney care and dialysis for everyone must be regarded as an occurrence in the past. Every patient should be treated as an individual with varied needs and goals with their applicable treatment plan reflective of these variances. Individuals who are empowered are engaged in their care and with their health care team (Edwards and Manera, 2022).

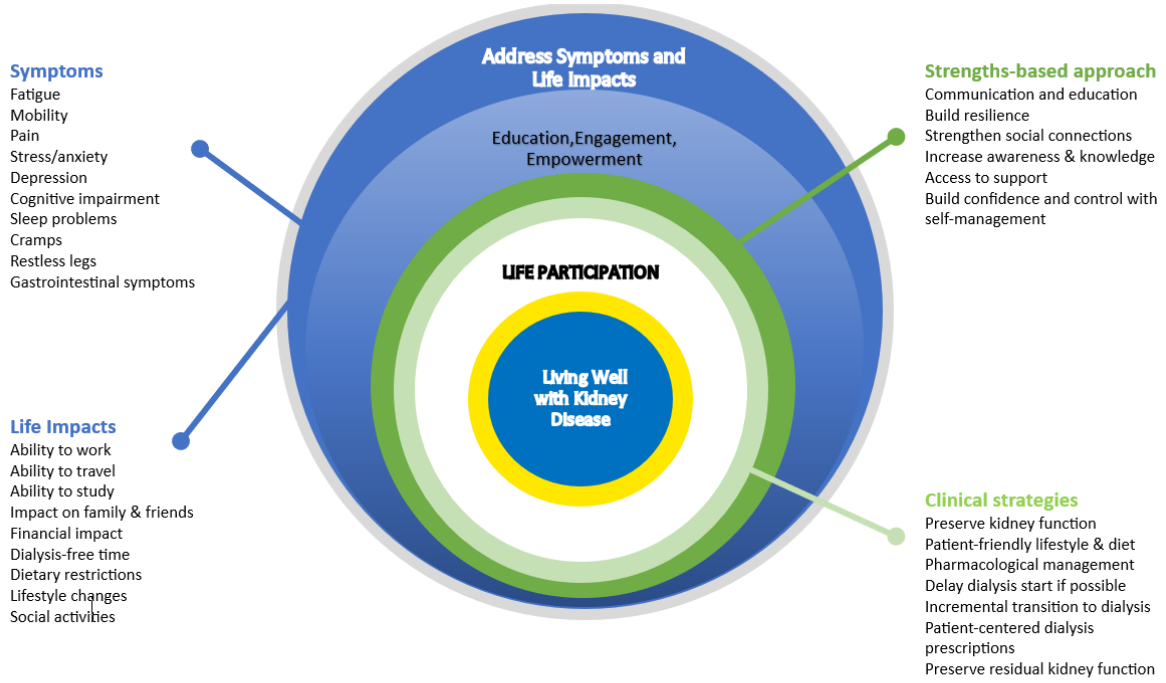

Figure 1: Conceptual framework of "Living Well with Kidney Disease" based on patient centeredness and empowering patient, with a focus on effective symptom management and life participation (Kalantar-Zadeh et al. 2021).

Patient activation

Patient activation is swiftly becoming a main principle in patient-centered care and an essential part in the pursuit of value-based care (Hussein et al. 2022). Patient activation involves the knowledge, skills, and confidence an individual has in managing their own long-term condition such as KD. The focus of person-centred care is enabling and empowering individuals to assume a more functional role in their well-being and healthcare. It is established as a key concept of self-management and is essential to support individuals to actively contribute to therapy choices, avert complications, and manage risk issues. It may enhance patient engagement and health outcomes by recognising an individuals' activation level along with establishing interventions to enhance their activation (Lightfoot et al. 2022a). The promotion of patient activation in KD is progressively being prioritised. It has emerged as fundamental to KD legislative policy in the US with two kidney care models now contain patient activation as a quality metric. The patient activation measure (PAM) is identified as the patient reported outcome (PRO) to apply when appraising in KD (Nair and Cavanaugh, 2020).

A large survey conducted in the UK by Magadi et al. (2022) to investigate the association with PROs specifically symptom burden and HRQoL, to comprehend the affiliation between patient activation and outcomes. Secondary data was used from the UK Renal Registry gathered as part of the National Transforming Participation (TP) - CKD service evaluation programme. The final sample recruited (n=3013) were from 14 kidney units across England and had comparable demographic attributes to the overall CKD and KRT in the UK. The findings indicated a robust association between patient activation and HRQoL and symptom burden. Those individuals who are highly activated described a better HRQoL and a lower symptom burden. However, almost 50% of all participants with KD across various treatment modalities had low patient activation. Individuals receiving HD, those that are older, disadvantaged or from a non-white background were all allied to reduced levels of patient activation. Since patient activation reinforces effective and sustained self-management; its

enhancement offers an appealing goal for interventions aiming to support and enable self-management behaviours. Further work recommended in this area includes the use of longitudinal studies which should determine changes in activation over time to comprehend how individuals adjust from higher to lower activation, and how doing this, influences outcomes valued by the individual. The association between PAM levels and PROs indicates that methods targeting to enhance activation may have the capacity to influence areas of health and life which are valued by the individual in addition to HCPs and healthcare provider organisations. The use of resources, support, education and advice with symptom management and physical rehabilitation may be necessary to assist self-management behaviours and enable the transition to higher activation states in this group (Magadi et al. 2022).

"My Kidneys & Me" is a theory-driven and evidence-based digital self-management programme for people with non-dialysis CKD. It is directed by an established process used for the successful development of the diabetes education program MyDESMOND (Diabetes Education and Self-Management for Ongoing and Newly Diagnosed, DESMOND). The planned outcomes of "My Kidneys & Me" were to enhance and sustain effective self-management behaviours, incorporating PA and lifestyle, enhance knowledge, promote self-care skills, improve self-efficacy and well-being. This was accomplished through the delivery of content and materials intended to increase CKD knowledge and patient activation, decrease health risks, manage symptoms, and enhance physical function. There were several theories and behaviour change techniques chosen to support the content and materials. Educational and behaviour change sessions, health trackers (e.g., observing blood pressure, symptoms, and exercise), goal-setting facets, and social support forums are components developed within this programme. The systematic application of theory, empirical evidence, and practical perceptions in the co-development of "My Kidneys & Me" content and materials were enabled by the application of the intervention mapping framework. The adopting and adapting of an established platform delivered a cost and time effective method for developing this digital intervention (Lightfoot et al. 2022b).

The efficacy of "My Kidneys & Me" will be tested next in an RCT. The main aim of this study (Self-Management Intervention through Lifestyle Education for Kidney health (SMILE-K) is to assess the impact on patient activation levels. The secondary aims comprise evaluating the possibility of using such an intervention in this population and investigating patient experience of the actual programme. It is hypothesised that access to 'My Kidneys & Me' will enhance patient activation, contrasted with usual standard care, in adults living with CKD (Lightfoot et al. 2022c).

Individuals with low activation are less likely to identify early warnings of imminent complications or more rapid decline in their condition. They are also less motivated to act and are less likely to have knowledge of what to do should they decide to act regarding these warnings (Hussein et al. 2022). The use of a multifaceted model of care is recommended to enable patient activation that includes individuals receiving HD, their healthcare team, dialysis providers and policymakers. **See Figure 2 for patient activation care intervention strategies**. The use of initiatives that aim to confront activation need to contemplate the challenges of including individuals with low activation, the intricacy of implementing a solution that takes on board the physical and emotional status of individuals receiving dialysis, and the contending pressures on both patients and staff time (Hussein et al. 2022).

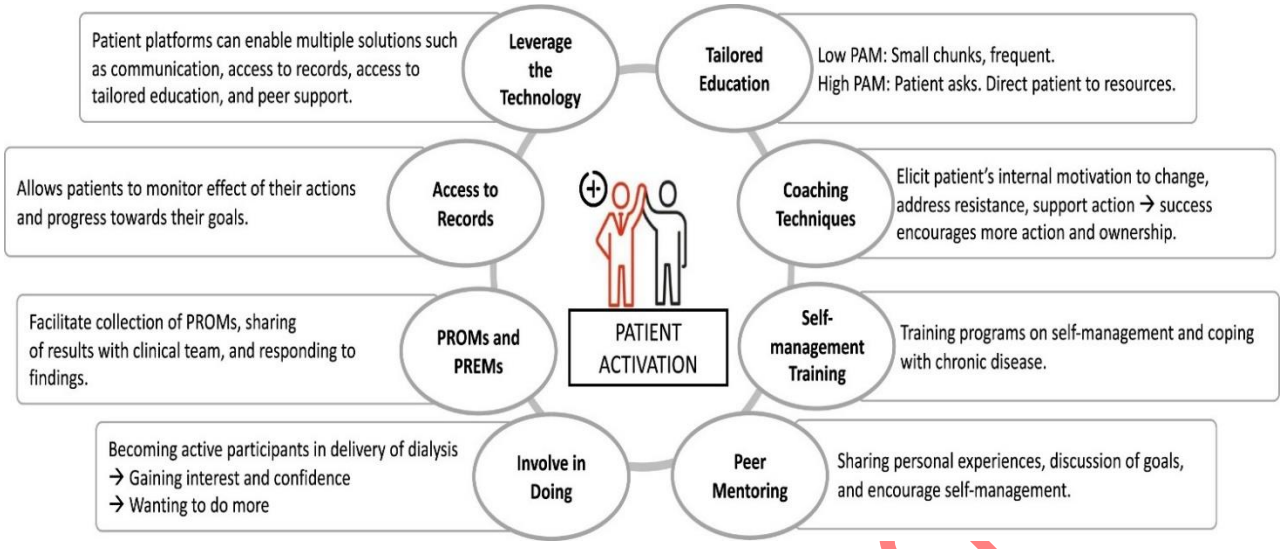

Figure 2: Patient activation care intervention strategies (Hussein et al. 2022).
Abbreviations: PAM, patient activation measure; PREM, patient-reported experience measure; PROM, patient-reported outcome measure.

Individual symptom management

The living well with KD and effective symptom management consensus conference (Rhee et al. 2022) provided a beneficial opportunity to assemble HCPs, advocates, individuals with KD and their caregivers to discuss means to enable the best management of unfavourable symptoms in KD. It was acknowledged that the necessity for members of the MDT to reframe their perspectives by connecting with individuals living with KD in describing their own individual values, likings, goals, and personal needs. There were a few management approaches contemplated that were regarded as central to provide personalised care such as conservative and preservative management with the goal to prevent or postpone dialysis, incremental dialysis, and home dialysis or home therapies (Rhee et al. 2022).

Individuals with KD experience '*a high burden of unpleasant symptoms that may be underrecognised, underdiagnosed, and undertreated*' (Rhee et al. 2022: 9). These symptoms include but are not limited to anxiety, depression, stress, cognitive impairment, fatigue, cramps, and sleep problems. It is crucial that individuals living with KD make continuing emotional adjustments throughout their journey with their long-term condition. This can be distressing and overwhelming, potentially leading to depression and anxiety. The emotional symptoms of KD are of equal relevance as physical symptoms, and a constructive and empathetic approach to addressing these should also be extended to partners, family members and caregivers. Person-centred communication is vital including engaging and listening with the individual to build rapport. It must be kept in mind that it is unlikely that an individual will ever be *"symptom free"*. However, using open-ended questions such as asking what is concerning them and providing them the opportunity to talk whilst the nurse listens. Every patient contact should count towards a healthy lifestyle for the individual concerned (Murphy and Byrne, 2022a). There must be an appreciation of what is most relevant to the individual living with KD and concentrate on each person's values, goals, and personal needs. This could be relevant to motivating them to engage optimal health instead of perhaps a clinical outcome measure such as recent laboratory results (Rhee et al. 2022).

Jones (2020) asserts that individuals cannot successfully communicate with their healthcare team about the difficulties they may have with their treatments as emotionally, they may experience phenomenon that they have never felt previously. It may be easier for an individual to communicate to their healthcare team whether a CKD-related symptom is based on emotional or physical conditions (or a mixture of both) if they are prepared as to what could happen. This could be provided through initial support with a first visit to a mental health care specialist when diagnosed (Jones, 2020). Emotional preparation and consequently support is as relevant as educational preparation (Perl et al. 2023). There needs to be early identification and management of emotional symptoms by nurses and other members of the MDT which can incorporate pharmacological and non-pharmacological approaches. They need to be educated in management and treatment of emotional symptoms such as anxiety and depression using standardised approaches of screening (such as the Patient Health Questionnaire-9 (PHQ-9) and the Becks Depression Inventory (BDI) and diagnosing but being mindful of social and cultural background and any potential learning challenges with the individual concerned such as HL (Rhee et al. 2022).

Both individual engagement and self-help management are central to enhancing kidney health (Li et al. 2020). Individuals and their partners, family members and caregivers need the necessary skills, knowledge and understanding to make informed decisions concerning their health, well-being, and life goals. Nurses and other members of the MDT play pivotal functions in empowering and promoting patient-centred care for individuals with KD. Nurses who engage in positive partnerships with patients, family members and caregivers can enable enhanced shared decision making and self-care. Any decisions made should be decided in a timely manner such as types of KRT, or CM (Murphy, 2019, Murphy and Byrne, 2022b). Every treatment option and their effects such as benefits and possible risks of treatment along with person-centred measures to competently manage symptoms should be discussed with the individual living with KD. They need to feel comfortable with the treatment and with the applicable healthcare team. To reduce the impact the long-term condition has on their QoL it is important to support treatment needs with the goals of the individual with KD. It is also important to recognise the wider impact of KD for the person and their partner, family members and caregivers (Rhee et al. 2022). The choice of modality should be preference-sensitive, informed, and individualised centred on perceived QoL, life goals, and symptom burden. Using a shared decision-making process preferably individuals, their partners (or family members and caregivers as applicable) and their healthcare teams will decide together on the most suitable initial modality (De Jong et al. 2022). Home dialysis should not be restricted to individuals with high levels of activation and participation in self-care as these can be enhanced with suitable education and support (Wilkes and Barnes, 2019). However, there may be more options extensively accessible in higher-income regions, where KRT choices are less likely to be limited by economic factors. It is important to advise the individual who commences ICHD urgently that switching modality following clinical improvement is a possibility. Existing evidence indicates that ICHD, HHD and PD are adequately similar in clinical outcomes to reinforce individualised and personal choice amid these options (Perl et al. 2023).

Strengths-based approach

The importance of a strengths-based approach and its applicability to CKD care was highlighted by the WKD Steering Committee. This method could empower individuals to live well with KD. It highlights collaborative approaches with individuals with KD in the growth, application, and appraisal of interventions for both practice and policy structures (Kalantar-Zadeh et al. 2021). The participation of patients and their families and caregivers is crucial throughout this process and examples of this can be seen in the UK with co-production central to the *"Think Kidneys"* programme wherein there is an equitable shared partnership approach (NHS England and the UKRR, 2016; Gair et al. 2019). The strengths-based approach is a shift away from the biomedical model wherein there was a focus on pathology, challenges, and failures (Ibrahim et al. 2014). It recognises that individuals have strengths and capabilities to suppress the difficulties and problems confronted and

necessitates partnership and nurturing their expectations, goals, interests, and values. The strengths-based approach embodies approaches to enable individual resilience, utilise social connections, enhance individual awareness, knowledge and understanding, enable access to support and determine confidence and control in self-management. There are suggested strategies provided that employ a strengths-based approach **(see Table 1)** (Kalantar-Zadeh et al. 2021).

Strengths based approach	Suggested Strategies
Build awareness and knowledge	• Empower patients to ask questions and participate in shared decision making about their care. • Provide information and support to facilitate lifestyle modification (e.g., information about diet. • Facilitate an understanding of CKD on various aspects of their lives including cognition. • Provide information about the different treatment modalities to include kidney transplantation and conservative management to empower patients to plan.
Build resilience	• Provide patients with the knowledge of the impact of CKD on their quality of life at different stages (e.g., transitioning to dialysis) • Offer skills and resources to manage stress and functioning when facing challenges, impediment and trauma (e.g., associated with CKD or initiating of dialysis).
Harness social connections	• Provide information and access to support groups with CKD and to learn coping strategies and for peer support. • Provide support to care givers/ families and provide them with information to access support groups.
Facilitate access to support	• Refer patients to other members of the interdisciplinary team (e.g., dietician, pharmacist, social worker, mental health professionals, occupational therapist) • Encourage patients to attend renal support groups. • Provide support to facilitate patients to engage in vital life activities (e.g., travel, work, attend family celebrations. This support may be in the form of facilitating haemodialysis for those who wish to go on holidays in their own county or beyond.
Establish confidence and control in self-management	• Facilitate patients through open communication to identify their own concerns, goals, and priorities. • Provide approaches to prevent or address complications (e.g., infection). • Encourage patients to identify what works best for them, to voice their concerns and collaborate to develop improved management approaches to enable them to feel better. • Support informed and shared decision making (including dialysis, kidney transplantation, conservative management).

Table 1: Suggested strategies for "living well with CKD" using a strengths-based approach. (Kalantar-Zadeh et al. 2021)

Haemodialysis

HD is the leading type of dialysis globally. During the last decade there has been considerable developments observed in HD delivery and outcomes. However, individuals receiving HD still face poor QoL and their PROs including fatigue, LP, depression, anxiety, sleep quality, cramps, and pain as well as financial and mortality are unsatisfactorily high. Furthermore, the outcomes of individuals receiving HD are monitored and reported inconsistently, and are substantially heterogeneous amid centres, regions, countries, and various sections of the population (Bello et al, 2022a).

Individuals receiving HD must remain at the centre of care delivery as vascular access is their lifeline to HD treatment. The renal healthcare team, especially the nurse, play a vital role in the management of patients' vascular access (Murphy, 2014). The UKKA vascular access guideline for HD recommends specific access advice using simple information describing the comparative qualities of the range of vascular access for all adults and children expecting or undertaking a period of HD (Aitkin et al. 2023). They advocate the choice of vascular access as a patient decision taking on board personal individual characteristics and priorities and allowing sufficient time, supported by the MDT to reach a decision. Fistula formation is recommended for adults and children with appropriate anatomy and a probability of lengthy HD. It is suggested that it is suitable for any adult or child preparing for HD and expected to commence within 12 months to be referred for vascular access and if appropriate fistula formation. Although timing for best vascular access is determined on the individual patient and institutional aspects (Aitkin et al. 2023).

NICE (2018) guidelines on renal replacement therapy and conservative management also recommend timely access to establish an arteriovenous fistula (AVF) about 6 months prior to the expected initiation of HD for this to mature. This timing considers the possibility of the first fistula failing or requiring additional interventions prior to use. These guidelines supported by expert commentary (Kharbanda et al. 2020 on behalf of the UKKA) also identifies the importance of averting unplanned KRT by using temporary vascular access which is related to adverse clinical outcomes.

Vascular access education is suitable for any stage of KD (Aitkin et al. 2023). However, all adults and children and their caregivers where suitable who are expected to need long term HD should be educated in vascular access and vein preservation. This must be adapted to their personal situation and can be provided by various members of the MDT. In both adults and teenage children fistula formation is favoured over graft insertion apart from when it is necessary for premature cannulation or where anatomy at established sites is detrimental; in this case it may be contemplated the use of a graft in adults (Atkins et al. 2023). Woo et al. (2022) strongly advocate the development and usage of a committed dialysis vascular access PRO which will target issues that are relevant to individuals and result in a holistic vascular access enhancement pathway. It is vital that individuals with KF have a voice to vent their struggles relevant to the daily influence of sustaining a functional HD vascular access. There must be continual collaboration with all relevant stakeholders and priority provided to patients QoL and satisfaction (Woo et al. 2022).

Psychological and social well-being must be focussed upon along with physical functioning to enhance adults QoL receiving dialysis. Tommel et al. (2021) Dutch study investigated a number of cognitive-behavioural and social issues, with an emphasis on negative outcome anticipations that may be pertinent for HRQoL in adults with ESKD treated with both HD and PD. The findings established that individuals' feelings and thoughts concerning their disease such as helplessness and worrying, are considerably related to HRQoL and, consequently, could be of crucial importance in enhancing HRQoL. The use of embracing realistic and adaptive feelings and thoughts in addition to determining a strong social support system is advocated for individuals to achieve a life as normal and as contented as feasible, despite the unchangeable outcomes of their disease (Tommel et al. 2021).

Fernandez et al. (2022) scoping review aimed to depict how mental health care is provided to adults treated with dialysis in Canada. The findings have various repercussions for health care providers, dialysis stakeholders/ programmes and researchers. There was a lack of high-quality studies found especially RCTs examining the impact of mental health interventions for persons receiving dialysis in Canada. There needs to be a concentrated endeavour by stakeholders and researchers to minimise this disparity. There are distinctive challenges that need committed methods for individuals living with dialysis such as fluid and diet restrictions and therapy schedules, concurring disease symptomatology, and an increased risk of side effects with pharmacological methods. There is a necessity to devise clinical practice guidelines and clinical pathways in addressing mental health worries. There is a deficiency of mental health resources devised by kidney care organisations across Canada. These mental health resources are copious; however, they are usually directed toward the general adult population. Mental health interventions and resources should be individualised to manage the recognised needs of this group since individuals living with dialysis have distinctive stressors. There is a necessity to undertake studies to ascertain the quality of websites that deliver information on mental health for individuals with KD. There is a lack of regulation on the internet concerning the quality and reliability of these websites. The mental health associated websites with quality content should deliver evidence -based information and interventions (Fernandez et al. 2022).

There are many challenges for individuals living with HD to adhere to their treatment itself and various regimes associated with same including fluid and diet restrictions, and a high medication burden. Treatment adherence of adults that receive HD is crucial and is a complicated ongoing process. Non-adherence to treatment could ensue in comorbidity, hospitalisation, mortality, and a worsening QoL (Ok and Kutlu, 2021). The aim of a study by Ok and Kutlu, (2022) (using a randomised controlled pre-test, post-test, and follow up design) established the impact of motivational interviewing (MI) on adherence to treatment and QoL in individuals receiving maintenance HD. MI can be regarded as a collaborative, person-centred type of guidance to prompt and strengthen motivation for change with individuals (Miller and Rollnick, 2009). It found the positive impact of MI on adherence to HD therapy using both objective and subjective factors. Furthermore, there was a statistical significance found in the mean scores pre and after the intervention concerning the deviations in pain, vivacity, social function, emotional role, and mental health in HRQoL. The use of MI could be regarded as an effective means in enhancing treatment adherences and QoL in individuals receiving HD. The main aim of patient-centred MI is to encourage and sustain behavioural change. This can be used as a suitable technique with treatment adherence challenges of adults receiving HD. However, nurses and other members of the healthcare teams who work with individuals receiving HD should use this method. However, they need to have specific MI training to employ interventions (Ok and Kutlu, 2022).

Bazrafshan et al. (2023) conducted a descriptive correlational study (n=218) with individuals receiving HD in Iran to exam the association between treatment adherence, procrastination, and complication in emotion regulation. The findings indicated that medication use, and attendance are associated to procrastination in these adults receiving HD. It also suggests that both the cause of KD and age were predictors of treatment adherence. To create any change, it may be better to concentrate on specific behaviours and not on general adherence. It is vital to recognise the issues impacting non-adherence of individuals receiving HD and again enhance their treatment adherence and QoL. There was a recommendation for additional studies in this area (Bazrafshan et al. 2023). A meta-analysis was conducted to evaluate the impacts of treatment adherence enhancement programmes on treatment adherence and secondary outcomes for adults on HD. There was a statistically significant impact of treatment adherence enhancement programmes for adults living

with HD. The findings offer evidence-based data for improving programme efficacy when devising treatment adherence enhancement programmes for this cohort (Kim et al. 2022).

The UKKA clinical practice guideline on HD recommend intradialytic exercise as a therapy for improving physical functioning in adults without contraindications; and should be accessible in all units. Intradialytic exercise should be regarded as a means of enhancing individuals' QoL and should be developed by suitably qualified staff (Ashby et al. 2019). The importance of PA and exercise is also recommended by the UKKA clinical practice guideline on exercise and lifestyle in CKD to enhance QoL including mental health across all spectrums of KD (Baker et al. 2021). Brys et al. (2020) conducted a study in Italy with adults receiving HD (n=37) to monitor spontaneous daily physical activity (DPA) with motion devices and examine its association with fatigue and depressive symptoms. Both these symptoms are regarded as main obstacles to PA with individuals on HD. It is important to develop a better comprehension of their interconnection to progress successful therapies. It was established that spontaneous DPA is influenced by age instead of fatigue or mood (Brys et al. 2000). Ferreira et al. (2021) systematic review and meta-analysis also indicated the impacts of exercise interventions are effective in decreasing mood disorders such as depressive symptoms and anxiety.

Bayülgen and Gün (2022) conducted a systematic review to establish the impact of complementary and integrative therapies on fatigue in adults receiving HD. Acupressure, aromatherapy, reflexology, massage, and yoga practice have all been identified in the literature to be useful in diminishing pain and anxiety along with enhancing sleep quality. It is advocated that these practices be incorporated into standard clinical care of adults receiving HD. Zhang et al. (2023) conducted a meta-analysis concerning the use of aromatherapy for individuals receiving maintenance HD. They concluded that aromatherapy can be used as an innovative alternative and complementary treatment to enhance sleep quality and decrease fatigue and anxiety in this cohort. Its use however does not considerably lower AVF puncture pain. There is a necessity for high quality multicenter trials with large samples to further investigate the intervention impact of aromatherapy on problems linked with maintenance HD. There should be additional research conducted to explore the practice of aromatic massage and the impact of various oil types and dosing protocols, concentrations, types, and practices in aroma diffusion (Zhang et al. 2023). Matthews et al. (2021) conducted a non-randomised pilot study (n=20) with individuals receiving ICHD in Northern Ireland to investigate the feasibility of providing intradialytic reflexology. It was identified that this intervention was feasible and well received. The outcomes of this study provide renal units with a greater insight of the possible value of reflexology which could encourage more HCPs to outline the use of these complimentary therapies with their patients. The use of reflexology could be promoted as a nonpharmacological therapy along with the usual treatments and care delivery.

The impacts of mindfulness meditation on trait mindfulness, perceived stress, emotion regulation, and QoL in adults undergoing HD was examined using an experimental study in Kuwait. Mindfulness meditation is usually successful in enhancing health outcomes and could be used as a means of coping for people receiving HD to assist with stress management and health. This was demonstrated by the end of the intervention by a reduction in perceived stress and a rise in trait mindfulness, emotion regulation and QoL amid the individuals from the experimental group (Alhawatmeh et al. 2022). Wilson et al. (2022) discussed their impending study to support a novel service development project in collaboration with Kidney Care UK by employing the four-session compassionate mindful resilience (CMR) syllabus, devised by Mindfulness UK and ascertain its usefulness for individuals with stages 4 to 5 CKD or have obtained a KT. This study will examine the impact of the CMR syllabus on anxiety, depression, self-compassion, the ability to be mindful, wellbeing, and resilience using a quasi-experimental design. It will also explore using a qualitative approach with individuals and their mindfulness teacher factors impacting the feasibility, acceptability and appropriateness of the

intervention and their dedication to practice. It is anticipated that the consequence from this study will involve an evidence-based mindfulness and compassion syllabus to use with individuals with KD (Wilson et al. 2022).

Kidney Care UK (2023b) outlines the concept of emotional resilience which encourages individuals with KD to being open to their experiences (even the distressing ones), living in the now (mindfulness/ noticing) and working on the values which matter most to them. They outline the use of an emotional resilience toolbox which involves 1) accepting that anxiety can impact on a person physically 2) reclaim control by concentrating on breathing with a technique provided 3) use an app to deliver some serene time such as a music or mindfulness app which may help with relaxing or with sleep 4) talk to someone; this could be a member of the healthcare team, a family member, a friend, Kidney Care UK patient support and advocacy services 5) practise mindfulness and 6) attempt to spend a set time to worry as being worried can easily take over an individuals' every thought. Individuals with KD are encouraged to make an ongoing commitment to apply these areas which can build resilience and can assist them to manage the unavoidable struggles of living with a long-term health condition (Kidney Care UK, 2023b).

Music intervention is a widely applied nonpharmacological therapy method or complimentary therapy. A systematic review and meta-analysis established that music intervention could partly enhance physical and emotional difficulties in adults undergoing HD. The substantial physical benefits of music intervention include impact on breathing, oxygen saturation levels, sleep quality, state anxiety and stress. Whilst music intervention has an average and beneficial impact on pulse rate, blood pressure readings, pain, and anxiety. There was a recommendation for further RCTs in this area (Yangöz and Özer, 2022). Another systematic review and meta-analysis by Wu et al. (2021) found similar beneficial impacts of music-based interventions for reducing pain perception, heart rate, anxiety, and blood pressure. The use of these findings should be contemplated when devising best practice guidelines for the management of physical and psychological symptoms in individuals receiving HD. Soliva et al. (2022) conducted a prospective group randomised intervention study in Spain with adults on HD to establish if the intervention of classical music live and "in situ" throughout HD therapy impacts on their HRQoL. The findings indicated that the application of live music enhances their self-perceived QoL. It can be used as a significant therapeutic resource that acts as an adjuvant to kidney therapies as well as positively influencing the individuals' well-being.

There is lack of evidence concerning the impacts of guided meditation (Yoganidra) on QoL among adults receiving maintenance HD. The use of guided meditation ensued in statistically significant enhancement in qualitative attributes of well-being including a level of happiness, eagerness, inspiration, vigour, attentiveness, cognisance, level of stability, self-confidence, self-reflection, clearer thoughts, in the intervention cohort of participants as determined by quantitative and qualitative methods (Vaishnav et al. 2022). There was a significant enhancement in stress levels as determined by perceived stress scale, KDQoL connected to burden and impact of KD, symptoms of KD and complete KDQoL record. It is easy to instigate guided meditation and is effective in improving several aspects of QoL and well-being. It can be advocated for addition in standard care for improving QoL of individuals receiving maintenance HD (Vaishnav et al. 2022).

The Renal Arts Group (RAG) at Queen's University Belfast was formed in 2016 as a partnership amid patients with KD, caregivers, HCPs, academics, and artists to devise a programme of research with the goal of enhancing the physical and psychological QoL of those living with KD through the medium of the arts. The group goals are to provide a voice to individuals living with KD, enhance public engagement and advance social impact through interdisciplinary collaboration amid

academics, researchers, healthcare professionals, service users and policy makers (https://www.qub.ac.uk/sites/renal-arts-group).

As part of the Renal Arts Group agenda, Wilson et al. (2021) discussed an initiative to devise guidelines for implementing volunteer-led arts activities for adults receiving HD. The applicable research team in discussions with the local healthcare trust made the choice that trained volunteers would be well situated to assist the artist-in-residence work, whilst being able to devote extended periods of time with individuals to concentrate on skills development and endorse sustainability and engagement of the arts intervention. The original initiative in the guideline's development was direct one-to-one bedside enablement of arts activities. This did not transpire because of the COVID 19 pandemic and the associated restrictions. The use of virtual volunteers reflects a flexible and responsive perspective were initiated in guidelines and can provide one-to-one support and encouragement for individuals by phone or online. It continues support for patients to sustain their art projects when non health care workers were not in positions to attend the renal unit and throughout periods of limited access to the renal unit. The pandemic restrictions may have relaxed considerably however the use of virtual volunteers may maintain for the predictable future (Wilson et al. 2021).

Carswell et al. (2019) devised a person-centred complex arts-based intervention in Northern Ireland for individuals receiving HD utilising the arts in health development framework. Example of arts-based interventions include creative writing such as poetry or short stories or visual art activities. There is a lack of evidence on the efficacy of complex arts-based interventions for enhancing well-being, health and QoL. A collaborative approach with service users, HCPs and main stakeholders in developing an evidence-based arts-based interventions can assist deliver access to amply satisfactory, safe, and holistic care (Carswell et al. 2019). A process evaluation was conducted by the same authors (Carswell et al. 2021a) as part of a larger feasibility study to discover both acceptability and experiences of an intra-dialytic arts-based intervention. Both individuals on HD and HCPs identified the intervention as a positive effect on them with better communications with a more humanistic focus identified by the HCPs with individuals in terms of discussing issues surrounding the applicable arts that was not associated with clinical issues such as patient disease. The acceptability of the delivery of a facilitator of an arts-based intervention who was not a professional artist was another main finding from this study. This use of arts-based interventions could offer benefits to the mental well-being of both patients and HCPs. There is a need for further studies in this area using high end methodologies along with advancing other holistic interventions to attend the mental health and well-being of individuals with KD (Carswell et al. 2021a).

Home dialysis

Home dialysis modalities or home therapies encompass HHD and PD. These modalities are associated with enhanced individual autonomy along with individual satisfaction with treatment in comparison with ICHD. However worldwide the rate of home dialysis use is poor. The rationales for this under utilisation are dependent upon a variety of situations including local resources, dialysis expenditures, access to healthcare, health system procedures, healthcare provider's partiality or preferences, cultural values, individual lifestyle worries, possible care-partner time, and financial difficulties (Perl et al. 2023). Ethier et al. (2020) and Castledine et al. (2013) identified other major factors that have been associated with reduced uptake of home dialysis include male sex, older age, minority ethnicity, enhanced comorbidities burden, reduced SES, obesity, and close vicinity to dialysis centers. There may be more barriers to participating in decision-making and/or to being offered alternate modalities with patient subgroups encompassing indigenous populations, specific religious groups, displaced individuals, those with lower HL, language barriers or cognitive impairment. Responsive strategies are required with these individuals. Both community and cultural

experiences can impact individual choice as some may feel embarrassed about being ill or that conversations about illness are verboten. There are numerous resources realistically required for successful home dialysis comprising a safe and clean environment, access to technology, and in many instances, support from family or community (Perl et al. 2023).

There is an increased demand for dialysis in the older population given the enhanced numbers of older adults living with KD progressing to KF (Wu et al. 2023). A review was conducted to evaluate some of the main challenges encompassing the delivery of home dialysis to older adults and suggest possible solutions established on updated evidence to overcome these challenges. The first challenge is HCPs negative perceptions and preconceived bias concerning the suitability of older adults for home dialysis. Solutions here involve education initiatives to enhance perception of the possibility and advantages of home dialysis for older adults highlighting patient-important outcomes compared to survival as the best metric of 'success'. The second challenge was anxieties concerning the burden of therapy upon commencement of home dialysis. Solutions proposed include to begin slowly using an incremental dose method for HD and PD. The concept of planning for the unplanned using buried PD catheters, urgent start PD, catheter, and single needle choices where suitable and creating transitional care units. Another challenge is that home dialysis-related complications can be more predominant in the older population with augmented frailty and co-morbidity condition. Solutions identified involve using an individualised, goal-based tactic in managing dialysis-associated problems which is probably more intricate in older adults. The clinical frailty scores should be regularly measured to appraise degree of frailty versus motivation levels to continue home therapy. The final challenge was the concept of caregivers stress and burnout continued from the responsibility of caring for the older adult accessing receiving home dialysis. Solutions suggested are both patient and caregiver financial incentives. The development of a realistic long-term care plan to assist caregivers with resources and personnel for recurring respite care, community nursing support and re-education programmes (Wu et al. 2023).

Home haemodialysis

HHD should be available in all units in the UK as part of an inclusive KRT programme (Ashby et al. 2019). However, globally in numerous regions including several high-income areas, individuals facing KF have limited or no access to HHD (Perl et al. 2023). There should be an individualised person-centred approach to training individuals for HHD and their family members, and caregivers as appropriate. The training method should include a specific set of competencies which should match the learners' speed (Ashby et al. 2019). The choice of HHD like PD is mainly determined by the individual patient's decision and education. There are major benefits for those who opt for HHD such as the home background, amenable scheduling, dialysis intensity, reduced pill burden and independence with nutrition and fluids. HHD should be deliberated and provided to all individuals considered appropriate (NICE, 2018; Kharbanda et al. 2020). Finderup et al. (2021) aimed to address how individuals continued to be involved in their treatment and care of their own health after an intervention on shared decision making on dialysis choice. Those individuals who opted for home therapies had become more encompassed in their care delivery of their own health with support from both family members and HCPs influenced positively to this choice. Shared decision making has the possibility to enhance self-management in persons with KD.

Peritoneal dialysis

PD remains an appealing, patient-centered type of KRT (Auguste and Bargman, 2022). PD has definite advantages compared with HD including the accessibility of home therapy, enhanced QoL, technical ease, better cost effectiveness in many countries and enhanced survival specifically in the first few years of commencing therapy (Bello et al, 2022b). The UK Renal Association clinical practice guideline on PD in adults and children acknowledge that the success of a PD programme is reliant upon specialised nurses with relevant knowledge and skills in assessing and educating individuals for

PD therapy, supervising treatment, and the appropriate resources to provide sustained community care (Woodrow *et al.* 2017). Radmore and Hyrkäs (2019) identified that the relationship between the PD nurse and individuals receiving PD is vital for meaningful outcomes. This collaboration is unique and develops over time. Nurses need to alter their educational matter and teaching style to best match the needs of individuals obtaining PD and more importantly let them feel supported and cared for to have a successful partnership working together.

Blake and Brown (2020) discuss the relevance of patient centred care and shared decision making for those that are approaching KF and need to make choices concerning modality therapies. Patient centred care is required for those individuals' commencing dialysis as well as PD prescription and care delivery. It is vital to any decisions made concerning goals of care, transplantation, conservative care, and withdrawal of dialysis. It is also applicable as to how PD is delivered for example possibilities such as incremental PD. The concept of engagement, education and empowerment of patients are essential within shared decision making which should be a standard value of care. A central focus of patient centred care in PD is PROs with individuals having the chance to relate any reported outcomes and obtain the relevant symptom evaluation and management. Whilst patient-reported experience of care is another vital measurement of how effective patient-centred care is in PD which could be assessed to enhance care delivery (Blake and Brown, 2020).

It must be ensured that those individuals approaching KF who wish to opt for PD can learn about PD and have a meaningful opportunity to be treated with this therapy. The PD healthcare team must be mindful that these individuals can be worried, distressed, and disadvantaged and they should be supported appropriately. Patients must be provided with a choice as much as feasible whilst being educated regarding the PD prescription they obtain including decision between CAPD and APD, the choice where applicable of pursuing an incremental PD approach, and the choices they have concerning how their PD prescription could be adapted to improve clearance, fluid elimination and control of symptoms. The importance of education for persons doing PD including knowledge and understanding about their condition as well as prognosis and provided with the option to express their goals of care. They should be advised of their choice to stop dialysis and change to a palliative care route if they so request and should be assisted by the healthcare team if they make this decision (Blake and Brown, 2020).

It is well acknowledged that the well-being of the individual on dialysis is relevant to many diverse factors with moving the focus from small solute clearance targets to what patients' need and their goals (Auguste and Bargman, 2022; Brown et al. 2020). Brown et al. (2020) on behalf of the International Society for Peritoneal Dialysis (ISPD) outlined their recommendations on prescribing high-quality goal-directed PD. Dialysis is only one element of care impacting outcomes including multimorbidity (symptoms, polypharmacy, reduced physical and cognitive function), age (reduced physical and cognitive function, frailty, dementia/ delirium), psychosocial (anxiety, depression, social support, money worries, diminished time for LP), dialysis-associated (symptoms, polypharmacy, reduced appetite, burden of dialysis) (Brown et al. 2020). These *"goal-directed"* guidelines focus on the individual doing the PD. There should be shared decision-making between the individual doing the PD and the healthcare team when prescribing PD. The purpose is to determine realistic care goals that uphold QoL for the individual as much as feasible by facilitating them to meet their life goals and diminish symptoms and treatment burden whilst ensuring high-quality care is delivered. The PD prescription should take on board the needs and lifestyle consequences of the persons requiring treatment involving those of their partner, families, and caregivers', particularly if delivering care assistance along with the local country resources. The delivery of high-quality PD care can be ensured by using a number of assessments such as PROMs. These are a measure of how an individual conducting PD experiences life and their feeling of well-being. It should take on board the

individuals' symptoms, influence of the dialysis routine on their mental health, daily life, and social surroundings (Brown et al. 2020).

The SONG-PD initiative based on the shared priorities of all stakeholders aims to determine core outcome domains for trials in PD. The core outcomes domains of PD were that of LP, inclusion of PD-associated infection, CVD, mortality, and technique survival (avoid transfer to HD). The concept of LP was regarded as a central goal to PD. However, fatigue was acknowledged as a possibly debilitating symptom that may impair LP. Participants identified the use of less negative terms such as "*PD failure*" and instead a more positive framed alternatives such as "*technique survival*". There is a necessity to establish a recognised measure for LP that is easy to process and appropriate to every patient incorporating those from low- and middle-income countries (Manera et al, 2019a, 2019b, 2020). A SONG-PD LP consensus workshop was conducted in 2020 with 56 participants (individuals receiving PD, caregivers, HCPs, and policymakers) from 20 countries through online videoconference. There were four main themes that signified viewpoints and fundamental features of LP to be encompassed in a core outcome measure for LP in PD. These were (1) reconfiguring expectations of daily living, (2) ensuring wide-ranging applicability and interpretability, (3) capturing changes between modalities and how they impact LP and (4) increasing possibility of implementation. Participants took on board the importance of widely implementing the chosen SONG-LP tool in trials of PD when available. Thus, there is a necessity for it to be concise, flexible delivery in various formats such as paper, phone app etc. and able to be translated into additional languages (Cheetham et al. 2022).

It has been identified that PD can assume an increased burden of self-care in PD persons homes and day to day life which could cause stressors for them and their partner, families, and caregivers. Participants receiving APD in a qualitative study in Australia used cognitive, emotional, and behavioural strategies along with a reliance on social supports to adapt to their therapy. The findings have contributed to proposals for dialysis care to enhance emotional well-being and coping which could be included into a forthcoming theory of comprehending adjustment to and coping with KD. These include routinely obtain and reassess patient preferences, personalise patient education and peer support, routinely evaluate and appraise psychosocial needs and support patient emotional well-being. Both the psychosocial pros and cons of APD should be particularly contemplated in pre-dialysis education and assist in shared decision making. The sometimes "shrouded" nature of home therapies has diverse significances for patients. Both disease milestones and times of transition can heighten emotional challenges wherein professional psychological support may be embraced by some individuals. Further investigations could include reviewing interventions that both assess and educate coping skills along with the caregivers' perspective (Duncanson et al. 2021).

Fissell et al. (2021) US single centre study outlined the novel concept of mindset for comprehending cognition, psychology and decision making in adults receiving PD. A health mindset is a person's belief about capabilities to change to enhance health. There is a necessity to support strategies to enhance prevalence and perseverance of home therapies as people may commence PD but following complications can transition to HD. The Health Mindset scale was used (n=101) to depict the range of fixed versus growth mindset as applicable to health. Both HL and health self-efficacy were also measured. Health self-efficacy was strongly related to growth mindset. Individuals may be identified through use of the health mindset scale who may gain from directed interventions to enhance mindset and promote PD modality specific perseverance (Fissell et al. 2021).

The importance of PA and physical function in life participation is a crucial PRO for individuals receiving PD. The Global Renal Exercise Network and ISPD reviewed evidence and international clinical experience to develop a set of clinical practice points for persons receiving PD. There was a sparsity of quality evidence to support clinical practice in this area thus expert consensus was

reached by persons receiving PD, experienced PD exercise investigators along with expert clinicians in PD exercise. There were various clinical practice points addressed such as the timing of exercise and activity (such as empty or full peritoneal space), the interest of particular activities (such as work, sex, swimming), possible unfavourable outcomes associated to activity and exercise (such as exit site care, fatigue, sweating, cardiovascular concession, intra-abdominal pressure), and the impact of exercise and activity on areas of interest (such as mental health, reduced fitness, obesity and frailty) and exercise nutrition (Bennett et al. 2022).

The use of assisted home dialysis including that of assisted PD (asPD) refers to the provision of assistance to individuals with PD by family members and/ or caregivers and/ or professionally trained dialysis nurses, community healthcare workers, personal support workers or other skilled assistants (Perl et al. 2023). The accessibility of asPD increases access to dialysis at home, specifically for the growing numbers of older and frail people with advanced KD (Brown et al. 2022). This assistance can vary and depends upon the individual's requirements and can be partial or complete, temporary, or permanent, and paid or unpaid. It can be non-technical such as bringing dialysate bags into the individuals' room. Technical assistance can entail setting up the PD dialysis machine and dialysis-related processes. Clinical assistance includes assessment of the individual's exit site and fluid volume (Perl et al. 2023).

The use of asPD has been extensively utilised for many years in some European countries; however, it remains inaccessible or poorly employed in others. Brown et al. (2022) established a group of European nephrologists consequently to the necessity to increase access to asPD across Europe as a way of facilitating individuals with advanced KD who were incapable to conduct dialysis themselves to still have their dialysis in their own home. Following completing a proforma concerning asPD it was established by this group that only 5 out of 13 countries surveyed offered publicly funded reimbursement for asPD. The availability of asPD should be prevalent in every renal centre and country in Europe. The main priorities to enable this process are education including education of HSPs about the benefits of PD, education of and conversations with individuals and their families as they approach the necessity for dialysis. There also needs to be engagement with both policymakers and healthcare providers to both develop and advocate assistance for PD (Brown et al. 2022).

The necessity for kidney supportive care in PD patients may be even bigger than those that are receiving HD. This is because of a number of issues. 1)There is possibly more complexity and bigger decision-making with a diverse range of therapies to consider, 2) the bigger extent of prognostic indecision with less obtainable prognostic tools, 3) potential variances in type or range of symptoms faced, and 4) subsequent relevance of comprehending personal PD patient motivations. These concerns require consideration to ambitious, longitudinal, goal-focused dialogues that modify individuals' values and significances throughout time. Individuals receiving PD and healthcare providers will be greater prepared not only to make dialysis choices through the window of personal goals and priorities by means of a kidney supportive care person-centred approach to KD care. They can also constantly reframe their kidney treatment decisions in the wider context of an enduring and possibly changing disease trajectory (Lu and Chai, 2021).

Kidney transplantation

KT is viewed as the best treatment option for patients with KF requiring KRT (Lai et al. 2020). However, KT is a momentous experience that encompasses intense emotional, relational, and social transformations both for the individual and their family situation (De Pasquale et al. 2020). The preparation for KRT or CM should commence 1 year prior to therapy required including those individuals who have a failing transplant (NICE, 2018). Whilst Kharbanda et al. (2020) suggest a timeframe of 6 months for listing possible recipients for KT prior to expected commencement of KRT.

The process should be completely individualised. The individual and their family members and caregivers (as applicable) should be included in shared decision-making throughout this assessment process. This incorporates clinical provision, psychosocial appraisal, planning and support, the individuals wish for type of KRT and when to commence and how choices are possibly to influence daily life. There should be additional assessment by a clinical psychologist or psychiatry for every child and young person being contemplated for a KT (NICE, 2018; Kharbanda et al. 2020).

Adults who may have adverse outcomes identified should also be regarded for additional assessment for example a deficit in social support, neurocognitive condition, non-concordance (such as medications, dietary, healthcare appointments), limited comprehension of procedure and intricacies of treatment, inadequately managed mental health conditions or SMI and substance abuse or dependency (NICE, 2018; Kharbanda et al. 2020). McCulloch and O'Leary's (2022) narrative review identified that there is limited evidence to propose psychosis as a contraindication to transplantation regardless of it often being seen as such by transplant teams. Positive outcomes instead are reliant on other aspects including stability of symptoms, motivation, and social support. It is important to recognise though that transplantation on its own can be an extremely stressful occurrence which could activate trauma memories. The need for enhanced psychosocial assessment and support should be acknowledged instead of viewing this as merely a contradiction for treatment. Additional research is needed into the resiliencies of individuals who have considerable mental distress. It is feasible that some individual's experiences have empowered them to acquire coping strategies that could also assist them to cope with the burdens of transplant (McCulloch and O'Leary 2022).

There is a necessity to discuss individual aspects that influence the risks and advantages of KT with all individuals who are expected to require KRT and their families and caregivers. Living donor transplantation should be included in this discussion concerning choices for KRT. A pre-emptive living donor transplant should be provided where there is an appropriate living donor. This is regarded as the ideal initial choice for KRT in suitable individuals. Following a complete assessment and if the individual is deemed eligible, they can be placed on the pre-emptive listing for deceased donor transplantation. A BMI alone should not exclude individuals from obtaining a KT (NICE, 2018; Kharbanda et al. 2020). It must be remembered that transplantation does not occur in clinical isolation, as the majority of pretransplant patients have been exposed to CKD and all its associated complications. This must be taken on board when assessing the individual for transplantation and their overall health along with the possible long-term impact of previous and current KD which could necessitate decades of clinical follow up post successful KT (Danovitch 2010a, 2017).

KT imparts significant survival and QoL advantages for many individuals with ESKD compared with dialysis (Ju et al. 2019). The SONG-Tx global initiative has established six core outcomes that should be reported in all KT trials. (Howell et al. 2016; Sautenet et al. 2018; Tong et al. 2018). In conjunction with clinical outcomes relating to allograft loss, CVD and mortality, cancer, and infection, LP was the PRO of greatest relevance to recipients, caregivers, and HCPs (Ju et al. 2019; Tong et al. 2022). However, participation in daily life activities can be impaired by complications and side effects of immunosuppression. LP is a significantly relevant PRO for KT recipients (KTRs) but is uncommonly and inconsistently measured in trials (Ju et al. 2019).

The SONG-Tx LP consensus workshop was held (n=16 KTRs and n=9 caregivers and n=33 HCPs from 8 countries) to establish an outcome measure for LP for usage in each trial in KT. The transcripts from the 6 facilitated breakout groups were analysed with four themes identified. The first theme of "*returning to normality*" expressed the individuals' goals to accomplish their roles (i.e., family, work, and community) and rebuild a normal lifestyle post-transplant. The second theme of "*recognizing the diverse meaning and activities of "life"* clearly recognised LP as a personal concept that could

refer to diverse activities (e.g., occupation, leisure, and family responsibilities) for each individual patient. The third theme referred to *"capturing vulnerability and fluctuations posttransplant*" (e.g., owing to side-effects and complications) and addressed the differentiation between the experiences during the first-year post-transplant along with the long-term influence of transplantation. The final theme was "*having a scientifically rigorous, feasible, and meaningful measure"* was estimated to facilitate reliable and recurrent assessment of LP in trials in KT. These first and second themes identified related to the content to be depicted in the measure. Whilst the third and final themes associated with measurement characteristics. There is a necessity for an achievable and substantiated core outcome measure for LP so that this significantly relevant PRO can be reliably and meaningfully assessed in trials in KT to advise decision making and care of KTRs (Ju et al. 2019).

Burns et al. (2017) explored the lived experiences of individuals waiting for a kidney transplant from a deceased donor whilst receiving KRT in Australia. This study highlighted that those individuals waiting for a transplant are overpoweringly hindered by their exposure to KRT. The concept of receiving a kidney transplant provides them with *"hope that one day they will be free"*. However, uncertainty continues when they are concerned as to the length of time waiting for a KT as well as would the transplant really affords them with the freedom they covet. Social networks including family members and fellow individuals on dialysis were identified as beneficial to those who waited. There were multifaceted emotions felt towards the deceased donor with aspirations that an organ would be available quickly; whilst valuing the immense cost to the donor and their family; *"wishing for a transplant is like wishing for someone to die"*

Living kidney donors

A living donor kidney transplant (LDKT) would nearly always be the preferred choice, with greater transplant and patient survival than for deceased donation (Andrews and Burnapp, 2018, on behalf of the British Transplantation/ Renal Association guidelines for living donor transplantation). However, living donation contests the ethical principle of non-maleficence in that it exposes healthy individuals to risks for the benefit of another individual. This generates safety, informed consent (IC) and education a priority. There are numerous benefits for the potential donor with living kidney donation but there are also associated short- and long-term risks. Whilst complete standardisation of IC is possibly unachievable, studies have highlighted the necessity for a standardised IC process to facilitate equitable educational and decision-making expectations for the deterrence of inequalities among transplant centers. The DESCaRTES (developing education science and care for renal transplantation in European States) Working Group of the European Renal Association recommend a 3-Step Model (Grossi et al. 2023). This is established on the shared decision-making Three-Talk Model by Elwyn et al. (2017). The 3-Step Model is wherein each step concurs with the three ideal timings of the process guiding the living donor (LD) to the verdict to participate with living donation. 1) Prior to the necessity for KRT there is a team talk; 2) there is an option talk with transplant HCPs at the local nephrology unit or transplant center before evaluations commence and 3) and during evaluation, specifically if there are second thoughts or uncertainties following learning about the various facets of donation; known as the decision talk (Grossi et al. 2023). The DESCaRTES recommend standardisation of the timing, content, modalities for imparting risks and assessment of comprehension preceding to donation. The 3-Step Model permits a successful combination between standardisation and individualisation of IC, facilitating a person-centred approach to possible donors (Grossi et al. 2023).

The Human Tissue Authority (HTA) in the UK advocate that all living donation regulations for organ transplantation must be sanctioned by them prior to any donation occurring. This includes that there is no remuneration has been or will be provided; consent has been provided for removal for the intent of transplantation. Living donation can only be warranted if the interests of the donor are

given prevalence irrespective of recipient benefit. Both safety and welfare of the potential LD must take priority always over the possible transplant recipient (Andrews and Burnapp, 2018). There must be ongoing continual support for the potential donor, recipient, and family members which is an essential component of the donation/ transplantation practice. There must be an identification at an initial stage of the emotional needs to enable that suitable support and/ or intervention is introduced which could be referral to specialist psychiatric and psychological services (Andrews and Burnapp, 2018; Chadban et al. 2020). There can be distress for both the donor and recipient if the potential donor is not able to donate because of a clinical rationale. This can ensue anguish for both parties and may relate to negative emotions of failure, fury, or blame. This could subsequently result in depression or other negative emotional outcomes. There is a necessity with this situation to anticipate and sufficiently provide emotional support. It can also be stressful for both donor and recipient and relevant family and friends whether to continue with living kidney donation and to make this decision. This decision-making process as to which donor should continue if there are a few family members considering donation can be complicated. The healthcare team play a crucial role here with providing relevant cohesive information at an initial stage so that relevant parties are as fully informed as feasible and make a choice (Andrews and Burnapp, 2018; Chadban et al. 2020).

Lentine et al. (2017) on behalf of the Kidney Disease: Improving Global Outcomes (KDIGO) clinical practice guideline on the evaluation and care of living kidney donors identified that psychosocial evaluation assists in determining if a donor candidate is psychologically fit for donation. There is a need for education and planning sessions with experienced HCPs to discuss the psychosocial evaluation and the process involved with the donor candidate. These sessions will advise the donor candidate that they should have a good QoL following donation; however, they should be advised that some individuals may experience psychosocial difficulties following donation. These sessions should concentrate on any worries that the donor candidate may have and ensure that any possible psychosocial risks and benefits of kidney donation are revealed and understood. The psychosocial evaluation can also be used to devise a plan to assist the donor candidate in having a positive psychosocial experience during the evaluation and donation procedures, and long-term following donation. Transplant programmes should adhere to procedures for assessing psychosocial factors that either exclude donation or stop any further evaluation until there is a resolution (Lentine et al. (2017).

There are many challenges in transplant-particular emotional adjustment facing both living donor recipients (LDRs) and deceased donor recipients (DDRs) with evidence recognising emotional adjustment limited. 182 KT patients (n=106 LDRs, n=76 DDRs) from Singapore completed a depression, anxiety, stress scale and a transplant effects questionnaire. The LDRs were a younger cohort and more educated. Both groups experienced moderate to severe symptoms of anxiety with younger participants highlighting greater risk of adverse emotional adjustment. There is a necessity for additional interventions aiming at improving anxiety and transplant-specific worry (Lai et al, 2020).

Post kidney transplant

The care post KT should not only encompass immediate postoperative surgical care and management of immunosuppression but also incorporate management of the failing and failed kidney allograft (Josephson et al. 2023). The monitoring of mental health does not finish when an individual receives a KT. There is major responsibility with a KT that derives its own demanding challenges and difficulties that could cause, or escalate, an individuals' depression (Jones, 2020). Depressive symptoms, anxiety and fatigue can depict as a symptom cluster known as sickness symptoms. These are prevalent amid individuals with a long-term condition. Sung et al. (2023) scoping review integrated available evidence for sickness symptoms in KTRs. There was no identification from the studies of sickness symptoms as a cluster, however observations were noted of the interrelations amid the symptoms investigated

with fatigue the most prominent sickness symptom with anxiety and depressive symptoms following. Prognostics of these symptoms encompassed demographic, clinical and psychosocial features and HRQoL was the highest researched outcomes (Sung et al. 2023).

Support for the recipient of a transplant can be divided into two major components: the psychosocial evaluation for transplant candidacy and symptom management post-transplantation. There is a bidirectional association between mental illness and KD. Poor transplant outcomes are related to co-occurring psychiatric conditions. This has been ascribed to behavioural influences such as non-concordance (non-adherence) along with physiologic factors, for example alteration of immunologic and stress reactions. There is a need for a biopsychosocial evaluation of individuals' post-transplant, addressing issues such as mood or worries, changes in perceptions, morose thoughts concerning self-harm or harm to other persons, behavioural symptoms including concordance, taking risks, substance abuse, along with environmental and personal stressors. These areas may be tempered by positive influences including social support, perception, spirituality, and the usage of adaptive coping methods (Danovitch 2010b; Sheny and Danovitch, 2017).

There are two main stages in the first-stage management of KT – avoiding acute rejection and avoiding opportunistic infection. The purpose of the second or later stage is to retain good graft function along with deterring the long-term consequences of immunosuppression such as infection, malignancy, and premature CVD (Baker et al. 2017; Pham and Danovitch, 2017). The foundation for the care of KTRs is that of education, as individuals need to acquire self-care skills including spotting the signs and symptoms of rejection (Murphy 2014, 2019). It is important that there is a continuous MDT alliance when discharging individuals from the transplant unit home and into the primary care setting (Murphy et al. 2011).

Individuals may encounter numerous psychosocial risks post-transplant, which may have a negative impact upon all concerned. Their family dynamics and working background may be changing, with some individuals finding it challenging to move away from the dependent '*sick role'* that they experienced on dialysis. The new associated freedom that comes with a transplant could be a risk to those persons who identified themselves within the sick role and it can be challenging to make the transition to health. Guilty feelings may be expressed by individuals who have received a kidney instead of another person. However, there is a need to re-emphasise to them that these emotions are common and that they are worthwhile in terms of receiving this altruistic donation from the donor and their family (Hersh Rifkin 2010, 2017). Jones (2020) however suggests that there needs to be an acknowledgement of the stigma that has developed within the KD community that if an individual receives a KT that they do not have the right to disclose any of negative attributes or it will appear that they are complaining and are unappreciative. This stigma could preclude recipients from pursuing necessary treatment for their mental health (Jones, 2020). The social aspects of dialysis sessions may also be missed by some individuals. These issues and concerns may result in personal relationship difficulties with partners and family members, along with anxieties about entering the workplace or genuine concerns about losing financial assistance such as potential disability benefits (Hersh Rifkin 2010, 2017).

The aim of a qualitative phenomenology study by McKeaveney et al. (2022) was to develop an in-depth comprehension of the lived experiences of KTRs (n=23) within two regional nephrology units in the UK. Participants regarded graft failure as life-threatening, resulting in fluctuating levels of anxiety of dialysis starting, re-dialysis, re-transplantation, or equally instant death. These ongoing fears and distress became amplified with the new vulnerability to the COVID-19 infection. There were reflections made by participants concerning the psychosocial challenges pre and post transplantation. These involved challenges surrounding treatment decision-making, evading talks

regarding living donation, diminishing work, reconsidering relationships, and disillusionment to recognise impending life goals adding to previously isolating reality. The participant's journey was a dominant theme throughout the findings and outlines that their experiences highlighted that there needs to be an understanding of the entire timeframe living with of a KT (i.e., pre-, and post-transplant); leading to enhanced integration into emotional support and information in renal healthcare (McKeaveney et al. 2022).

De Pasquale et al. (2020) systematic review highlighted that pre- and post-transplant screening process should comprise a medical evaluation and an in-depth psychological and psychiatric assessment for enhanced therapeutic adherence. It is vital to prevent and identify nonadherence in KTRs (Baker et al. 2017). The side-effects mentioned above could cause individuals to not take their medications as prescribed, so it is important to assess their opinions towards these side-effects. Some of the side-effects can be reduced by concentrating on lifestyle, including diet and exercise. Patients can be encouraged to self-manage their care instead of expecting failure. The issue of concordance or adherence can be a major concern due to its highly associated threat for both acute rejection and graft loss. It is recommended to identify factors **(see Table 2)** that are associated with non-concordance and identify the necessity for a care pathway that would assist those persons who are regarded as an increased risk or with recognised non-concordance. Education, prevention, and treatment strategies can be provided to minimise nonadherence. Individual counselling sessions may be necessary to assist individuals and their partners and families in dealing with the life-changing event that transplantation presents. Patient support groups can also assist (Hersh Rifkin 2010, 2017; KDIGO 2017; Kee-Low et al. 2015; Baker et al. 2017).

Table 2: Risk factors for non-concordance of medication (KDIGO 2017)

- History of non-concordance behaviour preceding transplantation.
- Mental health illness.
- Personality conditions.
- Reduced social support.
- High risk behaviour such as substance abuse.
- High education level.
- Teenager.
- Period since transplantation.
- Limited sufficient after care with transplant specialists.
- Inadequate education prior to transplant.
- Challenging medication regimens.
- Numerous adverse effects from medications.

Cossart et al. (2022) conducted a qualitative study using semi-structured interviews to investigate medication-taking behaviours of KTRs (n=14; transplanted at 60 years of age or older) in Australia. It considered how KTRs presently manage their immunosuppressant regimen and how they manage post transplantation with the intricate routine. The main themes that emerged were variability in HL toward medicines, the relevance of support networks, the necessity to modify health expectations, issues that were motivators for self-care, various approaches to medication management and to medication taking. It was found in general that older adults prioritised medication taking above everything else, and appreciation to their donor was a significant influence to adhere. However, approaches to support medication taking were occasionally ineffective when individuals' routine

altered. Future interventions should consider approaches to promote flexible medication taking behaviours that can endure changes in everyday routine (Cossart et al. 2022).

KT can enhance mental health in the widest sense and this on its own is a commanding motivation to endure transplantation in numerous patients. A collaborative mental healthcare approach is crucial to assist individuals adjust to their new post-transplant realism and assist to sustain adherence. Individuals with a KT incline to have lesser rates of cognitive disturbance, anxiety, and depression than individuals receiving HD and PD. Transplant recipients function better on handling speed, attention, short-term memory and select functioning compared to transplant candidates. However, those that have a transplant endure the continual appearance of graft failure. There will be a need to re-establish their role within the family alongside adapting to enhanced autonomy and return to purpose by many persons living with a transplant. There can be concerns with the challenges of bodily integrity and physical adaptation to the immunosuppressive medications and their associated side effects. Depression can steer towards poor adherence, whilst remission from depression and positive adjustment to KT has been demonstrated to enhance post-transplant outcomes (Sheny and Danovitch, 2017).

Failing kidney transplant

The recent updated UK guidelines from the British Transplantation Society on the management of the patient with a failing KT includes a new chapter on psychosocial issues (Griffin et al. 2023). Individuals with a failing transplant may need psychosocial support and or intervention. It has been recommended that every individual with a failing transplant should undergo psychosocial screening by renal clinicians using screening and assessment tools endorsed such as the Patient Health Questionnaire-4 (Kroenke et al. 2009); Distress Thermometer (NCCN, 2019); the Work and Social Adjustment Scale (Mundt et al. 2002) and the Medication Adherence Report Scale 5 (© Professor Rob Horne). It must be recognised that being at this stage of their kidney care is difficult emotionally for the individual concerned which can assist normalise this experience. The use of tailored information should be provided to assist in relieving the individuals' experience of loss, grief, and depression. Risk factors for example, self-harm and/ or suicidal thoughts, evasion of health decision making or risk-taking behaviour must be identified. Psychosocial screening is recommended to occur at the initial attendance to a *'low clearance/failing transplant support clinic'*; yearly following the initial appointment; more regularly if there is apprehension about an individuals' psychosocial well-being and when switching therapy modality (De Pasquale et al. 2020; Chadban et al. 2020; Davison et al. 2019; Davis et al. 2022).

Following the screening results, there are three probable outcomes; 1) there is no additional psychosocial support or intervention needed at present; 2) the individual is referred to community support-adult social care or low-level psychological intervention and 3) the individual has a suitable psychosocial support and intervention plan developed with them including a qualified psychosocial co-worker in the renal department or continuing referral to mental health services/ psychiatry (Griffin et al. 2023). An adapted four-tier care model of professional psychological assessment, support, and intervention is recommended. This model considers both the variety and diversity of psychosocial skills provided by different professional disciplines. In level 1 all health and social care professionals will provide general emotional care through listening skills, empathy and understanding. Whilst health and social care professionals providing level 2 support are necessitated to have had some training in psychological assessment and intervention and receive consistent supervision by level 3 & 4 practitioners. Those practitioners only with a mental health or psychological qualification can deliver level 3 & 4 interventions (Griffin et al. 2023).

KDIGO conducted a controversies conference to focus on when the KT is failing or has failed. It was identified that early communication and psychological preparation and support are crucial factors in patient emotional well-being and adjustment to graft failure (Josephson et al. 2023). It is important to prepare the individual with early discussions even prior to the kidney failing which enhances planning and individual acceptance. These conversations regarding dialysis modality and type of vascular access should commence as a minimum 6 months before the estimated onset of dialysis as established for example by the estimated glomerular filtration (eGFR) trajectory particularly in those adults without operational vascular access. The re-transplantation evaluation procedure should commence at a minimum 12 months prior to predicted return to dialysis. Patients should be relisted as soon as they meet eligibility norms in those countries where pre-emptive listing for a decreased-donor transplantation is permissible. Commencing the re-transplantation evaluation procedure early enhances the prospect of detecting a living kidney donor and pre-emptive re-transplantation. Individuals should be completely advised from their initial communication with the transplant team of all potential transplant outcomes, including the potential of the necessity for future re-transplantation. The potential for allograft loss although a challenging area to address should be considered with the individual at the juncture of each immunologic or nonimmunologic episode that has the possibility to adversely influence kidney function. Once biopsies are conducted because of reduced kidney function, the trajectory of possible additional decline should be shared, incorporating some broad idea of the timeline for graft survival (Josephson et al. 2023).

The individual must be placed at the centre of the care, promoting patient activation, and providing emotional support throughout this challenging time. The importance of communication with the receiving dialysis unit and establishing that the individual comprehends the plan are significant as they transition back to dialysis. HCPs should educate themselves about how CM/ supportive care decisions can assist individuals through periods of transition of care. There is a necessity for more research in this area including psychological management for individuals with failing and failed allografts (Josephson et al. 2023).

Conservative kidney management (non-dialytic options)

It is important that persons with advanced CKD have all treatment options discussed with them and their partners, families, and caregivers. There are many older people presenting for dialysis who can be frail, require assistance and have co-morbidities such as heart disease and diabetes. With some older patients' dialysis may be a difficult treatment option and may not necessarily lead to an improved QoL along with prolonged survival (Murphy, 2014, 2019).

Winterbottom et al. (2020) undertook a review to appraise patient decision aids (PtDAs) developed to support patient–professional shared decision-making between dialysis and CM treatment pathways. PtDAs are devised to proactively support individuals' reasoning when choosing between therapy options. The findings propose that CM and dialysis decision aid needs to be based on evidence concerning how individuals with deteriorating KD make decisions concerning their health now and in the future. PTDAs should also highlight how HCPs navigate the various service pathways to provide care to individuals as their kidney fails and their care needs change (Winterbottom et al. 2020).

Choosing a treatment option is a very personal decision. HD or HHD might be desirable whereas for some individuals might prefer PD. Other individuals who present with serious medical problems might be better advised to manage their symptoms. CM is where the individual opts not to have dialysis but will have continual assistance from the interdisciplinary team in terms of symptom management and control, emotional support along with palliative care and social work support (see chapter on CM for further information).

Depression

Depression excessively impacts individuals with KD including those managed without dialysis, KF needing dialysis and KT recipients (Gregg et al. 2021). Depression can be experienced in 2 to 10% of the general population. However, it is prevalent in 20 to 30% of patients receiving dialysis (Palmer et al. 2013; Ossareh et al. 2014; Treadwell, 2017). Individuals living with dialysis have selected depression as a significantly crucial clinical outcome in nephrology trials (Natale et al. 2019). Jennifer Jones from the US lived with KD and has since received a KT; she detailed her experiences of living with depression throughout her journey with KD. *"Depression should be treated as a side effect that is constantly monitored throughout every stage of CKD. This approach could erase stigmas and could change the outcome of so many kidney patients who are suffering from the physical and mental effects daily"* (Jones, 2020: 1693).

Pearce et al. (2023) conducted a scoping review using a narrative synthesis with the aim to examine the approach for how depression is identified, managed, and treated in adults with CKD. Depression was most recognised using self-report screening tools (85.3%) with variations of the BDI (33.7%) being the most utilised. In terms of managing depression the use of nonpharmacological interventions was more commonly examined (n=55 out of a total of 123 studies), The use of CBT, (n=15) was the most frequent nonpharmacological intervention and understood to have a considerable impact on depressive symptoms. However, it was not evident how such methods could be applied as part of routine care delivery. There was inadequate evidence with a limited number of studies for the use of antidepressants in individuals with CKD. There is a need for more robust RCTs concerning antidepressants including studies addressing the withdrawal of these medications as well as nonpharmacological interventions (comprising combined methods). There is the necessity for further research to demonstrate more current measures in depressing screening tools such as the PHQ-9 and to comprehend how it operates across modalities. Screening procedures need to be progressed to increase recognition of depression at crucial points of kidney care. Additionally, it is essential to have methods and tools that are culturally modified, valid and suitable. There is limited evidence exploring current clinical practice patterns which is necessary to better comprehend how screening and interventional practices are implemented in routine kidney care. This comprehension of national clinical practice patterns may also enable the advancement of specific kidney guidelines for the detection and management of depression in CKD (Pearce et al. 2023).

Gregg et al. (2021) asserts that every 6 to 12 months individuals across the range of KD must be screened for depression using self-report questionnaires. An interview with a suitably qualified practitioner should follow to reinforce the incidence of sadness or anhedonia when depressive symptoms are recognised. Gregg and Hedayati (2020) maintain that it is usually more practical for nephrology providers in the clinical setting to identify individuals with depressive symptoms initially by administration of self-report questionnaires. This is to recognise risk if they meet the proven cut-offs followed by verification of the following: 1) the existence of sadness or anhedonia; 2) the existence of symptoms as a minimum for 2 weeks for major depressive disorder diagnosis; and 3) the lack of active suicidal ideation, which could require critical attention or vigilant follow-up (Gregg and Hedayati, 2020).

Kondo et al. (2020) conducted a systematic review to detect depression screening tools (and/or thresholds) suitable for individuals with KF and to better comprehend the impact of screening for depression in this population. The BDI Inventory II was the best studied along with an extensive range of thresholds described. Shorter assessment tools such as the PHQ-9 and the Geriatric Depression Scale 15 (adults > 60 years) executed well but were not well studied. The use of the BDI-Fast Screen may be a suitable option for a preliminary screen. The findings also identify that there is inadequate research evaluating the diagnostic precision of most screening tools for depression in

individuals with KF with shortcomings in both methodology quality and/ or reporting. The authors suggest that the current studies may not be generalisable to US populations. HCPs should be willing to approve positive screens prior to making treatment decision that could be burdensome or initiate the likelihood of harm. There is a necessity for further research aimed at extensively used, free tools such as the PHQ-2 and the PHQ-9 (Kondo et al. 2020).

Lin et al. (2020) cohort study (n=275) in China identified that the frequency of depressive symptoms in individuals receiving CAPD was 31.3% with female gender, diabetes and reduced eGFR all independently correlated with depressive symptoms in this group. An increased risk of all-cause mortality and technique failure were independently associated with depressive symptoms. There is a necessity for closer monitoring of individuals' psychological difficulties when they attend the PD clinic including frequent screening to detect depressive symptoms along with suitable intercession and treatment which may enhance clinical outcomes for these adults. Sleep disturbance and depression are highly predominant symptoms in individuals receiving HD and are associated with adverse clinical outcomes. A correlational cross-sectional study in Saudi Arabia (Almutary, 2022) investigated the influences of depression and excessive daytime sleepiness (EDS) on QoL of adults undergoing HD (n=180). The results demonstrated that more than 50% of adults on HD had depression (a main predictor of lower QoL scores) and about 33% had EDS (Almutary, 2022). These studies were like the findings in other studies (Al Naamani et al. 2021; Al-Ali et al. 2021; Palmer et al. 2013).

Dziubek et al. (2021) assessed the frequency of depression symptoms, anxiety and measure the level of life satisfaction within three cohorts of adults in Poland living with KD (n=283) based on stages 3 and 4 (n=94) CKD, stage 5 CKD HD (n=87) and post KT (n=102). The BDI, the Satisfaction with Life Scale (SWLS), and the State-Trait Anxiety Inventory (STAI) were used. Anxiety as a trait was identified to be the factor most substantially allied with depressive symptoms within the three cohorts of adults. Those adults in the dialysis cohort had the highest percentage of depressive symptoms; whilst those pin the pre dialysis group (stages 3 to 4) had the lowest percentage with high satisfaction with life. There was a significant association between BDI and SWLS and STAI in all cohorts whilst a significant association was noticed amid BDI and handgrip strength in those individuals on HD and KT. It is necessary no matter what stages of CKD including that of KT that the emotional status of individuals is both screened and monitored (Dziubek et al. 2021).

Bossola et al. (2017: 414) maintain that individuals *"care little for PTH, Kt/V and phosphate values but much about comfort, mobility, functionality, energy level, sleep and mood".* This absence of consideration by healthcare providers to what individuals regard as their quality objectives is challenging. Treadwell (2017) suggests that Orem's theory of self-care deficit is suitable for recognizing depression, discerning motivation for change, and inspiring self-care practices. Utilising the theoretical framework of Orem's nursing process, the capacity to highlight and address psychosocial concerns in adults may offer essential information to support them with self-management skills to enhance concordance and QoL. There is a need for large clinical trials to ascertain the best method to manage depression in individuals with ESKD (Treadwell, 2017; Pearce et al. 2023)

Gerogianni et al. (2019) outline a variety of treatment methods for anxiety and depression in people receiving HD that may be diminished by a diversity of therapy approaches including CBT, pharmacological, routine exercise, relaxation techniques, acupuncture. Intradialytic exercise training schedules also has a positive influence on individuals' physical and emotional functioning. The importance of social support from family and friends alongside social background and the delivery of education and information typically leads to a decrease of anxiety and depressive symptoms. There is a necessity for a comprehensive psychiatric evaluation of individuals receiving HD for initial detection and treatment of depressive symptoms (Gerogianni et al. 2019). Gregg et al. (2021) outlines the use of therapy through pharmacological measures such as selective serotonin reuptake

inhibitors which has not constantly demonstrated benefit compared with placebo and may be related with serious adverse outcomes including cardiovascular events. A watchful trial with careful observation based on the accessibility of alternative therapies for therapeutic and adverse effects is acceptable including the use of CBT and physical exercise. These should be recommended to individuals who have access and are agreeable.

Natale et al. (2019) updated their Cochrane review to evaluate the impact of using psychosocial interventions against standard care or a second psychosocial intervention for averting and managing depression in adults with ESKD receiving HD. The use of CBT, exercise or relaxation techniques possibly reduced depressive symptoms (with evidence of moderate certainty). The HRQoL was possibly enhanced using CBT. The use of counselling could slightly reduce depression amid those receiving HD. There was a low certainty of evidence for the use of spiritual practices, acupuncture, telephone support and meditation. There was also low or very low certainty of evidence for impacts of psychosocial interventions on suicide risk, major depression, hospitalisation, withdrawal from HD, and adversative outcomes (Natale et al. 2019).

Sexuality

Sexual dysfunction has been associated with reduced HRQoL, anxiety, and depression (Johansen et al. 2020). It is common in individuals living with CKD and has been identified as an important research gap (Harrison et al. 2020). There is a high prevalence of sexual difficulties in patients with CKD, with 75% of men receiving dialysis experiencing erectile dysfunction and 30 to 80% of women with symptoms associated with sexual dysfunction (Navaneethan et al. 2010). This systematic review and meta-analysis of observational studies highlighted that, despite the incidence and clinical importance of this area, there were many limitations to the studies reviewed, including a poor response rate and lack of validated tools to assess sexual difficulties. There were also limited studies addressing this area in women with non-dialysis CKD (Navaneethan et al. 2010).

Pyrgidis et al. (2021) identified that in women with ESKD that sexual dysfunction (SD) remains underestimated. They subsequently conduced a systematic review and meta-analysis to investigate the prevalence, correlates, diagnostic approach, and therapy modalities of sexual symptoms in women with ESKD. The pooled Female Sexual Function Index (FSFI) scores were determined. There were 47 studies included with 61 patient group entries and 3490 women with ESKD. The SD incidence in all women with ESKD was 74%. Whilst the SD in those women with HD was 80%, 67% in PD and 63% in women with a KT. Both older age and menopause were related with higher incidence of SD. The total FSFI score augmented post KT. Female SD is extremely prevalent in women with ESKD, but KTRs described better sexual function. QoL is negatively impacted by sexual symptoms and necessitates suitable clinical interventions. There is a necessity for studies on methods of treatment of SD in women with ESKD as these are limited along with the need for clinical recommendations in this area (Pyrgidis et al. 2021).

A literature review was carried out by Chou et al (2021) to describe the pathophysiological and the psychosocial causes of SD regarding KRT specifically HD and PD. This review highlighted that there is substantial heterogeneity when comparing SD between different KRT. There are no clear guidelines for transferring modalities for individuals for example to resume menstruation, improve libido and standardise hormonal profiles. The intricate and multifactorial causes of SD is a major impediment, and comorbidities that also impact upon individuals can add to these difficulties. Whilst KT enhances many facets of sexual function and fertility, it is far from without its challenges. Iatrogenic causes of SD can also be a source of exasperation for individuals with KD and HSPs alike. Additionally, the delicacy and stigma associated with SD has been an established barrier to advances in clinical practice. There exist many disparities for both men and women in this area of research. There is a

necessity for robust RCTs and large cohort studies to address the numerous unknowns in the detection and management of SD in individuals with KD. Sexual function as a recognised predictor of QoL should become an aspect of focus in the quest for patient-centred care specifically to enable individuals living with dialysis to achieve a "*normal*" a life as feasible (Chou et al. 2021).

The development and expression of sexuality is influenced by biological and psychosocial factors. Sexuality can be a challenging concept to define. It is a multidimensional concept that incorporates a wide range of enjoyable sexual activities that may or may not include coitus but also touching, kissing, and embracing. It also includes body image, self-esteem, self-image, and how other individuals perceive each other. It can be viewed that being a sexual individual is healthy. Therefore, participating in sexual intimacy might permit a means of helping individuals who are living with long-term condition to feel '*normal*' (Sheils 2003; Lemieux 2004; Murphy 2012; National Kidney Foundation 2023).

There are many contributory factors that can lead to the development of sexual difficulties whilst living with KD. These include medications, alterations in hormones, vascular, neurological, and psychological factors (Navaneethan et al. 2010; Johansen, 2020, Chou et al. 2021). **Table 3** indicates the numerous physical and psychosocial sexual concerns associated with living with CKD. These sexual concerns do not just impact upon individuals themselves but also their partners. It can affect their overall QoL and can impact significantly upon their personal and overall family relationships. It can also be challenging for individuals who are not in a relationship and who may be looking to meet a partner, or for those that are content not being in a couple, as overall body image can be altered when living with KD (Murphy, 2014, 2019).

Table 3: Physical and psychosocial sexual concerns living with CKD.
Adapted from Auer (2008) and Levy et al. (2016).

Men	Women	Men and Women
Tiredness	Tiredness	Anxiety, stress, and depression
Decreased libido	Decreased libido	Fear of failure
Sexual arousal difficulties	Sexual arousal difficulties	Struggle in relationship with partner
Erectile dysfunction	Absence of vaginal lubrication	
Premature or delayed ejaculation	Pain during intercourse Difficulty in achieving orgasm	Roles changes leading to reliance
Difficulty in achieving orgasm	Altered menstrual patterns Anovulation	Sense of guilt towards partner
	Fertility problems	Diminished confidence in sexual identity
		Changes in body image and reduced self-esteem

Body image is intertwined closely with sexuality. Individuals living with PD and HD require vascular access surgery, which can lead to scars and potential deformities. There is also the psychological impact on how people feel with a potential foreign body in terms of a PD catheter inserted into their abdomen or living with a central venous catheter (CVC) in the neck or an AVF in their non dominant arm. They may feel that such vascular access is a constant reminder of living with their long-term illness. This may be regarded as the individual's *'lifeline'* and therefore must be monitored carefully. Concurrently individuals can feel unattractive and self-conscious of these '*lifelines'* and may alter their self-image accordingly, for example avoiding wearing short sleeve tops or keeping their shirts

or tops buttoned up to avoid showing their central lines or fistulae when out in public, in case they attract people staring (Murphy, 2014, 2019). Silva et al. (2018) used a qualitative exploratory study (n=30) in Brazil to comprehend the experiences of individuals receiving HD using AVF. The study highlighted that vascular access results in signs that alter the body aesthetics leaving it damaged. These changes result in low self-esteem and embarrassment with individuals camouflaging the AVF. They may also find it difficult to undress in front of their spouses and partners or become intimate, for fear of being rejected by them. This may be a more significant issue in individuals living with PD in terms of their abdominal catheter and positioning it when trying to be intimate with their partners (Murphy, 2014, 2019).

Individuals who were on HD because of KF was asked to perceive their bodies as considered in drawings and narratives. The participants (n=29) completed an anonymous questionnaire which contained the following instruments: the Centre for Epidemiological Studies—Depression (CES-D), Multidimensional Body-Self Relations Questionnaire (MBSRQ), and the MOS 36-Item SF health survey. Individuals drew their self-figure prior to and after their diagnosis of KF. The findings highlighted elevated levels of depression and concerns regarding body fitness and weight (Lev-Wiesel et al. 2022). Individuals can also complain of abdominal discomfort and distension with dialysate fluid, which can impair their body image regarding clothes size having to be increased to accommodate an extended abdominal girth. This can, again, all impact on their self-esteem and overall body image, leading to them potentially feeling unattractive, unwanted, and depressed – and leading to social isolation. One could argue that there is a double-edged sword with regards to the use of some medications that individuals must take to manage their treatment, such as antihypertensive drugs, and possible side-effects such as erectile dysfunction (Murphy, 2014, 2019).

The use of immunosuppression medications with KTRs can result in side effects that can affect body image such as hirsutism and weight gain. These side effects are usually temporary and can be managed. Body-image concerns may not always be obvious to individuals and their partners. They might not be discussed or addressed by either party or within the transplant unit. There is a need for sensitivity and open discussion by the relevant HCPs (Murphy 2012; Hersh Rifkin 2010, 2017). Women for example may be anxious to conceive post-transplant and may potentially risk their transplant if they do not concord to the recommendations of planning for conception and being carefully monitored by kidney and maternity health care providers throughout the pregnancy (Murphy, 2014, 2019). The UKKA clinical practice guideline on HD advocate counselling women of reproductive age who are undergoing or intending to start dialysis, so that they are advised of the connections between KRT and pregnancy which could affect family planning and modality choices. They recommend altering as soon as feasible to an individualised, enhanced HD schedule for women wishing to maintain their pregnancy. This should be as a minimum 20 hours weekly provided over at least 6 sessions (Ashby et al. 2019).

UKKA clinical practice guidelines on the post-operative care in the kidney transplant recipient (Baker et al. 2017) and pregnancy and renal disease (Wiles et al. 2019) identified that women should wait for one year post transplant and have stable function before attempting conception. The advice concerning contraception should be comparable to the general population. Women and their partners should be offered counselling regarding fertility and reproduction either before transplantation or soon afterwards. Prior to conception applicable immunosuppressants as advised should be discontinued and substituted as appropriate. The advantages and disadvantages of breastfeeding should be considered. It is suggested that there should be care pathways for managing SD. This issue should be discussed ideally at the annual review clinic. It is recommended that there should be close cooperation with local andrology facilities. The drug Sildenafil is safe and effective in males post KT not prescribed nitrates (Baker et al. 2017). The findings from a systematic

review and meta-analysis evaluated the effect of KT in individuals with ESKD and erectile dysfunction (using the same study population pre and post KT) established improvement in erectile dysfunction post KT in comparison to pre-KT evaluation (Miron et al. 2023). Sexuality is not just relevant with patients who are receiving dialysis and KT but also those that have chosen CM. It can remain an integral part of their lives and should not be assumed that it is not relevant towards end-of-life care. The concept of emotional connection may take priority over the physical aspect of sexuality at this stage of the patient's life (Murphy 2012).

The management of these sexual difficulties includes optimising dialysis treatment, addressing dietary, anaemia, endocrine abnormalities, and hyperparathyroidism issues, reviewing drug therapy and erectile dysfunction and psychosocial issues (Levy et al. 2016). It is important to broach this sensitive subject with individuals as if members of the healthcare team, especially nurses, do not do so there can be a strong possibility that patients will not introduce this subject as they could feel embarrassed and uncomfortable in discussing it. Renal nurses must be comfortable with their own sexuality to discuss this subject and put aside their own preconceived ideas. They must be good communicators and be able to recognise when some individuals do not want to discuss this subject, watching for verbal and nonverbal cues and being mindful of cultural issues and the physical environment at the time in terms of privacy. Not all individuals living with KD identify sexual concerns as being an issue for them; this must also be acknowledged by nurses. However, the matter should be introduced and then it should be ascertained whether this is an issue for further discussion. It is important to involve the individual's partner as much as feasible to enable them to feel included in this process and to ascertain their experiences. Individuals must be educated in how to manage these sexual concerns and where to seek further assistance and advice, as nurses are usually not trained counsellors (Murphy 2012, 2014, 2019). Kidney Care UK and the National Psychosocial Working Group (2022) identified that an individuals' level of need should direct the required psychosocial interventions. The kidney healthcare team needs to be educated in how to discuss this subject and to recognise that it can be a real and valid concern for individuals with KD. They must acknowledge that this area is an intrinsic part of their care delivery. Should this intrinsic aspect of care not be addressed by nurses who are usually at the front and centre of care delivery; individuals with KD could needlessly suffer in silence (Murphy 2012, 2014, 2019).

Caregivers' role

Caregivers' role must be acknowledged and the impact that this role has on them. They play a crucial role in supporting individuals living with long-term conditions. A caregiver is usually an informal carer who tends to be a family member of the individual patient. They undertake a diverse number of duties including arranging transport to healthcare appointments, dispensing treatments, dietary assistance and supporting with home therapies. Caregivers of individuals living with KD have expressed feelings of fatigue, anxiety, depression, and burnout. The role of the caregiver has become more noticeable throughout the COVID-19 pandemic with the growth of remote services and telemedicine (Subramanian et al. 2019). Family dynamics can be impacted when an individual living with advanced CKD is relying on the ongoing support of a caregiver. It can contribute to additional burden on the caregiver themselves as the individual becomes more reliable on the caregiver to the potential detriment of the caregivers' own priorities and life goals (Kalantar-Zadeh et al. 2021).

Williams et al. (2017) highlights that male caregiver of persons living with advanced CKD experience burden, symptoms of depression as well as alterations in their physical health because of their care provider role. The findings of this study suggest that the male care providers share similar experiences to female care providers of persons living with advanced KD. Ghahramani et al. (2022) conducted an RCT to examine the efficacy of a designed peer mentoring (PM) programme on burden

of care amidst caregivers of individuals with CKD. It is well documented CKD is associated with an intensified burden on caregivers. The concept of PM enhances numerous outcomes in many long-term conditions. There were 3 groups of caregivers randomised (n=86) to obtain 6 months of intervention; group 1 (n=29) face to face; group 2 (n=29) online PM and group 3 (n=28) usual care: textbook only. There was 16 hours of instruction provided to peer mentors; every participant accessed comprehensive information about KD via a copy of a textbook. Online PM was identified as a valuable strategy that leads to enhanced caregiver burden in CKD. COVID-19 pandemic highlighted the necessity for online substitutes to face to face mentoring. Online programs also permit access to mentoring by people with reduced ability to travel and for areas with inadequate resources (Ghahramani et al. 2022).

De Pasquale et al. (2019) investigated unforeseen negative experiences with ESKD therapies amid family members of dialysis (ICHD and home therapies) and individuals post LD transplantation in the US to recognise significant focus for family-centred research and clinical care. Participants engaged in 8 focus groups with 49 family members in total with 4 themes emerged. These included becoming a caregiver with unexpected responsibilities and sleep disturbances, poor emotional therapy reactions in patients (e.g., depression) and family members (e.g., anxiety), treatment delivery and logistical information, and dialysis-associated health issues and fatigue. The need for more family-centred individualised care though education and interventions to prepare them earlier for ESKD therapies with a need for more collaboration and effective communication with all key partners (DePasquale et al. 2019).

Carswell et al (2021b) identified that there are limited studies concerning the experiences of informal carers for those individuals who have KF and opted for CM instead of dialysis therapies. These informal carers can experience high degrees of psychosocial burden. This intended qualitative study will illustrate the experiences of informal carers of individuals with KF who are accessing CM. It will assist in outlining the unmet support needs of these individuals to appraise future growth of a psychosocial intervention (Carswell et al. 2021a). The concept of LP is also related to caregivers and family members included providing any care delivery with the individual living with KD (Kalantar-Zadeh et al. 2021).

Conclusion

This chapter has outlined the emotional challenges that individuals may present with whilst living with CKD and KRT. It explored the importance of emotional well-being and identified means of support for them and their partners, families, and caregivers. Nurses and other members of the MDT must enable persons living with KD to learn to adapt to their treatment modalities in their life journey whilst living with this long-term illness. There must be clear appropriate care pathways. Positive partnerships with individuals and their partners, families and caregivers can foster increased shared decision making and self-management. Persons living with KD do require emotional support from their healthcare team, and it is important to acknowledge and act upon this from the initial diagnosis right through the trajectory of KD.

Emotional well-being is a crucial factor for individuals to live well with their long-term illness. Individuals must be enabled to reach their own *'Holy Grail' as identified in this patient advocate excerpt as below:*

The 'Holy Grail' for most people with a chronic disease is to reclaim what is often lost in the face of a long-term condition: hope; empowerment; independence; control and well-being; but for most of us, reclaiming what is lost in our daily lives - often without or outside of the support of the healthcare system - is a mammoth struggle with no guarantee of success".

…" when given the right support, tailored to each individual living with a chronic health condition, we can be empowered to reclaim as much control, health, and well-being in our lives as we are able – despite the very significant burden that living with such a condition may entail".
Jonathon Hope, MBE (Gair et al, 2019: 4).

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