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Biographical dialectics: The ongoing and creative problem solving required to negotiate the biographical disruption of chronic illness

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ABSTRACT

Here we propose the term ‘biographical dialectics’ as a sister term to ‘biographical disruption’ to capture the ongoing problem solving that characterises the lives of many people living with life limiting chronic illnesses. The paper is based on the experiences of 35 adults with end-stage kidney disease (ESKD) in receipt of haemodialysis. Photovoice and semi-structured interviews showed that ESKD and the use of haemodialysis was widely agreed to be biographically disruptive. In talking about and showing disruption through photographs the participants’ ongoing problem solving was universal across their diverse experiences. ‘Biographical disruption’ and Hegalian dialectical logic, are drawn on to make sense of these actions and to further understand the personal and disruptive experience of chronic illness. Based on this, ‘biographical dialectics’ captures the work that is required to account for and manage the enduring and biographical impact of chronic illness that follows the initial disruption of diagnosis and continues as life progresses.

1. Introduction

Understanding how people respond to and live with chronic illness is fundamental to the improvement of health and social care provision, treatment options and individual lived experience (Morden et al., 2017; Kierans, 2005). Concepts, theories and strategies such as biographical disruption (Bury, 1982), self-identity work (Trusson et al., 2021), liminality (Trusson et al., 2016), status passage (Roberti et al., 2021), chronic illness trajectory (Corbin and Straus, 1991), practice theory (Lubi, 2019), and self-management (Lightfoot et al., 2022; Washington et al., 2016; Lorig, 1993) have all been used to improve understanding of the experience of chronic illness.

In this paper, the literature addressing biographical disruption is used to think through personal accounts of the use of haemodialysis by people with end-stage kidney disease. In doing this we highlight the continually evolving, creative and resourceful strategies individuals with life limiting chronic illnesses, such as end-stage kidney disease (ESKD), engage in as a result of the ongoing disruptions to ‘normal’ life caused by their particular illness and mode of treatment. To capture this need for repeated problem solving, we propose a sister concept to biographical disruption, ‘biographical dialectics’, informed by Hegel’s dialectical logic (Hegel, 2002). We use the concept of ‘biographical dialectics’ to position life limiting chronic illness as a continually disruptive experience and highlight skills associated with endurance, resourcefulness and creativity needed to manage the ongoing tensions associated with life with a chronic illness. While we focus on accounts of those with ESKD using haemodialysis it is likely that our findings and suggestions will be transferable to both the experience of other forms of kidney replacement therapy and, indeed, other life limiting chronic illnesses such as COPD, MS, and Motor neurone disease.

Globally over 800 million people live with chronic kidney disease (CKD) (Kovesdy, 2022. End stage kidney disease (ESKD) is the fifth and final stage of CKD. It occurs when the kidneys have lost almost all of their function and is defined as having an estimated <15% of normal kidney function. It is the final common pathway of all process that cause renal fibrosis and scarring and although it is more common in older people often with multiple long term conditions, it can also affect younger people and children. ESKD is associated with a number of complications and often, individuals experience symptoms that significantly impact their activities of daily living. For many, dialysis is the

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only available treatment to support kidney function, both to relieve symptoms and maintain life. For example, at the end of 2020 in the UK around 24,000 adults were receiving in-centre haemodialysis and nearly 4000 were receiving peritoneal dialysis (UKRR, 2022). At the same time, in the USA, 109,107 people started haemodialysis and 16,528 people started peritoneal dialysis (USRDS, 2022).

This paper focuses on experiences of living with ESKD and receiving incentre haemodialysis (ICHD) in the UK. In the UK, the majority of those receiving ICHD attend dialysis sessions three times a week, following an every other day schedule, typically with a two day break over the weekend (this will be similar in other countries too). Most in-centre haemodialysis sessions run for 4–5 h (UKRR, 2022). In addition to this, people using haemodialysis are required to adhere to a limited fluid intake to reduce the risk of mortality from cardiovascular disease. Specific dietary requirements restricting potassium, phosphorous and sodium intake (Lindley, 2009) are also required.

It is widely acknowledged that ESKD disrupts people's lives. In a systematic review of qualitative studies exploring the experience of ESKD Roberti et al. (2018 p.1) conclude 'being a person with ESKD always implied high burden, time-consuming, invasive and exhausting tasks, impacting on all aspects of patients' and caregivers' lives'. Mirroring Roberti et al.'s (2018) findings, for the participants in this study, ESKD and the need for haemodialysis presented ongoing and ever more disruptions to anticipated biographies that required numerous and ongoing adaptations and management strategies. Here we pair the literature addressing biographical disruption and Hegel's dialectical logic to move beyond the acknowledgement that ESKD is disruptive, to consider how disruption impacts patients' lives and how they respond in order to further understand the disruptive impact of life limiting chronic illness.

While biographical disruption has been liberally applied to the experience of many chronic illnesses, comparatively limited attention has been paid to the problem solving required to respond to the intrusive impact of chronic illness. The literature addressing self-management and symptom burden/burden of treatment addresses this to a certain extent, however, the focus tends to be on symptom management rather than issues pertaining to biographical disruption (Lightfoot et al., 2022; Washington et al., 2016). Specifically, as Roberti et al. (2018, p.2) state 'structural, relational and resilience factors' associated with the burden of treatment for people with chronic kidney disease remain under explored'.

Here, we draw on findings taken from the analysis of a qualitative workstream of the NightLife study (ISRCTN87042063). NightLife is a randomised clinical trial (RCT) to evaluate the outcomes of in-centre, nocturnal haemodialysis compared with daytime care. In this paper we focus on analysis from qualitative interviews and photovoice accounts from people receiving day-time in centre haemodialysis (ICHD), collected as part of an integrated ethnographic process evaluation. Before the findings are presented and discussed in relation to our proposed sister concept 'biographical dialectics', we provide an overview of the biographical disruption literature and consider this in relation to ESKD.

2. Biographical disruption

Initiated by Bury (1982) in a study to explore the diagnosis of rheumatoid arthritis, biographical disruption captured the early experiences of chronic illness. Bury (1982) highlighted the disruptive impact of the diagnosis of chronic illness on three key aspects of life, including (1) disruption to the 'normal' way of being, where attention is focused on bodily performance and help seeking; (2) disruption to self-identity, involving change to the individual's sense of self and position within society; and (3) disruption of the social and material resources that people rely on for everyday life.

The third element of disruption, and perhaps the least explored, relates to coping strategies and the utilisation of additional resources to manage disruption. Bury's (1991) later conceptual development of biographical disruption focuses on the enduring nature of chronic illness and highlights the need for coping strategies, framed as 'styles' and 'strategic management'. 'Styles' include the way individuals perform their illness, how they respond to it, define it, and interact with others. 'Strategic management' or 'strategies' refer to the adaptations people make in their lives to account for and manage their chronic illness. Bury (1991, p,462) links these coping behaviours to the need to 'maintain a sense of hope for the future'.

Biographical disruption has been used to explore experiences of a wide variety of chronic illnesses such as breast cancer (Trusson et al., 2021), prostate cancer (Schultze et al., 2020), frailty (Cluley et al., 2021), HIV (Carricaburu and Pierret, 1995), Meniere's disease (Bell et al., 2016), stroke (Faircloth et al., 2004), and mental ill health (Perry and Pescosolido, 2012) a to name but a few. Biographical disruption has also been used to explore differing experiences of chronic illness such as chronic illness in old age (Cluley et al., 2021), across different ethnicities (Liamputtong and Suwankhong, 2015), as experienced by couples (Hudson et al., 2016) and across life courses (Larsson and Grassman, 2012) and to explore experiences of the social determinants of health (Morgan and Burholt, 2020). Consequently, biographical disruption has expanded to unpick and understand all aspects and stages of the chronic illness trajectory rather than onset and initial diagnosis.

In broadening the concept to explore such a variety of experiences, biographical disruption has been critiqued and developed to include additional concepts. Alternatives include: biographical continuity (Williams, 2000), biographical flow (Faircloth et al., 2004), biographical reinforcement (Carricaburu and Pierret, 1995), biographical oscillation (Bell et al., 2016), recurrent disruption (Saunders, 2017), biographical erosion(Lippiett et al., 2022) and biographical reconfiguration (Reynolds, 2002). These will be discussed further as the paper progresses.

3. The disruptive nature of ESKD

Few studies have applied biographical disruption to the experience of ESKD and the need for haemodialysis; however, the diagnosis, symptoms and treatment options are widely agreed to be disruptive. In a study exploring older people's choice to elect for active conservative care (symptom management without any form of kidney replacement therapy) instead of dialysis, Llewellyn et al. (2014) found that particular treatment choices and their associated limits caused more disruption than the physical symptoms of end-stage kidney disease.

In exploring the personal narratives of people with ESKD Kiernans (2005 p.345) states,

> 'shifting and altering pain and sudden, unexplainable sensations burst upon daily life in unexpected and uncontrolled fashions …. all-encompassing symptoms that travel well beyond the site of the kidney, evidencing somatic, psychological, and cognitive affects, intensifying body image, and disrupting everyday routine and practice. There is little constant or anticipated'.

Roberti et al. (2021) draw on Corbin and Strauss's concept of 'status passage' to explore transitions between kidney disease, need for dialysis, transplant and transplant failure. Like biographical disruption, status passage focuses on issues of identity, social interaction/relationships, societal norms and expectations, and the response of others (Corbin and Strauss, 1991). When talking about dialysis, Roberti et al.'s (2021) participants reported a range of disruptions to their sense of self and role in society caused by the frequency of treatment and associated side effects. Consequently, Roberti et al. (2021, p.13) conclude 'after the initial changes, a continuous transformation of the patient's identity takes place. The uncontrolled passage affects all aspects of the individual's life, competing with other status passages and with catastrophic effects'.

Similarly, in a qualitative study to explore the impact of the burden of treatment associated with dialysis, Roberti et al. (2022) found that the high demands of treatement often resulted in negotiations with healthcare providers that in turn could lead to the modification or interruption of treatment.

It is widely known, moreover, that ESKD and the need for haemodialysis is disruptive to anticipated life course. Building on this literature, to explore how patients navigate the disruption they experience, we draw on research findings from the study detailed below.

4. Methodology

NightLife is a randomised clinical trial (RCT), (ISRCTN87042063) that compares day-time and night-time, in-centre, haemodialysis (ICHD) by analysing both clinical factors and personal accounts through five multimethod workstreams, including a qualitative process evaluation using observations, field notes, patient and staff interviews, document analysis, and photovoice. The findings drawn on in this paper are taken from the photovoice work and semi-structured interviews with patients recieving, day-time ICHD. This work aimed to build an in-depth understanding of the experience of daytime dialysis to be compared with a similar and forthcoming exploration of night-time experience.

Thirty-five participants were included in this aspect of the study, accessed across four renal units in England. The renal units were chosen for their diversity to ensure the study sample was representative of the UK ICHD population. The sample was opportunistic, including adult men and women, varying ethnicities and ages, and people who had been using daytime dialysis for a range of time periods (see tables one and two for further details).

VC (principal researcher for the qualitative process evaluation) approached patients on day-time dialysis in the treatment setting (renal units) while they were dialysing. On first meeting, potential participants were informed about the study as a whole and were then invited to take part in the photovoice element of the study. If photovoice was not possible (in this case if participants had a visual impairment or didn't own a smart phone) or participants did not want to take part in a photovoice exercise, participants were offered the option to take part in a semi-structured interview. Of the 35 participants, photovoice work was carried out with 12 and semi-structured interviews were carried out with 23 (see Tables 1 and 2 for demographic detail). All research interactions took place in the renal unit, at participants' bedsides for ease of participation (Kaushal et al., 2022).

Table 1
Demographic detail for interview participants.

Participant number	Sex	Age	Ethnicity	Years on haemodialysis
PI/001	F	53	Black Caribbean	Five years
PI/002	F	58	Indian	35 years
PI/003	F	34	White British	Two months
PI/004	M	55	White British	One year
PI/005	M	70	White British	Four years
PI/006	M	72	Indian	18 months
PI/007 withdrew consent				
PI/008	F	68	White British	Two years
PI/009	M	81	White British	18 months
PI/010	F	78	White British	Two years
PI/011	F	57	Indian	Seven months
PI/012	M	77	White British	Three months
PI/013	M	55	White British	Six years
PI/014	M	76	Indian	10 months
PI/015	F	38	Indian	Seven months
PI/016	M	67	Indian	11 months
PI/017	F	57	Black Caribbean	Six years
PI/018	F	87	White	11 years
PI/019	M	82	Black	Two years
PI/020	M	64	Black Caribbean	Three years
PI/021	M	76	White	Five years
PI/022	F	68	Black Caribbean	Two years
PI/023	F	80	Black	Six years
PI/024	M	80	White British	Two years
PI/025 withdrew consent				

Table 2
Demographic detail for photovoice participants.

Participant number	Sex	Age	Ethnicity	Years on haemodialysis	No of photos
PV/001	F	46	Not stated	Seven years	21
PV/002	M	42	White British	Three years	Seven
PV/003	M	66	White British	18 months	Seven
PV/004	M	52	White British	One year	Five
PV/005	F	30	White British	14 months	Seven
PV/006	M	19	White British	Six months	Nine
PV/007	M	22	Lithuanian	Four months	32
PV/008 withdrew consent					
PV/009	M	30	Indian	Four years	Nine
PV/010	M	32	Portuguese	Three years	Four
PV/011	F	30	Romanian	Two years	Four
PV/012	M	50	White British	Six years	132
PV/013 withdrew consent					
PV/014	M	50	White British	One year	22

Photovoice is a visual method that uses participant-led photography. Originating in health promotion research as a participatory action research method to facilitate social change (Wang and Burris, 1997), photovoice is now widely used across social science disciplines and has been used to explore a wide variety of phenomena and experience (Salim et al., 2022; Cluley et al., 2021; Badanta et al., 2021). Photovoice has developed into a flexible research tool that can be adapted to suit diverse research needs and settings (Catalani and Minkler, 2010). Photovoice was chosen for the NightLife study to reflect the all-encompassing impact on everyday life that ICHD has and to facilitate a participant-led approach. As highlighted in the studies to explore disruption and burden of treatment (Roberti et al., 2022, 2021 and Kierans, 2005) much of the impact of dialysis is felt outside of the treatment setting. In order to capture as much of this as possible, a research method that could be taken outside of the clinical setting was needed.

Participants were asked to use their smartphones to take photographs over the period of a week and were given an open brief to take photographs of anything and everything to show their experience of daytime haemodialysis and how this impacts everyday lives. Photographs were sent to VC's study-specific mobile phone using WhatsApp. At the end of the week, VC returned to the renal unit to talk to the participant about their photographs, using an adapted version of Wang and Burris (1997) SHOWeD framework of questions to guide conversation.

For the participants who were interviewed, without having done the photovoice element, a flexible topic guide was used to focus participant both types of interview were audio recorded and transcribed. Written, informed consent, including consent to used shared photographs, was provided (NHS REC reference 20/WM/0275). In addition to this, VC discussed the ethics of taking photographs for research purposes with all photovoice participants. Participants agreed to ask permission before taking photographs in shared spaces and it was agreed that any photographs containing people other than themselves would not be shared further than with VC. Participants provided consent for photographs that did not contain imagery that could result in identification to be used for publication.

VC and HE (process evaluation lead) used thematic analysis following Braun and Clarke, 2021 to analyse both the photographic content and the participant talk across the photovoice work and the semi-structured interviews. Open coding was used in the following way: VC and HE coded half of the transcripts each using NVivo. VC and HE then met to share codes and discuss similarities, overlaps and discrepancies. VC then checked all transcripts to ensure coding continuity. From the agreed codes, four crossing cutting and relational themes in relation to this analysis were identified; biographical disruption, relationality, continuity and endurance and, temporality. This paper expands on a particularly significant issue revealed in the biographical disruption theme – the ongoing problem solving people with ESKD experience and the creative solutions they construct to account for, manage and limit disruption. It was at this stage, that Hegel's dialectical logic was considered useful to expand the understanding of this pattern of identified behaviour. The findings illustrated and discussed below, show how we used dialectical logic to make sense of the participants' continual need to problem solve.

5. Findings

> I was pregnant, I was in my seventh month of pregnancy, and … it was devastating. If I think about it now, I wonder how I went through all that. Because I lost the baby as well. (Amanee, female, age 58)

> It just seems hard. You know, you retire, I mean I did retire a bit early, but you retire, you expect to be able to go away and do all sorts of things you planned. And then ….that's it … you are not able to do most of the things you were hoping to do. (Katherine, female, age 68)

So I live at home with my mum. I was living by myself, but I thought its best that I come back home (Hina, female, age 38).

As illustrated above, participants shared stark examples of how their ESKD diagnosis and the need for dialysis disrupted their lives. All 35 participants openly shared the disruptions and challenges experienced as a consequence of their ESKD and day-time ICHD. The participants were not asked directly to do this, the topic guide did not include an explicit question about challenges/disruption, rather in talking about their experience of dialysis all participants talked extensively about challenges and disruptions. Additionally, as seen in the extracts above, all participants discussed the challenges and disruptions they faced in relation to their previously expected biographical trajectory. In other words, ESKD and the need for ICHD was universally agreed to be biographically disruptive, regardless of age or time using dialysis. Participants talked about employment changes, financial worries, changed retirement plans, changes to living arrangements, lost friends, missed social activities, giving up hobbies, negative body image, parenting issues (including losing the opportunity to be a parent), and deteriorating physical and mental health.

In talking about the disruptions they face, the participants also spoke about the problem solving required to negotiate, mitigate and reduce disruption. Such work is often associated with a desire for continuity/return to normality (Becker, 1999, Bury, 1991). The disruptions faced by the participants in this study often caused such a rupture to biographies that a return to a previous normality was challenging. Much of the work the participants did to mitigate disruption was not in an effort to return to a previous normality, rather it was to create a new normal, a life that could be reasonably lived.

Across the interviews and photovoice, the ongoing need to problem solve was identified as fundamental aspect of the participants' experiences. It was generally not the case, however, that problem solving provided permanent and/or satisfactory solutions. Rather, in solving one problem or managing one disruption, other problems and disruptions were created that also required management. While the disruptions experienced and the problem solving/management strategies devised depended on individual circumstance and life stage, the ongoing need to problem solve was common to this diversity. The examples provided next, are grouped under specific instances of lived experience that were commonly discussed across the photovoice and interviews, including: work, parenting, home life, and social life. Disruption and problem solving are highlighted in each example.

6. Work

For the participants of working age, ESKD and the need for ICHD had a significant impact on employment, including employment status, work pattern, job role and mode of employment. Most of the participants of working age were currently not in employment. Of these participants, unemployment was attributed to their ESKD and need for haemodialysis.

Sam (male, age 52) previously worked outdoors as a security guard but had to stop when he required dialysis. Sam described the impact of ESKD on his life as devastating.

> How I used to work, pretty much any dialysis shift would devastate it. I was doing 12-hour shifts. I got in touch with my company and asked whether they could rearrange my shifts. They weren't prepared to.

Sam missed the exercise and natural beauty his job provided him.

> All this sitting down now, it's very different. I like to have a walk around. Walking round the outsides of the quarries, so much wildlife around them. You know, I used to take my camera with me and take pictures round there. I miss that, walking round, dragonflies flying around.

To cope with the loss of income Sam experienced after losing his job, Sam moved in with his elderly parents. While this change provided a solution to the financial strain Sam experienced, it also created a new problem; Sam described living with his parents as 'suffocating'.

> They just consider me disabled now, you know, and they say 'oh, go and get yourself your disabled badge' and whatever. I don't want a disabled badge.

Although Sam discussed a range of often deliberating symptoms, Sam did not want his illness to become part of his identity. Sam used an example from before he stopped working to demonstrate his physical ability.

> After my fistula[1] was formed, as I say, I was still working. One night a tree fell down outside the site where I was working at, my colleague was working there, called me, said I need some help. And two of us sawed this tree up and moved it.

In contrast, Sam shared a photograph of two full bags of food shopping. When asked to talk about the photograph he said he had taken it to show his parents' changed perception of him and how frustrating he found this. Having moved in with his parents following his need for dialysis, Sam did the weekly household food shop.

> They panic about my fistula arm. "you can only carry the light stuff".

Hence, Sam's and his parents' perception of his ability differed considerably. For Sam, this was an additional tension emanating from his need for dialysis and consequent loss of employment and return to the family home. Sam attempted to alleviate this tension by removing himself from tense exchanges between him and his parents. This further problem solving is discussed in the home life section.

Like Sam, Junior (male, age 32), also experienced a range of challenges following loss of employment. When working, Junior frequently missed dialysis sessions and was unable to find a dialysis pattern to suit his working hours. This had a significant impact on his health.

> I was working in a factory. I'm a butcher. So you know, it's a really heavy job. And when I start doing dialysis I couldn't, with my first fistula, I couldn't move and anything. I couldn't lift things. My boss was like, 'I don't know what to do with you'. Simple jobs like OK, try

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[1] A fistula is the connection of an artery and a vein to create a robust vessel that will tolerate regular insertion of needles, using located in the arm.

> to clean … I was cleaning, but still was getting tired. My body wasn't reacting well, was fainting. So that's why I have to stay home.

While giving up work had allowed Junior to maintain regular dialysis, loss of employment had a significant impact on Junior's identity.

> For a man like me, you know. It's hard. I want to be a man, I want to help, I want to be a provider. I just don't want to be someone that's always asking for help.

To mitigate financial disruption, Junior reluctantly received state benefits and was considering alternative, less strenuous employment options to suit his dialysis schedule and, importantly, to provide for his family and regain his lost identity. This, however, presented additional challenges.

> They pay you £59 for a month. What am I going to do with £59? All of this, It's really, really hard. But if I'm doing dialysis it's because I love my family, I want to live more. And be with them. I want to be able to provide for them again.

Unemployment, consequent of the participants' ESKD, ruptured their anticipated biographies to such an extent that disruption to identity, sense of self, financial security and living arrangements were all discussed at length. These ruptures required solutions such as moving in with parents, finding activities to fill the void left behind by unemployment, seeking benefits. These solutions often created additional disruptions and tensions such as financial strain and changed relationships within family units that in turn required further problem solving to mitigate.

For the participants who were in employment, all had either changed their job or adapted their work to accommodate dialysis and the symptoms of end-stage kidney disease. These changes often required much thought, planning and resourcefulness. For Marisol (female, age 46), who is now self-employed, financial worries about the future and her capacity to work full time lead her to re think her position as a journalist and find alternative and flexible employment.

> 'My job is actually- it's [come about] as a result of my kidney failure. When I lost my kidneys, I realised, I just thought, I won't be able to work. You know it will just be really difficult. You know when I am older how will I get any income? Because I can't work full time. You know, I'm here like 20 hours a week. If not here, last week I had another appointment, so, you know. I just had to think of something else'.

Although Marisol had been able to find alternative employment that allowed her to accommodate the time demands of dialysis, she continued to experience challenges. Marisol spoke about a recent job offer that would require more hours and relocation. While the job presented an excellent opportunity for Marisol she turned it down due to her need for dialysis. Marisol also talked about a conference she had been unable to attend in full.

> I was at a conference away from home last week. That was great but I had to reorganise everything with dialysis. I couldn't stay the whole time, I had to leave early, come back, straight away back on dialysis. So that was … and they asked me to come you know, so it was really good to go but I couldn't experience the whole thing.

Sunil (male, age 29) worked in insurance and had decided to take a career break due to the anxiety he experiences as part of his ESKD and the requirements of ICHD. With his free time, Sunil now provides wrap around childcare for his sister's children.

> I worked for an insurance company. I'm still there. But I've taken a career break because I said to them I don't feel well. Because of the anxiety and coming here. It's just too much for me ….I look after my niece and nephew now, take them to school on the days I am not here, pick them up every day. Do homework with them, get them some food. Just look after them.

While Sunil valued the opportunity to play a significant role in his family, living with his extended family caused him to reflect that he would like a family himself. His need for dialysis prevented him from seeing beyond this desire. We discuss this tension further in the next section.

Other participants such as Robyn (female, age 30), a retail manger, and Ross (male, age 50), a forklift truck driver, had chosen to reduce their work hours to account for their symptoms and need for dialysis. While changes to work patterns and job roles could be made, this was not an easy option and entailed numerous additional pressures and challenges to identity such as reduced income, additional planning, and changed employment status from full to part-time. All participants who were either unemployed or had adapted their work lives to accommodate their ESKD expressed knock on effects that required additional problem solving.

The participants' work experiences expand on Roberti et al.'s (2018) review where it was found that people on dialysis tended to experience financial concerns due to unemployment, working in precarious occupations, and reduced hours. In a study exploring the work identities of women who had been diagnosed with breast cancer, Trusson et al. (2021, p.130) found that their participants responded to the disruption of their diagnosis and illness by 'enacting agency to change their work patterns … to seek meaningful work activities outside the paid labour market to fulfil emotional rather than material needs'. Unlike breast cancer which, in many cases, can be recovered from, ESKD cannot. Treatment is not a temporary disruption, it is a continuous one. For this reason, while some of the participants were able to enact agency to change their employment status, their options for change were limited and the choices available often had restrictive consequences that required ongoing problem solving.

7. Parenting

Some of the participants had young children. For these participants managing their symptoms, fitting in dialysis and additional health related appointments, often conflicted with their role as parents and required resourceful problem solving. When Marisol found out that she would need haemodialysis, she and her family moved to her home town to live with her parents.

> I think it was really useful to come to [location], my parents really help out, because being on dialysis, you know, even if you're at work, *you* could just ring up one day if *you* need to and say 'I'm sorry, I can't come in', [for example] if your child's ill. But I can't do that. I have to come in [for dialysis]. (Marisol, female age 46).

Joyce (age 53), a single parent talked about her struggle to find childcare for her son who has additional needs. After various attempts at using formal childcare that frequently could not accommodate last minute changes and did not provide overnight stays, a family friend agreed to act as a flexible childminder. Joyce talked about the feeling relief that her son was now receiving the care he needs. At times, however, as demonstrated in the extract below, the stress and the need to think of additional alternatives returned.

> And then if I'm at dialysis or if I have to stay in the ward he'll go and stay over at their house. But then if, he [childminder] had a holiday last week. So [son] stayed at home. It was a worry. My brother looked after him but he don't cook. The cupboards are full of food. He give him toast! So you see I need to talk to him again.

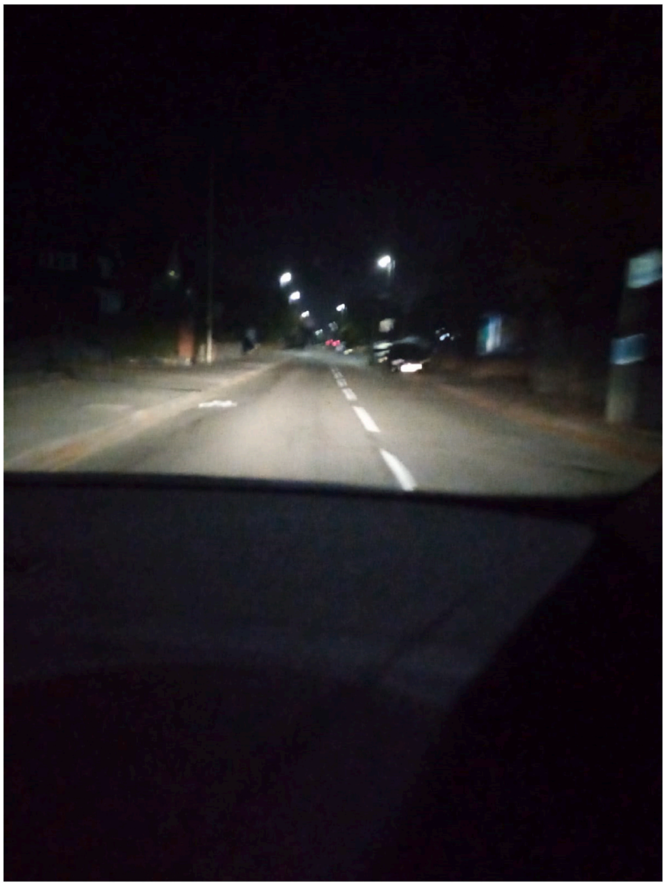
Marisol experienced a similar pattern, in resolving her childcare needs by moving in with her parents, her mother later became ill and couldn't sustain the childcare she was providing. Marisol then had to consider other options. Robyn (female, age 30) chose to reduce her hours at work to accommodate her symptoms and also to allow her to do the school run for her two children. This, however, came at the expense of financial security.

> I've gone down to 32. It's working a lot better. So now I just do all my hours in four days rather than over five, and yeah its less money though so that's a bit of a struggle. 32 is still a lot. Can't just fall asleep on the sofa.

8. Home life

For many of the participants, tiredness limited the things they could do. This impacted significantly on their home life and capacity to maintain independence. The participants drew on a range of strategies to cope with this.

Regardless of age, many of the participants had made the decision to move in with parents or relatives for additional support. While returning to the family home was helpful, many of the participants discussed the difficulties that this change brought and the additional issues created. As outlined earlier, for Sam (male, age 52), moving in with his elderly parents was extremely challenging. The photograph below was taken by Sam one evening when living with his parents became too much.



> I'd been in home most of the night and the family don't like me going out in the dark. They panic. I just had to get out and have a few minutes on my own. So I went out, and the roads were just deserted at that time so I thought 'take a picture of it'. I like to be on my own, I like to have my freedom.

In this example, Sam discussed removing himself from family tensions and the short-term relief this provided. While he could escape his parents' panic for short moments in time, this was not a satisfactory long-term solution for Sam.

As also outlined above, Sunil (male, age 30) moved in with his sister and her family for reasons of mutual support. While Sunil enjoyed and valued being so involved in his family's life, he expressed much anxiety for his future, questioning if he will ever live alone, marry and have children. For Sunil, these biographical milestones were personally and culturally important. Anxiety over these unknowns had impacted significantly on Sunil's sense of self.

> 'I am happy with it, but I do sometimes, you know, when I do feel down, I do feel like, you know, feel like I want to kill myself. I have felt like that before'.

Low mood and suicidal feelings were common across the participants' accounts of their lives and the dissatisfaction they felt. Not being able to find a route to their previously anticipated biographical trajectories had a devastating impact for many of the participants.

9. Social life

All of the participants experienced reduced social lives. Junior (male, age 32) discussed not being able to go on a family holiday, Katherine (female, age 68) could no longer play tennis and Silas (male, age 66) had stopped visiting London. This was something the participants talked about with much sadness.

> Well to be honest I used to go to the pub most days. Just have a few pints. I've missed that, and the social side with mates. I've not been in a pub for, well for nearly four year now, so. Yeah, well if I have a couple of cups of tea, a pint of beer and you're well over sort of thing. I just knocked it straight on the head. I don't see them anymore. Occasionally I bump into one of them in town, but that's about it. And the reason I was doing it, I mean my wife died when she were 48. So I'm living on me own. I just got into that routine to be honest. I did enjoy it. The days are long when … If I can get a couple of hours down there see some friends. It was ideal like (Alan, male age 70).

In adapting to his required fluid restrictions, Alan had made the decision not to socialise at the pub. While this change helped him to manage his fluid intake and, therefore, improve the efficiency of his dialysis treatment an additional problem was created, Alan no longer had a social life. Alan raised options to improve this situation, however, he hadn't felt able to act on any of them.

In an effort to replace the value they had lost the participants discussed a variety of attempts to find satisfaction elsewhere. Many of the participants had taken up alternative hobbies such as colouring, jigsaws, gaming including games on mobile phones such as Candy Crush and Mah-jong, reading, and watching more television. For many of the participants, these replacement activities were often sedentary and individual rather than social. Benjamin (male, age 19), the youngest participant, worked hard to maintain an active social life and had devised a solution to continue meet his friends

> I don't really see my mates Tuesday, Thursday and Saturday [dialysis days]. Well I see my mates on Saturday night, because all my mates go out then. Normally I go out of hospital, get the train to [location] from [dialysis centre location]; I'll leave my car somewhere, then get on the train and go and meet them.

While this strategy solved one problem, with it came another; retrieval of the car the next day and the added hassle this caused and the need for planning of such logistics removed the opportunity for spontaneity.

These findings mirror Roberti et al.'s (2018, p.18) review where it was found that dialysis patients 'arranged their daily activities between treatment sessions, adjusted the timing and intensity of their activities to their fatigue'. The findings presented here also illustrate the ongoing need for participants to engage in problem solving behaviour, to think of alternative solutions to things that were not a problem prior to ESKD and the dissatisfaction and additional problems that are often created as a consequence of this problem solving.

10. Discussion – biographical dialectics

The examples above show how the temporal demands and ongoing side effects of daytime, incentre haemodialysis (ICHD) impact and disrupt life courses. For the participants in this study, ESKD and daytime ICHD was undoubtedly biographically disruptive. The examples show the participants' use of various 'strategies' (Bury, 1991) to respond to this ongoing disruption. Since Bury's original conception, studies have since shown that disruption can be adapted to (biographical reconfiguration), can come and go (oscillation), can be gradual (biographical erosion) and can be assimilated into normal life (biographical flow). Here we argue that the disruption caused by ESKD and the choice to receive ICHD is continuous and changeable. Not only this, we also argue that continual and changing disruption requires ongoing problem solving to negotiate disruption.

Problem solving addressing the use of everyday objects and technologies has been explored in a number of studies addressing disability. Ginsburg and Rapp (2020) discuss the modification of household and supportive objects by people with disabilities to tailor them to individual needs. Similarly the 'Disability at Home' website (Mauldin, 2022), presents findings from Mauldin's ethnographic study of spousal caregivers, and shows a wide variety of 'homemade' home adaptations. Mauldin (2020) refers to this modification of objects in terms of 'disability-world making', where people with disabilities engage in creative and individual problem solving to adapt and modify objects to improve their use. To some extent the modification of everyday and supportive objects/technologies and 'disability world making' can be framed in terms of adaptation. Certainly, the photographs of modified objects shown on the Disability at Home website show a range of objects that have been adapted to meet individual needs. It is important to note that such adaptations and modifications are born out of frustration directly created by ableism.

For the participants in this study, changes were made as an attempt to cope with disruption to expected or anticipated biographical trajectories and to lessen the impact. While the participants attempted to return to their pre-dialysis identities, it was generally not the case that the changes participants made to deal with disruption resulted in adaption. To adapt to something implies that changes made result in suitable or equivalent satisfaction to that experienced previously. Nor did any participants discuss an end to disruption or a return to previous biographical assumptions/plans. As can be seen disruptions and the management strategies used varied depending on individual context and circumstances.

Other concepts have been developed to capture the differing impact and management of disruption but tend to position disruption and management in terms of a procedure where progress is made from disruption towards acceptance, adaption or return. Faircloth et al. (2004) propose biographical flow to explain this. Biographical flow describes how illness can be integrated into biographical trajectories without too much disruption. Faircloth et al. (2004, p.256) state, 'instead of disrupt-ing a biography, an illness such as stroke can be integrated with various social contingencies in constructing a biography that continues to flow across time and space'. Similarly, Reynolds (2002) proposes the concept of biographical reconstruction. Reconstruction is about 'regaining a satisfactory sense of self' (p129) by reconstructing lived experience to account for the challenges of chronic illness. In order to reflect the progress of chronic illness Saunders (2017), suggests the concept of recurrent biographical disruption whereby the experience of chronic illness is peppered with disruptive episodes; 'considering biographical disruption as recurrent means it can be seen both as a discrete event, but also as one which intimately links the past, present and future' (p.737). Similarly, both 'biographical oscillation' (Bell et al., 2016) and 'biographical erosion' capture the temporal nature of chronic illness and its long term impacts. 'Biographical oscillation' describes the ongoing movement between disruption and normal life (Bell et al., 2016). While 'biographical erosion' illustrates the gradual change and associated disruptions as chronic illness progresses and worsens over time.

These concepts capture some of the experiences of disruption and the consequent management strategies presented in our analysis. However, in the case of deeper ruptures such as employment status, childcare, living arrangements and sense of self, the changes shown here often resulted in feelings of frustration and dissatisfaction, creating further problems.

This recurrent pattern of *issue, problem, answer,* is known as a dialectics. The coming together of two things (generally opposites), in this case life before dialysis and life with dialysis, creates something new. In creating something new (the solution), other issues arise that also have to be considered and solved. These issues may not be immediate but may arise over time. This approach to dialectics originates in the philosophical work of Hegel. Writing in the early to mid-1800s, Hegel mapped the historical progression of philosophical thought and proposed its trajectory to be dialectical (Hegel, 2002).

While Hegel proposes a particular philosophical approach to understanding the world, it is not his philosophy that is the focus here, rather it is his dialectical logic for understanding motion and change that is drawn on to make sense of the ongoing problem solving reported by the study participants. Dialectical logic describes the development of things (thought, phenomena, experiences) through the acknowledgement and acceptance of difference and contradiction by focusing on its productive capacity.

Dialectical understanding begins at the level of the whole and studies the relationship within and between parts and totality (Cluley et al., 2021). For example, Hegel studied the development of philosophical thought by exploring its progress from beginning to end, considering each development in relation to ideas that came before and after (Roberts, 2013). For Hegel, philosophical thought developed as an imminent, processual unfolding of ideas consequent of contradiction and negation, that in turn produces further contradiction and negation (McKenna, 2011).

Hegel's dialectical method is characterised by the spiralling thesis, antithesis, synthesis triad (Hegel, 2002). Thesis and antithesis refer to the inherent contradiction within things. In relation to the study discussed here, life before ESKD and life with ESKD are an example of thesis and antithesis. The patients in this study could not have either without the other, they exist because of each other. This logic is fundamental to dialectics and represents the acknowledgement that contradiction is productive. Thesis and antithesis are directed against each other, they are opposites that exist in tension with each other but also because of each other. The coming together of thesis and antithesis over time produces a solution or 'synthesis', which in turn is a product of both and so necessarily includes elements of both thesis and antithesis (Fagerström and Bergbom, 2010).

It is important to note that synthesis is not a teleological destination, rather the triad of thesis, antithesis and synthesis is an ongoing, cyclical process that captures motion and progress. Synthesis is typically the beginning of another thesis-antithesis relationship, and so dialectical logic spirals on and on. Because synthesis is a product of thesis and antithesis the dialectical spiral remains ongoing. Hegel calls this process 'negation of negation', whereby tension between thesis and antithesis is sublated to a higher level (synthesis) which in turn creates its own oppositions (McKenna, 2011).

It is also important to note that the dualism, that is part of dialectical logic, is not binary – it is relational. Opposites depend on each other for existence and therefore contain each other. Hegel uses infinity to illustrate this relationship; infinity necessarily contains finity for existence (Hegel, 2002). It is also important to note that dualisms are not purely antagonistic they are in fact productive. Based on this, Fagerström and Bergbom (2010) describe dialectics as a 'landscape where dissimilarities can meet'. Helenius (1990) proposes dialectics as an approach rather than a method, where the aim is to trace motion and change across entire phenomena/thought. In the case of ESKD, the experience of health and illness is the landscape where dissimilarities and the tensions and solutions inherent within can meet. Here we draw on dialectical logic to make sense of the participants' experiences of disruption and their attempts to negotiate it.

For the participants who had given up their jobs or reduced their hours to accommodate the demands of daytime haemodialysis and the side effects of ESKD, while this change removed stress and allowed them to focus on their physical health, it also created new problems requiring resolution, such as financial insecurity, reduced social interaction and changes to identity. These additional tensions furthered the biographical disruption experienced by the participants. The loss of Junior's job as a butcher allowed him to dialyse in a regular pattern, however, Junior's unemployment greatly affected his sense of masculinity. Not only had Junior lost a job in a male dominated employment sector that is associated with strength and machismo, his significantly reduced income stripped him of his role as provider within his family, a role he personally associated with his male identity. At the time of participation, Junior hadn't found a solution to this tension but was striving to. Similarly, Sam also struggled with the changes unemployment and his need for dialysis had brought. As outlined, prior to his need for dialysis, Sam had worked as an outdoor security guard, much of which required physical exertion. Sam described how his family members had changed their opinion of him and compared this to his experiences at work to illustrate the frustration he felt.

For the participants who had moved in with family members, while this solved their need for additional support, it also created new issues to be solved such as the tension between Sam and his parents, the unknown future Sunil described, and the childcare issues reported by Marisol. In this way, the management of disruptions often produced additional disruptions to be further managed. Similarly, in adapting their social lives to account for their ESKD and need for dialysis, the participants were able to make replacements, however, many of these involved individual pursuits. While they passed the time, they often didn't provide the social interaction the participants were missing.

To capture this disruption, dissatisfaction and ongoing problem solving, we propose the term 'biographical dialectics'. Biographical dialectics has some parallels with other suggested concepts such as biographical flow, reconfiguration and oscillation. However, biographical dialectics operates on the basis that biographical disruption is fluid, relational and can create further disruption. Schultze et al. (2020) touch on the dialectic creation of disruption in their discussion of the disruptive effects of prostate cancer, describing their participants' navigation of 'a non-linear and individual process of dealing with a chaotic and liminal state, which goes beyond binary concepts of before and after the illness'. Similarly, Lubi (2019) acknowledges that disruption results from a clash between old and new identities. Lubi (2019) uses practice theory to show two parallel processes associated with the disruption caused by chronic illness; a desire to continue old practices and new illness-related practices of self-management.

Underpinning many of the alternatives to biographical disruption is the assertion that people with a chronic illness are motivated by what Llewellyn et al. (2014, p.50) describe as an 'underlying will to continuity'. Indeed, the desire to maintain pre-illness aspects of the self is thought to drive how people respond to and manage disruption (Becker, 1999, Bury, 1991). As with many of the other explorations of experiences of chronic illness, the participants in this study missed the freedoms of their previous lives and who this allowed them to be. Many of the participants were not happy with the lives they now found themselves living and attempted, through their ongoing problem solving, to achieve some form of reconfiguration or flow.

In contrast to previous conceptualisations of disruption such as biographical flow, reconfiguration and oscillation, and the use of alternative theories such as practice theory (Lubi, 2019) and status passage (Roberti et al., 2021) we propose that the management of disruption is not always teleological. Disruption is complicated and relational. Rather, we argue that adaptations are less procedural (end-point orientated) and more processual (continuous). In solving one problem through the use of a particular strategy, another problem arises that requires more problem solving and this can continue as illness and life progress. We propose that this process is dialectical in that the ongoing problem solving process is underpinned by clashes between opposites. The most obvious here, but not limited to, the person a patient with ESKD using dialysis was and expected to become versus the person they have become following diagnosis and choice to receive dialysis.

The ongoing disruption and continual problem solving reported by the participants in this study, moreover, did not result in regaining a satisfactory sense of self, as argued for in the case of biographical reconfiguration (Reynolds, 2002). Nor did it result in the assimilation of chronic illness into normal life as in the case of biographical continuation, normal illness or biographical flow. It was not the case either that the participants oscillated between episodes of disruption as is the case with biographical oscillation, rather the participants experienced ongoing disruption.

Our findings find more similarity with Larsson and Grassman's longitudinal study of chronic illness over 30 years and Mauldin's (2022) ethnographic study of spousal care givers. Larsson and Grassman (2012) found their participants 'repeatedly tried to adapt (normalise) at new levels of health and functioning, only to have to experience disruptions of the acquired new normality due to illness complications'. When discussing the modification of homes and household objects made by people with disabilities and their spousal carers, Mauldin (2022) highlights the tension between everyday homes and objects (generally not designed for people with disabilities) and providing healthcare at home, in relation to the disability expertise that is created from this tension. Biographical dialectics captures the continuous nature of disruption, the ongoing need to problem solve, and the creative motion that tension creates.

11. Limitations

The NightLife study is based in the UK, and therefore, the findings presented reflect healthcare provision in the UK where dialysis is free for all. Roberti et al. (2018, 2022) present tensions relevant to other models of healthcare provision and found that lack of insurance created not only extra but absolute stress.

It is important to note that this study focused only on individuals with ESKD in receipt of daytime ICHD. Some of the participants had experience of peritoneal dialysis (an alternative form of dialysis that uses the abdominal lining to filter the blood and can typically be carried out at home) and some had previously had both successful and unsuccessful kidney transplants. Some patients also had experience of nighttime ICHD. While these participants offered some talk about these treatment options, particularly discussing preferences, their experience of those options was not focused on in depth due to the focus (in this part of the study) being daytime ICHD. From this limited talk, however, it is likely that biographical disruption and problem solving is also a feature of the lives of people receiving alternative kidney replacement therapies, including transplant. Even, patients who had received successful transplants (typically the most desirable treatment option) in the past, talked about how this further still changed their biographical trajectory. None of the participants in this study had experienced home haemodialysis and it is likely again, that patients receiving dialysis at home will experience differing disruptions to those receiving ICHD.

In addition, our study did not focus on clinical reasons for ESKD and ICHD. ESKD can result from a range of conditions such as diabetes, polycystic kidney disease (PKD), and high blood pressure. Participants varied in their awareness of the factors that has led to their ESKD. In the case of diabetes and PKD, where ESKD is a consequence of progression, ESKD may be biographically anticipated (Cox* and Starzomski, 2004). Further research is recommended to explore the role of biographical dialectics among patients with conditions where the chance of ESKD may be anticipated and also those receiving other forms of kidney replacement therapy.

Regarding participation, the photovoice participants were typically younger than those selecting interview only. This method likely attracted younger participants due to the increasing use of images to convey stories among younger demographic groups, as illustrated in the popularity of visual social media platforms. The younger demographic also, likely reflects our request for participants to use their own smartphones to take photographs and the use of an instant messaging service to share photographs. Our study was conducted during the UK Government COVID-19 restrictions; personal smartphones and the instant messaging service were chosen to limit in-person interaction. This limited participation to those who owned a smart phone and were comfortable using them to take photographs. Other reasons for declining the photovoice option included a desire to avoid thinking about dialysis outside of the renal unit and an attitude of associating photographs with more positive experiences than their disrupted lived reality. However, while the demographic taking part in the photovoice work was younger, both the photovoice and the interviews reveal ongoing disruption and problem solving regardless of age.

12. Conclusion

Chronic illness is undoubtedly disruptive and people with chronic illness invariably have to engage in ongoing creative problem solving. For the participants in this study, ESKD and the need for haemodialysis created significant ruptures in expected/anticipated biographical trajectories, to the extent that a teleological end (return to previous ways of being or adaptation) was curtailed. Reflecting the findings of other studies addressing biographical disruption and chronic illness experiences, the participants strived for a return to previous ways of being or satisfactory adaptation to a 'new normal'. Indeed, their problem solving behaviour was ultimately motivated by this aim. Biographical dialectics captures the progressive motion towards this desire and illustrates the productive and creative nature of tension between current position (life with ESKD and use of dialysis) and desired end point (adaptation or return to previous way of being).

It must be remembered that dialectical logic is not teleological, it is progressive as was the participants' problem solving. It was not the case that solutions/synthesis ended the need to problem solve, rather, as demonstrated, from the solutions often emerged additional tensions and problems to be solved. In this way, biographical dialectics captures the ongoing need to problem solve caused by the disruptive nature of chronic illness. Based on the patients' stories presented here we propose 'biographical dialectics' as a sister term to be used alongside biographical disruption to further our understanding of how people with chronic illnesses manage the disruptions they face.

While our formulation of biographical dialectics is based on the experiences of people with ESKD in receipt of haemodialysis, we anticipate that biographical dialectics will be a useful concept for progressing the understanding of the lived experience of other chronic illnesses, especially those with significant treatment burden and/or progressive effects. Biographical dialectics is concept that could be used alongside studies to explore self-management, patient activation, burden of treatment and wider lived experience. It is now generally accepted that diagnosis of chronic illness is a disruptive life event; biographical dialectics is a concept that can be used to expand understanding of how people manage and live with their diagnosis and its consequent effects in order to improve treatment, care and support.

Data availability

Data will be made available on request.

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