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Is there anything left to eat? A lived experience insight of following a restrictive type 1 diabetes and dialysis diet

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ABSTRACT

Objectives: Chronic kidney disease has a global morbidity burden of >10%, with diabetes being a major cause. Nutrition therapy is vital in managing both chronic conditions, yet CKD dietary guidelines contradict healthy eating advice, and can result in major psychological and social burdens. Few studies investigate the patient's experience of being placed on such a restrictive diet. This auto/biographical review provides a unique perspective and aims to assist practitioners as they guide patients on 'what is left to eat.'

Method: An auto/biographical approach, supported by a comprehensive literature review using data from MEDLINE, Embase, and PsycINFO, was used to answer the question: 'What are the diet and lifestyle challenges of following a restrictive Type 1 Diabetes/CKD dialysis diet?'

Results: Restrictive dietary and fluid regimes have a major effect on patients' illness beliefs, anxieties, and independence. This is discussed through five themes: Food is belonging; Normal is a Fallacy; Your numbers define you; A disease disguised as a virtue and Meeting the Elephant: ESKD diagnosis and the burden of dialysis.

Conclusion: Dietary intervention is crucial in the management of T1D and ESKD, but equally important is to consider the implications of strict dietary regimes without sufficient evidence, guidance, and support.

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KEYWORDS

Type 1 diabetes; end stage kidney disease; dialysis diet; CKD; lived experience; eating disorders

1. Introduction



Chronic kidney disease (CKD) is a global health burden with a morbidity of >10% across the developed world [1]. With the aging population, increasing rates of obesity and type 2 diabetes, prevalence is set to rise. Diabetes is a major cause of CKD and medical nutrition therapy (MNT) is an important aspect of managing both chronic conditions. Yet, these dietary guidelines are difficult to follow as they contradict normal healthy eating advice, and have limited evidence, due to the challenges of conducting research on this patient group [2]. While much has been written to describe the physician view and process of caring for these patients, a literature search revealed no first-person accounts of the day-to-day experience of managing these dietary and lifestyle challenges [3,4]. A large cross-sectional and longitudinal study (involving 13 784 patients in the Dialysis Outcomes and Practice Patterns Study) measured the physical and mental components on quality of life (QoL), via questionnaire, and found that QoL was strongly associated with mortality [5]. Given the decline in psychological support for renal patients over the past 15 years, the aim of this research is to start the body of work that centralizes the patient experience to support both the patient and practitioner [6]. It aims to provide a unique insight into

this lived experience via an auto/biographical format, to help humanize clinical practice and provide strategies that patients and healthcare practitioners can employ, to address and manage patients who are living with both chronic conditions.

1.1. Overview and current management strategies of CKD

Chronic kidney disease (CKD) is defined as a progressive loss of kidney function over time and diagnosis is based on the anatomical structure of the kidney, its functional efficiency, and the duration of the altered structure and/or function [7]. Biomarkers are measured to classify disease progression into one of five stages, of which stage 5 is known as End-Stage Kidney Disease (ESKD) (Table 1). In the UK, 3.5 million people are living with CKD (stages 3–5) with the number projected to rise to 3.9 million by 2030 [9].

Risk factors can be divided into initiating and perpetuating factors, and include ethnic, genetic, socio-economic, age, and lifestyle [10]. The most common direct causes of CKD are diabetes mellitus (type 1 and 2), although observational studies suggest that obesity may increase CKD independent of metabolic risk factors, such as hypertension [11]. It is

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Table 1. The stages of chronic kidney disease (CKD).

CKD Stage	GFR (mL/min/1.73m ²)	Description
1	≥90	Normal or increased GFR, but with other evidence of kidney damage
2	60–89	Slight decrease in GFR, with other evidence of kidney damage
3a	45–59	Moderate decrease in GFR with or without other evidence of kidney damage
3b	30–44	
4	15–29	Severe decrease in GFR with or without other evidence of kidney damage
5	<15	Established renal failure

Source [8].

important to note here the work of Sedaghat et al. who demonstrated how various confounding factors, such as the preferences of researchers and healthcare system data availability showed a more than 10-fold variance on the frequency and spectrum of nephropathies [12].

There is no cure for CKD and clinical trials into alternate treatment options are highly restricted due to the multiple barriers of conducting research on patients with often-complex co-morbidities [13]. Treatment is aimed at relieving symptoms, slowing disease progression to minimize the risk of associated adverse outcomes and complications [14]. The level and type of intervention depends on the stage of kidney damage, and ranges from dietary adjustments to dialysis, transplantation, and conservative management. Although transplantation is considered the gold standard in treatment, both the physical and mental conditions of patients are important considerations [15].

1.2. Dietary management of CKD and T1D

Medical Nutrition Therapy plays a major role in the management of both T1D and CKD [16]. Carbohydrate counting and meal planning are vital components of an overall healthy diabetes diet, yet there is currently no agreement in isocaloric comparisons recommending a specific amount of carbohydrate intake for diabetes [17]. The dietary management for CKD is highly dependent on disease progression, and as kidney function declines and estimated Glomerular Filtration Rate (eGFR) drops, the risk of complications arising from

malnutrition, metabolic acidosis, hyperkalemia, and mineral imbalances becomes more prevalent [18]. By stage 4, patients are placed onto strict diet regimes limiting the intake of potassium, phosphorus, sodium, and protein [19] (Table 2). A 2020 consensus report from Kidney Disease: Improving Global Outcomes (KDIGO) acknowledged the validity of dietary potassium restriction in managing acute hyperkalemia in CKD patients but also noted that such diets may deprive patients of the additional benefits of potassium-rich foods, including access to vitamins, minerals, phytonutrients, and fiber [19,22]. These guidelines are therefore difficult to follow, as they contradict eating guidelines that are advocated prior to the patient developing CKD, and following such a restrictive regime can result in major emotional, physical, psychological, social, and existential burdens, as food choices and daily fluid restrictions come into effect [23,24].

1.3. Lifestyle management

Fluid restriction is a major lifestyle adjustment for dialysis patients, and as the ability to urinate declines, the recommended levels of daily fluid allowance become more restricted [25]. Fluid overload is an independent risk factor for all-cause cardiovascular mortality in patients on dialysis [26]. For people with T1D (PwT1D) with hyperglycemia, fluid restriction becomes more challenging as polydipsia increases. PwT1D on peritoneal dialysis face further complexity due to the dextrose content in the dialyate fluid [27]. This treatment is in itself challenging, as blood glucose remains high, polydipsia

Table 2. Dietary recommendations for patients with type 1 diabetes compared to patients with ESRD.

	Diabetes Diet	End Stage Renal Disease Diet
Protein	The Joslin Diabetes Centre advocates a protein intake of 20–30% of total energy intake for those without kidney disease [20]	<15% of total calories or RDA 0.8g/kg BW/day for CKD, modified to 1.2g/kg BW/day in ESRD patients on dialysis.
Protein foods (avoid/limit)	Processed Meats	Meat, Poultry, Dairy, Fish, Yoghurt
Carbohydrates	Emphasise nutrient dense carbohydrate sources that are high in fibre.	No specific recommendations provided but monitor potassium and phosphate levels.
Carbohydrate Foods avoid/limit	Ultra Processed Foods (UPFs); Simple sugars.	Wholegrains, Brown Rice, Bran Cereals, Peas, Lentils, Dark Chocolate, Cocoa.
Fat	20–35% of total calories should come from fat, limited Saturated and Trans fats.	No specific recommendations provided.
Fats to avoid/limit	Margarine; Seed Oils.	Nuts, Seeds, Olive Oil, Egg yolks, hard and soft cheese, avocados.
Sodium	As per the general population, PwT1D should limit sodium to 2,3mg/day.	1.5–2.3mg of sodium/day.
Additional Guidance	Stay well hydrated. Eat fresh fruit where possible, limit/avoid Ultra Processed Foods.	Limit Fluid intake to individualised ratios, Limit fruits and veg high In potassium (eg tomatoes, peppers, dark green leafy veg). Avoid soft drinks, especially colas).

Sources for Dietary Reference Intakes in PwT1D and ESKD: [8,17,20,21].

increases, and the requirement for additional peritoneal dialysis exchanges; or using dialyzate with a higher dextrose concentration, may be required [28,29].

2. Literature

Published data were searched using the Medline National Library of Medicine, EBSCO, and PsycINFO, and included only English papers published between 1990 and 2023 (Figure 1). The search identified 65 papers and after an initial screening, reading the title and abstract for relevance, 17 titles remained. Further screening removed all duplicates ($n = 1$) and any that included irrelevant participant demographics. Additional papers were included from a manual search of reference lists, resulting in eight full texts reviewed for inclusion (Appendix 1).

A narrative review, adopting a systematic synthesis of the available evidence was conducted. Thematic analysis was used to identify the diet and lifestyle challenges experienced by PwT1D on dialysis who are placed on a highly restricted renal dialysis diet. Three core themes were identified from the eight papers included, and these will be discussed below.

2.1. Effects of diagnosis

While all chronic diseases require challenging life adjustments, patients diagnosed with ESKD are required to alter their entire outlook on life, accepting a life-threatening diagnosis and need for lifelong treatment [30]. The emotional experience of a person facing imminent death is different from one who is critically ill [31], yet for

a patient awaiting a transplant, the lines between critical illness and imminent death are divided only by the hope of salvation arriving on time. At the time of writing (July 2023), 4,744 patients in the United Kingdom are actively registered on the kidney transplant waiting list [32]. While many think of dialysis as a life-saving treatment, it is also a life-changing experience. Adapting to a new normal to accommodate treatment cycles, being dependent on a dialysis machine for hours each day and being restricted to when, where and how to meet with friends and family all influence a patient's quality and outlook on life, leaving some to feel isolated [5,33].

Depression and anxiety are the most common psychiatric complications in both T1D and CKD [34,35]. Both are associated with increased hospitalization and all-cause mortality, as well as decreased adherence to dialysis and a lowered outlook on quality of life [36,37]. Many patients find the transition to dialysis frightening and traumatic, experiencing periods of distress and feelings of isolation throughout their time on dialysis due to the stress of treatment, altered body image, loss of sexual function, and decreased physical and cognitive functioning [38,39].

2.2. Paradoxical dietary interventions

Much has been written about the questionable efficacy of dietary interventions in ESKD and the strategies to promote adherence to nutritional advice [40–43]. Current clinical guidelines do not wholly address all areas of dietary management in CKD, due to existing controversies and gaps in knowledge about specific interventions such as dietary

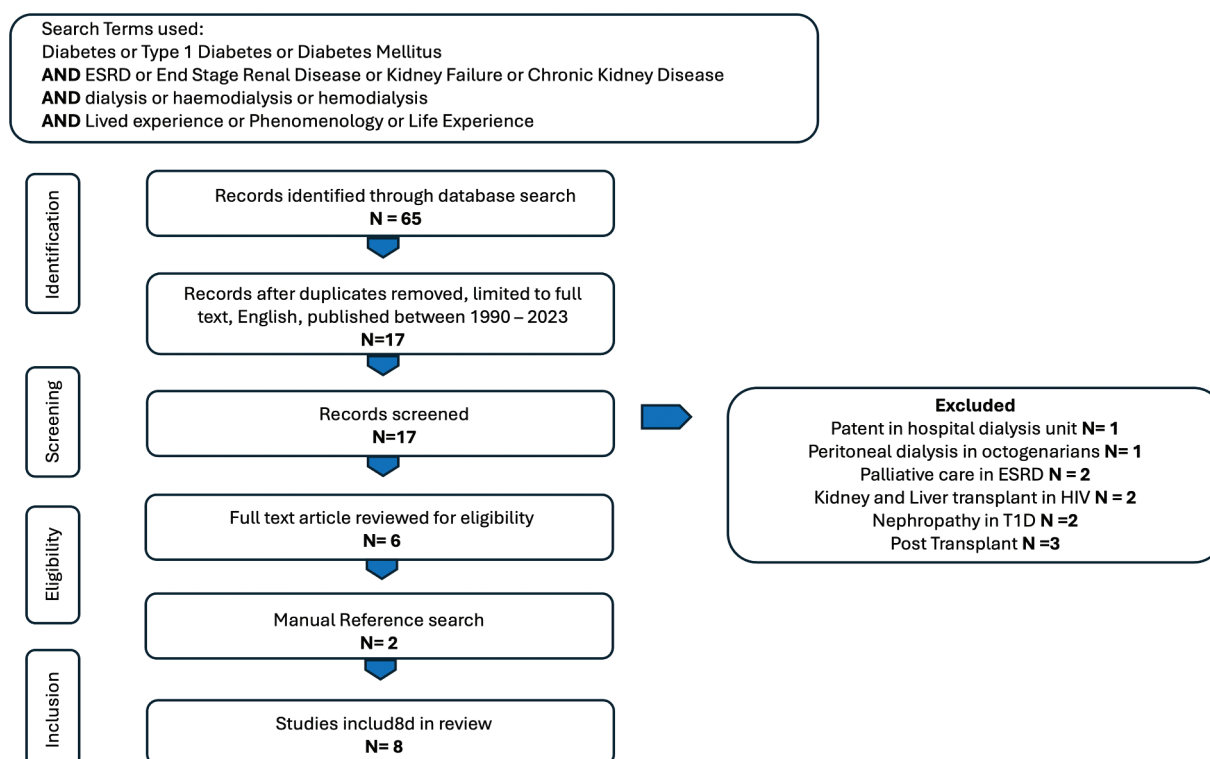


Figure 1. Literature review strategy.

protein restriction [9]. While dialysis patients have increased protein and energy requirements, with an accelerated decline in skeletal muscle mass and strength during chronic hemodialysis treatment, high protein intake may lead to increased glomerular hyperfiltration and intraglomerular pressure, causing structural damage to the kidney [44]. For this reason, depending on the stage of kidney function decline, KDIGO (2020) guidelines recommend low protein diets (LPD) (0.5–0.6 g/kg/day) for the management of CKD [45].

A four-year prospective controlled trial with concealed randomization, involving 82 PwT1D with progressive diabetic nephropathy were followed, to determine the effect of a low-protein diet (0.6 g/kg/day) (LPD) with a usual-protein diet (1.02 g/kg/day) (UPD) to determine the effect on survival and progression to ESRD. During follow-up, the mean declines in eGFR were 3.9 mL/min/year (2.7 to 5.2) in the UPD group and 3.8 (2.8 to 4.8) in the LPD group. ESRD or death occurred in 27% of patients on a UPD as compared with 10% on an LPD (log-rank test; $p=0.042$). The relative risk of ESRD or death was 0.23 (0.07 to 0.72) for patients assigned to an LPD, after an adjustment at baseline for the presence of cardiovascular disease ($p=0.01$) [46]. Confounders for this study were that participants needed to have lived with T1D ≥ 10 years, and therefore the longer-term effects of poor glycemic control (and not just the effect of protein intake on kidney health) could have impacted outcomes. There was also no record of protein composition, which may differ across animal or plant-based sources.

By contrast, a more recent comprehensive literature review including randomized control trials or quasi-RCTs of adults with diabetic kidney disease not on dialysis was conducted, to determine the safety and efficacy of low protein diets (LPD) (0.6 to 0.8 g/kg/day) in preventing the progression of CKD, it also recorded potential side effects (e.g., malnutrition, hyperglycemic events, or health-related quality of life (HRQoL)). Four hundred and eighty-six participants were included, with an average of 0.6 to 0.8 g/kg/day prescribed protein/day in the intervention groups; and ≥ 1.0 g/kg/day, or a calculated protein intake ≥ 1.0 g/kg/day in the control groups if prescribed protein was not stated [47]. Results showed that LPDs may have little or no effect on death (5 studies, 358 participants: RR 0.38, 95% CI 0.10 to 1.44; $I^2=0\%$), and the number of participants who reached kidney failure (4 studies, 287 participants: RR 1.16, 95% CI 0.38 to 3.59; $I^2=0\%$). Compared to usual or unrestricted protein intake, it remains uncertain whether a LPD slows the decline of glomerular filtration rate over time. The review did not reveal much about the impact of nutritional restriction on HRQoL and longer-term RCT with sufficient follow-up are required for different stages of CKD.

The trials used to support the 2020 guidelines provided by KDIGO therefore do not support that a LPD ultimately slows kidney disease or lowers the risk of ESKD as it ignores the totality of evidence. LPDs are also poorly tolerated, and adherence rates were lower than study goals, even in clinical settings [48].

2.3. Eating disorders in T1D and end stage kidney disease

Eating disorders (ED) are characterized by a persistent disturbance of eating that impairs health or psychosocial functioning [49]. While the etiology of eating disorders is complex, with psychological, biological, and sociocultural factors contributing to susceptibility, dietary restriction is believed to contribute to the development and maintenance [50]. Given the emphasis placed on the attainment of glucose control, stringent measurement of macronutrient content, and in the case of dialysis patients, the frequent assessment of nutritional status and compliance with guidelines, PwT1D on dialysis are at increased risk of ED development.

The Modified Dual Pathway Model described by Petersen (2015) [51] suggests three main risks of ED development in PwT1D namely 1) **Food preoccupation** in the form of carbohydrate counting, as part of insulin dose adjustment; 2) **Changes in weight linked to insulin use**, resulting in body dissatisfaction and weight gain; 3) **Emotional distress resulting from the weight gain**, which can initiate disordered eating behaviors such as binge eating or insulin omission. ED may also develop because of the continual reinforcement and praise for practicing restraint and self-control around food; wanting to be seen as a 'good diabetic' [52]. These shared traits of anxiety, need for control and valuing diet adherence as a proof of self-control put PwT1D in a high risk for developing this 'disease disguised as a virtue' (Volpe, 2015, pg2) [53].

As ESKD progresses through a decline in eGFR there is a significant reduction in appetite, increasing the risk of malnutrition, muscle protein wastage, and poor patient outcomes [44,54]. Anorexia, which is defined as the loss of desire to eat, and a BMI of <17.5 kg/m² is relatively common in patients on hemodialysis (HD) [55]. The pathogenesis of anorexia in HD is unknown, but uremic toxicity, inflammation, altered amino-acid patterns, hormones (e.g., leptin and ghrelin), and neuropeptides are involved [55–57]. ESKD patients, with or without dialysis have lowered Essential: Non-Essential amino-acid ratios and reduced branched amino acids compared with healthy individuals; and these reductions are known to increase anorexic tendencies [58,59]. For peritoneal dialysis patients, this effect may be further exacerbated by the discomfort of abdominal distention caused by the dialyzate fluid; and the absorption of the osmotic agent [60]. The current literature highlights that the treatment strategies used to manage PwT1D and ESKD are only partially effective in preventing acute and chronic complications. What is unclear is whether such strict dietary regimens help or hinder long-term patient outcomes, particularly when patient reviews focus primarily on quantitative biochemistry data (Figure 2).

3. Methodology

Having explored the literature associated with the lived experience challenges faced by PwT1D on a dialysis diet, it is clear this is a vastly under-researched area. A 2017 review by the National Kidney Foundation found that most kidney research (73.18%) did not involve any direct patient

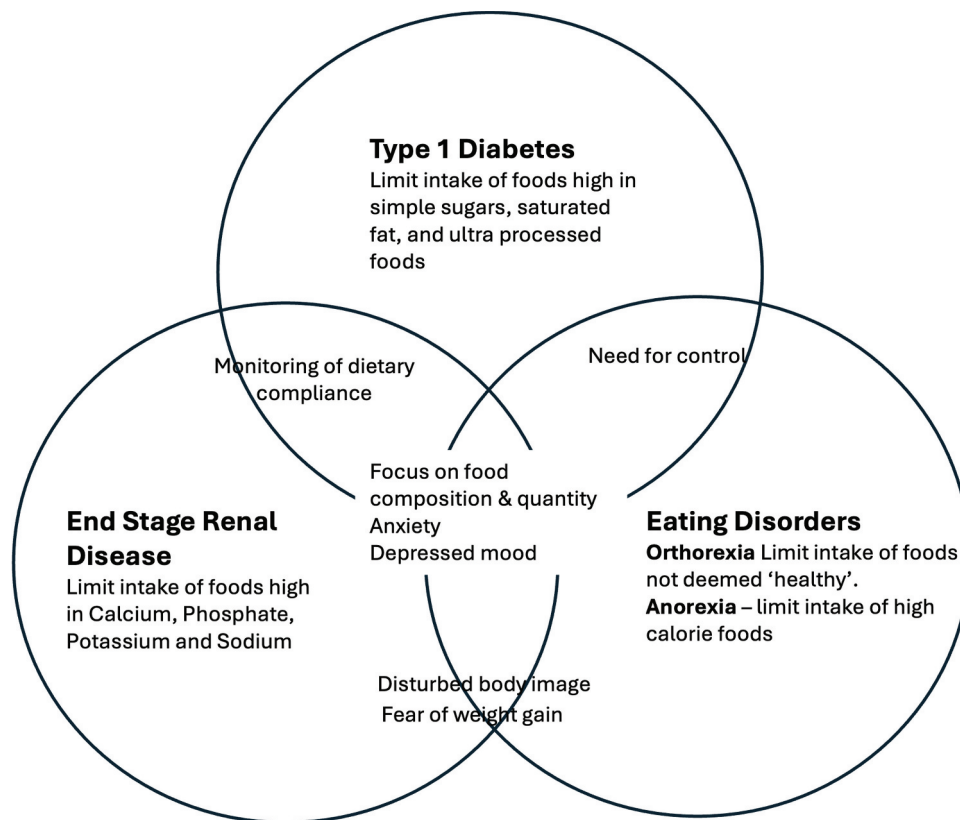


Figure 2. Intersection between feature of T1D, eating disorders and end stage disease.

involvement [61]. Current literature provides an insight into potential clinical outcomes, but gives little insight into the patient's experience, motivations, and challenges of adhering to these strict dietary guidelines, nor their reasons for discontinuation. Patient and public involvement is increasingly used to enhance the quality, acceptability, and relevance of research and priority setting [62]. Lived experience accounts are a valid format for generating new understanding of the ways in which illness and healthcare affect patients and their families [63]. This research aims to address this imbalance.

A qualitative research approach, using Reflective Topical Autobiography (RTA) was therefore used, to explore the individual lived experience account of this phenomenon.

Working within a paradigm that is focused on meaning and interpretation, this qualitative 'researcher-as-participant' and 'primary unit of analysis' used the studied collection of a variety of empirical materials to describe routine and problematic moments to assign meaning, increase understanding, and 'make the lived experiences more visible and intelligible to others' [64,p.1]. Using the first-person voice and expressions to portray the experience of illness, the researcher was able to bypass the impersonal medical terminology often used to describe chronically ill patients. Although some argue that qualitative researchers need to account for the fact that their presence has some influence on the research findings, auto/biographical research positions the author as the 'key informant' or the 'consummate insider' [65,pg 27]. As members of a culture or group, these researchers are privy to information and experiences that may be withheld from outsiders [66].

The primary data for this research was collected from empirical sources captured from diary entries as well as personal published blog posts and contemporaneous accounts captured between January 2019 and January 2020. The researcher documented the main components of 'turning point experiences' from the time of being diagnosed with T1D to the time leading up to the transplant [67]. The researcher also engaged on social media, connecting to a community of transplant survivors, professionals working in the field and patients still on the transplant waiting list, to validate some memories and thoughts that have emerged. While none of their conversations or quotes were published in this research, they served as sources of insight that helped to describe, explain, and give meaning to the particular life event.

4. Reflective topical autobiography

An auto/biography is an account of a person's life as lived, as experienced, or told by that person. It is a narrative expression of life experiences through which we can start to understand public issues. It uses both 'inductive reasoning' (searching for patterns from observation and the development of theories to formulate a hypothesis; as well as 'abductive reasoning' (to provide the best possible explanation) [68; 69]. Various forms of autobiography exist within sociology, of which the three main formats identified by Denzin are [67]:

- **Reflective Topical Autobiography (RTA)** provides a fragment view of the persons' life story that is of

'topical' interest, and which has the reflective process built into the interpretive research design. It comprises an excision from the life of the subject and invites comparison with other (similar) lives [70].

- **Comprehensive Autobiography** documents the life story from the earliest recollections up to the time of writing.
- **Edited Autobiography** provides an abstract version of a person's comprehensive life story.

While both Comprehensive and Edited Autobiography might provide rich text, they risk the oversimplification of key factors due to the sheer volume of text. By focusing on a specific period, RTA enabled a more detailed and focused view of the question being investigated. This RTA followed the framework undertaken by Johnstone [64] and Moustakas [71] initiating with the deep-felt engagement with the topic.

5. Author's engagement with the topic

Diagnosed with T1D at age 11 and living away from home at boarding school from age nine, I was exposed to the challenges of managing a chronic disease from a young age. Being the only diabetic in the school, with no access to the conveniences of online support groups or conversations with 'people like me,' all contributed to the feeling of isolation and 'being different' [52]. Diagnosed with ESKD at age 33 I was placed on peritoneal dialysis and then hemodialysis for 3 years while waiting for a potential donor match. All these experiences influenced my research journey and contributed to the findings described.

6. Data analysis

For qualitative research to be deemed successful, it needs to prove its validity, authenticity, and credibility. Credibility in auto/biography is described as 'the ability to seek verisimilitude,' to evoke a feeling in the reader that 'the experience described is lifelike, believable and possible' [72] (pg3). From a researcher's perspective that requires total honesty when writing the reflective logs, regardless of fear of judgment. Reliability and trust were enhanced in this study by corroborating on social media with fellow transplant survivors, professionals working in the field and patients still on the transplant waiting list. The final notes were analyzed for thematic grouping, before writing a cohesive and coherent summary; using a consistent and visible method [64,71,73]. While this review is a self-reflection, and the replicability of the personal experiences are impossible to copy, the physical, emotional, and psychological aspects are representative of 'people like me' [74] (pg. 273).

7. Results

Many of the themes identified within this research merged into each other. Writing these experiences into a chronological order helped me to express how entangled and complicated life with two chronic illnesses can be.

7.1. Food is belonging

Food to me has always been more than fuel. It has been central to my sense of identity and feeling of belonging. The way any group of people gather and eat helps us assert our sense of hierarchy and connection. From the age when I was diagnosed with T1D, food became a way of highlighting my belonging to a group of people who had to eat differently from everybody else. Food became a symbolic representation of how different I felt to my peers.

"Even drinking tea is no longer normal. 'Normal' kids drink tea only to dunk their biscuits. I realize I'm not getting a digestive biscuit like everyone else. I'm not sure whether it's the bitterness of the Canderol or the frustration at having to be different, but no spoonful of sympathy is enough to make this medicine go down.'

(Reflection in hospital, shortly after being diagnosed as T1D)

Being placed on a 'special diabetic diet' means you often have to say 'no' when all you really want is to say 'yes.' For many families and friends, food is a way of communicating love and saying no to an offered dish sometimes feels like a personal rejection.

'I've been issued with a list of "foods to eat and foods to avoid." It's really hard to think that I'll never have my own birthday cake again. Everything I like suddenly seems "bad" and I feel like everyone is judging what I eat.'

(Reflection in hospital, shortly after being diagnosed as T1D)

7.2. Normal is an illusion

This was a common theme throughout my teenage years; wanting to fit-in and 'just be normal' like my peers. Having moved to boarding school at age nine, peer acceptance became a coping strategy from a young age.

'My friends want to know what I'm doing when I leave the room, carrying my test kit. I've started referring to it as "going to do my thing." Not actually saying the words "Test my blood sugar" so that I can pretend I'm not that different.'

(Diary entry, 16-year-old self)

'Sometimes I feel really alone. I just wish I knew one other person who understands what it's like to always worry about your health. Some days I think my body just hates me.'

(Diary entry, 16-year-old self)

Playing sport was a form of escape and my confidence grew as I improved and started representing my county in swimming, tennis, and hockey. Here was somewhere I felt I fitted in! And yet my diabetes was always there. Filling me with dread at the thought of having a hypo in the middle of a swimming gala.

'In the water we're all equal and my numbers get measured on my performance and effort like everyone else, unlike a blood glucose number I don't seem to have any control over.'

7.3. Your numbers define you

As a T1D and CKD patient, each visit to the doctor is filled with anxiety as you await the results of blood tests, urine samples,

or weigh-ins. The number on the screen defines your success at ‘managing your disease.’

‘I felt like screaming when Dr Vinal* asked me how “my control” has been. As if I control any of this? I weigh myself every morning, and the number on the scale dictates what type of day I’m going to have. Then I move to my blood glucose monitor to determine what type of breakfast I’m allowed. Routine and discipline. There’s never a SCHNEIDERday off.’ *Not his real name! (Blog entry written while on dialysis)

I hate the pre-dialysis weigh-ins, and the loud shout from the nurse across to whoever is at the desk, to register how much weight I’ve gained since last time. I’m so scared that they will increase my fluid restriction. When you’re not supposed to drink more than 1 L a day, it’s all I can think about ...’

(Blog entry written while on dialysis)

7.4. A disease disguised as a virtue

The language used in diabetic and ESKD consultations seems focused on negative outcomes and judgments, and whether intended or not, led me to experience feelings of shame, guilt, and resentment. Repeated rhetorical phrases used in consultations seemed to imply that I am to blame for having this autoimmune disease and that I’m either a ‘good diabetic’ or a ‘bad’ one. Managing two simultaneous chronic illnesses, while trying to ‘be a good diabetic’ I developed a fixation with eating ‘good and right foods’ as a way to avoid judgment and be viewed as ‘compliant’ or even admired. If nothing else, at least I could control my willpower.

‘I spent an hour grocery shopping last night, reading every product label I picked up. Even if this way of eating is mentally exhausting, at least no-one can say I’m not following a “good” diet. In reality I’m really scared what might happen if I did just eat what I want.’

As the fixation on eating ‘healthy and right’ foods grew, it became easier to say ‘No’ to foods that didn’t match my strict criteria. Being diabetic became a useful excuse to avoid the confrontation with food. Paradoxically, as an ESKD patient when the option to freely meet with friends became more difficult, I could no longer choose to meet even if I’d wanted to. Now the confrontation was imposed on me, rather than by me, and I had lost my sense of independence.

7.5. Meeting the elephant: the diagnosis of ESKD

Facing the diagnosis of ESKD was the most devastating moment of my life. I felt as if my once invincible, athletic body had failed me. How could this happen to me? A mixture of fear, disbelief, and shame followed the shock of diagnosis. Had I done this to myself?

‘Meeting the elephant’ was a theme repeated throughout the process of waiting for my transplant. The big, scary, intimidating presence of something unknown that would ultimately dominate my existence.

“I was sitting in a green consultation room chair, facing a man who was wearing a striped, red tie. For some reason I remember the most insignificant details. I remember feeling the cool air blowing

through the open window. But for the life of me I couldn’t understand a word of his Sentence.

‘You need a kidney and pancreas transplant.’

My eyes filled with tears, and I fisted them away. There is no way I can cry in front of this man. He’s obviously looking at the wrong column of numbers, and besides: I’m too young to need a transplant (...). My life as I knew it was over. I was being chained to an elephant and I didn’t know how I was going to cope. As I understood it, my life would be limited to moving in smaller and smaller circles, eating a diet as restricted as a zoo animal. I’d bloat up and have a permanent grey and sad look on my face. For all intents and purposes: I would become an elephant.”

It took me 8 weeks to process the news, before I could finally talk about The Elephant. It had been in the room for so long that I was almost able to ignore it and pretend it wasn’t there. Except it was and I had to accept that unless I found a suitable donor, I probably wouldn’t live to see many more migrating seasons. I hadn’t even started dialysis yet and already it felt like I was walking across the Serengeti, carrying a heavy load, and not knowing when the rain would come, or even if...

(Taken from a blog written 1 year post transplant)

‘Yet again I’m facing a list of “foods to eat and foods to avoid,” only this time the list is completely switched. The “healthy, and good foods” have all moved from the “good” to the “bad” column. I honestly don’t know what to eat – either I follow a healthy diabetic diet, or I try to keep my kidneys healthy. Some days I just want to give up.’

8. Discussion

Findings from this study identified five core themes, which are now discussed in relation to the literature.

Food is a physical representation of the basic hierarchy of human needs and **belonging**. From sustenance to security, self-love to self-actualization: food reflects our state of mind, cultural and social standing within a group [75]. Often even the smallest deviation from an established routine results in branding a person or an entire group as different or strange [76]. Throughout this paper, food played a central role in expressing identity and explaining the motivational strategies for managing chronic illness (Figure 3).

There is an acknowledgment within the literature that highlights the significant impact of imposing strict dietary, lifestyle, and fluid restrictions on ESKD patients, affecting their illness beliefs, anxieties, and sense of personal control [24,77,78]. As more dietary restrictions are imposed, food choices can no longer be based on spontaneity (self-actualization) or freewill, and many ESKD patients start to doubt their ability to cope (self-esteem) [77]. The stress and physical impact of dialysis treatment disrupts patients’ ability to lead normal lives, affecting their overall outlook and quality of life [24,38]. The basic hierarchy of need shifts down from a focus on progression and self-actualization, to one of survival.

Normal is an illusion for many T1D, as while they appear to look exactly like their peers, the practicality, and highly visible nature of managing the disease makes them stand out [52,79]. While adolescence is a period of self-discovery and major emotional, physical, and hormonal upheaval, it is also a time when most teenagers push for independence from their parents, and where peers provide a major source of

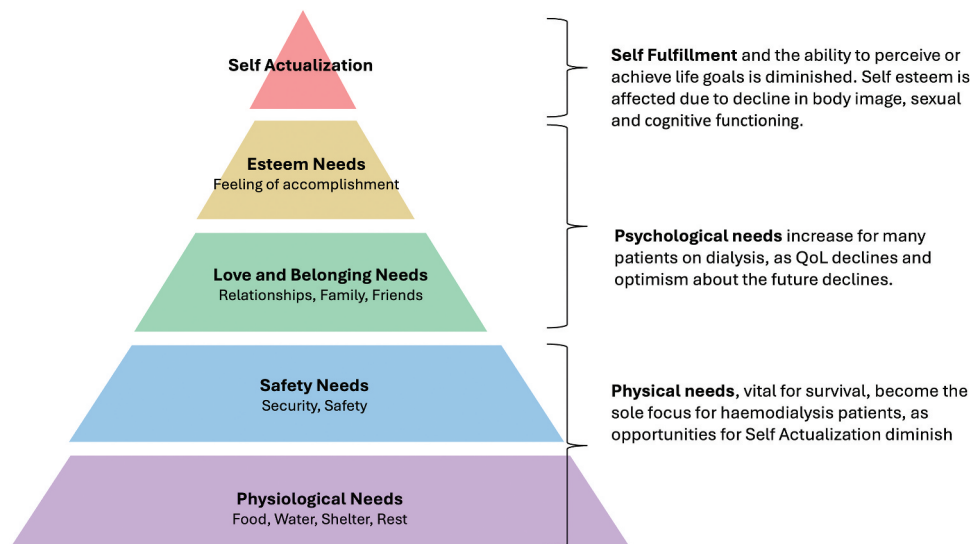


Figure 3. Maslow's hierarchy of need, as experienced by dialysis patients.

social influence [80]. Being 'normal' is highly desirable, and yet the physiological changes that occur during puberty increase insulin requirements, which can result in weight gain [81,82]. This can be highly distressing, especially when attempts at weight loss are more challenging when compared with non-diabetic peers [51].

Chronic dialysis has a major impact on the daily life of ESKD patients. While peritoneal dialysis is aimed at giving patient autonomy and improved quality of life, many experience a loss of freedom, due to the relentless repetitive treatment cycles, and the reliance on a dialysis machine to retain a semblance of normality [77,83]. The normal trajectory of treatment outcomes does not apply to chronic dialysis patients, as the progressive symptoms of ESKD are not necessarily prevented with strict treatment compliance [84]. Although some dietary restrictions appear justifiable, overzealous restrictions may lead to poorer patient outcome due to diminished nutritional status [55]. Many patients acknowledge that life on dialysis is hard and that receiving a donor organ would mean that somebody else would be losing theirs. What might normally be considered a miraculous second chance, is a bittersweet acceptance [85,86]. Life with T1D and ESKD will never be normal, but this research highlights some of the additional challenges faced by patients as they try to accept their new normal.

'Your numbers define you' describes the often-judgmental language used in diabetes care. Health organizations worldwide (including the ADA, Diabetes UK, and Diabetes Australia) recognize the impact of language on health outcomes and the effect of semantics on patients' understanding and ownership of their disease [87,88]. While there is strong evidence showing that words can impact patient empowerment, this research highlights that the everyday language used in diabetes care reinforces the feeling of constantly being judged. This includes the simple act of labeling a person by their medical condition, such as calling someone 'a diabetic,' which reinforces a tendency to define a person by their disease, and not see them as an individual whose identity

is obscured by a set of pervasive generalizations [89]. Conversations around diabetes management, which focus solely on numbers, are bound to fail as quantitative data cannot entirely capture the day-to-day complexities that encompass life with T1D or ESKD [90].

Given the detailed meal planning, precision in food composition, and constant monitoring of food intake in both T1D and ESKD, it is unsurprising that eating disorders are common in these patient groups [56,91]. The theme '**a disease disguised as a virtue**' highlights how ED may develop in T1D, precisely because of the continual reinforcement and praise for practicing restraint around food [52]. This disguise can easily go undetected as strict adherence is regarded as proof of 'being a good diabetic.' The avoidance of intradialytic weight gain is another major cause of anxiety for many hemodialysis patients which may lead to restrictive eating [92,93]. While patients want to be viewed as compliant in terms of fluid intake, restriction of nutrients can lead to the development of malnutrition and cachexia [93]. Furthermore, the catabolic and metabolic effects of dialysis may exacerbate poor nutritional status and contribute to lower dietary intakes [58].

Meeting the Elephant and being diagnosed with a life-threatening illness has significant emotional and psychological effects on both the patient and their families; and left untreated can result in distress, poor emotional adjustment, and reduced quality of life. There is limited understanding of the specific support that patients need and want, from whom, and when, particularly in the early days of ESKD diagnosis [38,94]. Dietary counseling and nutrition education are important aspects of managing both T1D and ESKD and despite the rising incidence of both chronic conditions, it is widely acknowledged that nutrition education for physicians is sorely lacking [95,96]. This research highlights the lack of robust data and insight into what helps or hinders healthcare professionals in identifying and responding to patient support needs. It points to the confusion and distress experienced by patients as they try to navigate their diet regimes when

knowledge about the effectiveness of restricting certain foods is limited. Adjustment to life with ESKD is a dynamic and constant process, rather than an experience with an end point. While the pressures on healthcare practitioners time forces a reliance on using long-standing methods that prioritize generalized population treatment approaches, this study points to the importance and relevance of using qualitative data to develop realistic treatment protocols in the design of dietary guidance for CDK and T1D patients.

9. Study limitations

Some criticize the accuracy and truth of memory recall and measurement bias in auto/biographic accounts and point to the influence of emotions and emotional goals experienced by the researcher at the time of data retrieval [97,98]. Yet it can be argued that the self will see life from a different perspective at different points in time, and that the researcher's present state of mind determines their perspective and memory of the past [99]. This RTA was compiled 4-year post-transplant, which allowed for sufficient emotional distance from the topic and enabled a process of reflection, to make sense of the situation. Additionally, the empirical data used included published blog posts, diary entries, and contemporaneous accounts, which were documented at the time.

10. Conclusion

As global cases of CKD and diabetes continue to rise the importance of nutrition knowledge among healthcare professionals and patients, needs to be acknowledged especially as this could affect patients' overall understanding of managing their chronic condition [100,101]. While dietary intervention is crucial in the management of both conditions, it is equally important to consider the implications of strict dietary regimes without providing sufficient evidence, guidance, and support and considering how this might affect mental health outcomes.

Lack of provision for renal psychosocial services means that despite evidence that patients desire improved support, there is limited understanding of the specific support they want, from whom and when [23,38,102]. Incorporating more patient involvement into renal research will help uncover these blind spots and improve adherence to nutrition protocols [61]. As food is central to our existence and experience as human beings, being able to guide patients on how to safely navigate 'what is left to eat' will greatly improve their overall outlook and quality of life [24,38].

10.1. Implications for practitioners and ESKD sufferers

This research will help to inform practitioners, dieticians, renal consultants, and nurses working with PwT1D/ESKD to help humanize their clinical practices. It adds to the paucity of insights from the patient's perspective and will help provide relatable experiences to fellow sufferers either starting their dialysis journey or to those struggling with similar challenges in relation to food, changed body image and an altered life expectancy.

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Author contributions statement

Diagnosed with T1D at age 11 and end-stage renal disease at age 34, the lead author (SS) has lived experience of the challenges of managing chronic health through diet. This knowledge contributed to the design, writing, detailed analysis and interpretation of the literature included in this review. Authors 2 (TB) and 3 ((MS) provided expert insights into the analysis and interpretation of the medical data. Author 4 (JT) was the methodology and methods expert for this paper. All authors agree for the final version to be published and are accountable for all aspects of the work.

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Appendix. Summary of Literature review items included

Author(s) and Title	Study type	Main purpose and Findings	Notes
1 Goh, Z.S., Griya, K., (2018); Anxiety and depression in patients with end-stage renal disease: impact and management challenges – a narrative review	Narrative Review study	Some studies have demonstrated higher prevalence of depression in patients with CKD/ESKD than that of other chronic diseases. The reported prevalence rate of depression in patients with CKD ranges from 20% to 30% particularly for those who have been on dialysis longer.	Wide variability among studies and this is mostly attributed to methodological differences in measurement and criteria to define depression and anxiety disorders (eg, self-reported vs diagnostic interviews).
2 Peri J, Karaboyas, A.,(2017). Association between changes in quality of life and mortality in hemodialysis patients: results from the DOPPS. Nephrology Dialysis Transplantation. 2017;2017: 521–527.	The DOPPS is an international prospective cohort study of in-center HD patients. N = 13,784 patients, aged 18 +years, mean age 62 years (standard deviation: 14 years); 59% male and 32% diabetic.	Investigated the impact of changes in health related-QoL on subsequent mortality, using the SF-12 questionnaire to measure the impact of changes between the physical (PCS) and mental (MCS) component summary scores. Median time between the 3 measurements was 12 months. Results: Median initial PCS and MCS scores were 37.5 (IQR: 29.4, 46.2) and 46.4 (IQR: 37.2, 54.9); median changes in PCS and MCS scores were –0.2 (IQR: –5.5, 4.7) and –0.1 (IQR: –6.8, 5.9), respectively. the most recent HR-QoL score was strongly associated with mortality, while changes in score from 1 year prior had no additional predictive value.	This study would have benefitted from noting the number of hospitalizations in those who had significant score changes to understand whether (PCS) or (MCS) had more or similar impact on hospital admissions.
3 Hansen, H.P., Rauber-Lassen E., Jensen, B.R., et al. (2002). Effect of dietary protein restriction on prognosis in patients with diabetic nephropathy. <i>Kidney International</i> , Vol. 62 (2002), pp. 220–228	4-year prospective trial with concealed randomization. N = 82 PwT1D with progressive diabetic nephropathy [pre-study mean decline in eGFR 7.1 mL/min/year (95% CI, 5.8 to 8.5)]. The main outcome measures were 1) decline in GFR and 2) development of ESRD or death.	To determine the effect of a low-protein diet (0.6 g/kg/day) (LPD) with a usual-protein diet (1.02 g/kg/day) (UPD) on survival and progression to ESRD. At follow-up, the mean declines in eGFR were 3.9 mL/min/year (2.7 to 5.2) in the UPD group and 3.8 (2.8 to 4.8) in the LPD group. ESRD or death occurred in 27% of patients on a UPD as compared with 10% on a LPD (log-rank test; <i>P</i> 0.042). The relative risk of ESRD or death was 0.23 (0.07 to 0.72) for patients assigned to a LPD, after an adjustment at baseline for the presence of cardiovascular disease (<i>p</i> = 0.01). Blood pressure and glycemic control were comparable in the two diet groups during the follow-up period.	No details were provided on the composition of the protein and whether these were from animal or plant-based sources.
4 Georgianni, S., Babatsikou, F., Gerogianni, G. et al., (2016). Social Life of Patients Undergoing Haemodialysis. <i>International J Caring Sciences</i> . 9:1 (122–134).	Qualitative study, using the KDQOL-SF36 questionnaire, with N = 100 HD participants. Age range: 50 to 59; 59% Male.	To investigate the social impact of HD on QoL, in people with ESKF, the KDQOL-SF36 questionnaire and a demographic questionnaire was used. 41.7% (<i>n</i> = 40) agreed that renal failure affected negatively their QoL ; 45.3% (<i>n</i> = 43) used to spend too much time trying to cope with nephropathy; 32.7% (<i>n</i> = 32) reported a lot of satisfaction from time spent with family and friends while 68.3% (<i>n</i> = 67) felt they were a burden to their family because of nephropathy. 17.7% (<i>n</i> = 17) often felt isolated from other people, Variables including age, gender, frequency and duration of dialysis, education and social functioning can affect either positively or negatively the quality of patients' social life.	The limitation of this paper was that it did not provide the median time spent on dialysis across the group (which may have impacted scores.

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	Author(s) and Title	Study type	Main purpose and Findings	Notes
5	Jiang S, Fang, J., Li, W., et al. (2023). Protein rescription for diabetic kidney disease. Cochrane Database Syst Rev. 2023;2023 [1].	Systematic literature review. N = 486 of adults with diabetic kidney disease to determine effect of low protein diet on progression to kidney failure, death and QoL.	To determine the safety and efficacy of LPD the reviewers included 8 papers in their review. Participants were divided into 2 groups: LPD of 0.6 to 0.8 g/kg/day prescribed protein/day; and a Control group taking in ≥ 1.0 g/kg/day. Results showed that LPDs may have little or no effect on death or progression to kidney failure.	These studies did not reveal much insight into the health related quality of life and the adverse effects such as nutritional measures on these outcomes.
6	Perianova, I. (2012). The Polyphony of Food by Irina Perianova. Cambridge Scholars Publishing.	A reference book on the on the impact of food on our interpretation of life and world around us.	This book explores the various elements of food, and the impact of family and society in our expression of solidarity, acceptance, affiliation and belonging. It covers how food can be a form of self-actualization and identify. It explores how our hierarchy of needs changes with changing health.	This book provided an unconventional way of looking at the relationship that humans have with food and broadened my exploration of the topic.
7	Desai, AM., Perrone, R., Dwyer, J. (2005). Eating disorder in a hemodialysis patient case report. Nutrition Reviews. 63:12(423–426).	Case Study report N = 1 ; 30-year-old male with ESKD, on dialysis for 10 years.	Malnutrition is prevalent in dialysis patients, with ~half of patients suffering from protein and energy malnutrition. Causes are multifactorial and include social, psychological and medical factors, although seldom assigned to eating disorder. Eating disorders risks (especially anorexia or bulimia) may be higher in ESRD because of attempts to achieve desired nutritional parameters, including controlling fluid gains. This case highlights the difficulty of diagnosing eating disorders when a patient has serious underlying medical problems.	This paper highlighted the similarity of increased risks for ESKD patients and those with T1D in developing eating disorders because of the rigorous dietary instructions and an emphasis on weight.
8	Powarthil, GG. (2023). The Experience of living with Chronic Illness: A qualitative study among End Stage Renal Disease Patients. Journal of Social Work in End of Life and Palliative Care. 2023.	Qualitative research involving face-to-face patient interviews. N = 12 patients who have been on dialysis for at least 1 year with no diagnosed psychiatric and neurological conditions.	The study investigated the inner experiences of ESKD patients, using face to face interviews, which were transcribed verbatim and analyses using Colaizzi's descriptive phenomenological method. Results: ESRD patients experience significant psychosocial and health-related issues. 4 themes emerged from the data analysis to support this: a decline in physical function, psychosocial distress, economic hardships, and impact on the support system. The important role of the clinical social worker was highlighted particularly in helping to resolve the psychosocial issues of patients with ESKD.	This was a small sample group which consisted of a single method of enquiry, meaning that there was little opportunity for reflection or tracking of progress over time.

Key: ESKF = End Stage Kidney Failure **HD** = haemodialysis **QoL** = Quality of Life;