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Managing disruption at a distance: Unequal experiences of people living with long-term conditions during the COVID-19 pandemic

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ARTICLE INFO

Keywords:

Biographical disruption
Long term conditions
Self-management
Qualitative research
COVID-19

ABSTRACT

The COVID-19 pandemic and ‘lockdown’ restrictions have affected people’s health and wellbeing globally. Those who are clinically vulnerable to COVID-19 mortality due to living with long term conditions (LTCs) are at greater risk of negative impacts on their health and wellbeing, and of disruption in management of their LTCs. This study explores how people with LTCs managed their health and wellbeing under social distancing restrictions and self-isolation during the first wave of the COVID-19 pandemic, and examines why some people were more able to manage than others. Interviews were conducted between May and July 2020 with people (n = 44) living in North East England, who had one or more LTCs and were recruited via a social prescribing intervention. Data were analysed using a social constructivist thematic analysis. We present our analysis of the possibilities afforded to people to manage the impacts of lockdown on their health and wellbeing. We find that while some people deployed a range of capitals and/or etched out ‘tactics’ to make life ‘habitable’, others experienced ‘zones of impossibility’ requiring that they rely on contingent events or formal support. Our analysis highlights inequalities amongst people with LTCs, particularly regarding access to and deployment of important resources for health and wellbeing under COVID-19 social distancing restrictions, including outdoor space or greenspace, exercise and social connection. The study is novel in showing the mechanisms for coping with a significant period of disruption in the life-course whilst highlighting that although resilience was common in people with LTCs, this was sometimes at detrimental costs to themselves.

1. Introduction

The threats to life and health posed by COVID-19 and the responses of ‘lockdown’ and social distancing have created unprecedented disruption to everyday life. However, we are not ‘all in it together’ (Sobande, 2020). COVID-19 is more likely to be experienced severely by older people and those with chronic and multiple health conditions (Huang et al., 2020; Wu and McGoogan, 2020). The increased risk of serious illness and death for older people and people with LTCs meant some were advised to take particularly stringent steps to ‘shield’ themselves from the virus. During the first wave of infections in the UK, when our study was conducted, large scale quantitative data showed increased loneliness, depression and anxiety in clinically vulnerable self-isolating older people (Steptoe and Steel, 2020). Moreover, people living in areas of socioeconomic deprivation are more likely to be living with chronic

ill-health, are more likely to contract COVID-19, and are more likely to become severely ill or die from infection (Bambra et al., 2020). The experiences and impacts of the ‘lockdown’ have also been experienced unequally across socioeconomic groups. For instance, recent UK survey data from April–May 2020 show people in lower socioeconomic groups were more likely to experience adversities relating to finances (including loss of employment and income reductions) and basic needs (including access to food and medications) (Wright et al., 2020) and less likely to access green space during periods of restrictions (Burnett et al., 2020). There is little substantive in-depth qualitative research with people living with long term physical or mental health conditions (Brown et al., 2021) during the COVID-19 pandemic, and to our knowledge, none that explores how people living with LTCs coped in the combined contexts of the threat of disease and extreme social restrictions, and socioeconomic (dis)advantage.

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<https://doi.org/10.1016/j.socscimed.2022.114963>

Received 25 October 2021; Received in revised form 21 February 2022; Accepted 4 April 2022

Available online 8 April 2022

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The dramatic changes to daily life wrought by the COVID-19 pandemic lockdown and social distancing restrictions can be considered a period of 'biographical disruption' in that normal life was put on hold, there was a "disruption of taken-for-granted assumptions and behaviours" and the future became uncertain for many (Bury, 1982:169). The notion of biographical disruption was first introduced in relation to chronic illness by Bury (1982) to describe how people with a newly-diagnosed LTC experienced bodily and relational disruptions and consequently re-examined plans and expectations for the future. However, we draw more on Johnson-Hanks' concept of the 'vital conjuncture', inspired by Bourdieu's term, 'conjuncture', which expresses the notion that "structures contingently combine to shape action in particular spaces of time" (Jeffrey, 2010:498), and 'vital', from demographic vital events such as marriage, migration or motherhood. Johnson-Hanks describes the 'vital conjuncture' as a "socially structured *zone of possibility* (our emphasis) that emerges around specific periods of potential transformation in a life or lives. It is a temporary configuration of possible change, a duration of uncertainty and potential" (Johnson-Hanks, 2002:871). A vital conjuncture is a duration where multiple possible futures come into play (Johnson-Hanks, 2016), and could include diagnosis of a LTC, chronic illness experience (Kingod and Grabowski, 2020), lived experiences of austerity and crisis (Hall, 2019) or as we suggest, the COVID-19 pandemic and associated restrictions on daily life.

Dominant discourses around choice, self-care and self-responsibility often divert attention away from the central role of resources, inequalities and poverty in management of LTCs (Marsland and Prince, 2012) and how public health problems can be understood and solved (Petersen and Lupton, 1996). For instance, Prince (2012) highlights how poverty shaped people's abilities to adhere to ART medicine regimes in Kisumu, Kenya, yet remained somewhat invisible within patient support centres that strived for "ideal clients" who were "responsible" for their self-management. Access to resources and abilities to accrue forms of capital (economic, cultural and social) affects the extent to which people are able to become "ideal clients" and thus manage LTCs in other contexts too.

For example, social prescribing interventions are considered an important resource for vulnerable people and a means to reduce health inequalities (NHS England, 2019). Mostly delivered in areas of high socio-economic deprivation (Wildman et al., 2019), social prescribing generally involves a non-medical link worker who helps people with LTCs achieve personalised goals by referring them into local authority or voluntary and community sector (VCS) activities and services (Calderón-Larrañaga et al., 2021; Husk et al., 2020; Kimberlee, 2015). There is however, little evidence that such interventions improve the health of populations experiencing high socio-economic deprivation, complex social problems and multi-morbidities (Mercer et al., 2019). Moreover, our ethnographic study with clients of a social prescribing intervention in Northern England argues that social prescribing may have limited effect in tackling the social and material factors that shape health inequalities (Gibson et al., 2021). This is because such interventions are built on the assumption that the accessibility of health practices is evenly distributed, when in fact, the ethnography showed that those with access to resources were better placed to take advantage of the opportunities provided by social prescribing as compared to those with limited capital who encountered the intervention from disadvantaged positions (Gibson et al., 2021). This, and other ethnographic work, shows how those living in disadvantaged and complex social circumstances often have to prioritise surviving in the present at the expense of investing in their future health (Warin et al., 2015).

Anthropological works on care practices surrounding type 2 diabetes (T2D) are useful in shedding light on how people manage challenges to health in the day-to-day, often involving others, including whole communities (Pollak, 2018; Guell, 2012; Seligman et al., 2015). Particularly pertinent is Guell's research which explores how Turkish Berliners negotiate self-care knowledge and use everyday 'tactics' to self-manage

and make their lives 'habitable' (Guell, 2012). A 'tactic' is the "inventive employment of possibilities within strategic circumstances" which "takes advantage of 'opportunities' and depends on them" (Highmore, 2002: 159). De Certeau's (1984) claim that many everyday practices, such as reading, talking, shopping, cooking and moving about, are tactical in nature helps to conceptualise how people innovatively manage their daily lives and health, especially, we argue, during a period of significant strategic constraints ('lockdown') featuring uniquely stringent and urgent health rules.

This study explored how people with LTCs, who were recipients of a social prescribing intervention, managed during the first COVID-19 lockdown period. The paper uses the concept of 'vital conjunctures' as a lens through which to examine how individuals with LTCs were (un) able to deploy resources or adopt 'tactics' to cope during a period of huge disruption and uncertainty about the future.

2. Methods

2.1. Context

This study was set in an ethnically diverse urban locality (including urban fringes) in North East England. The locality is one of the 20% most deprived Local Authorities in England with higher than national average rates of premature mortality from cancer, cardiovascular, respiratory and liver disease, and starkly unequal life expectancy between more and less affluent areas (Public Health England, 2019).

While participants were recipients of a social prescribing intervention, their engagement with the intervention varied significantly. All participants had had at least one conversation with a link worker since they had been referred into the intervention and some had extended engagement over more than two years. Some had been linked into health-related activities or VCS organisation, such as gym referrals, benefits and housing advice, and community classes. The social prescribing intervention was managed and delivered by VCS organisations and was part of a complex landscape of intersecting VCS services in the local area. Detailed description of the intervention and analysis of how the intervention was delivered and received during the pandemic are published elsewhere (Moffatt et al., 2019; Morris et al., 2022).

During the time of this study (May–July 2020) the UK population was living under changing government COVID-19 'lockdown' restrictions (Dunn et al., 2020). From March 2020, any face-to-face contact by social prescribing link workers ceased and remote services were offered in line with government guidance. The UK response to COVID-19 also included 2.2 million clinically extremely vulnerable people being advised to 'shield' in their homes for 12 weeks from 22nd March 2020, which included avoiding all in-person contact with others even in their own households (Department of Health and Social Care, 2020; Office for National Statistics, 2020).

2.2. Participants

This study recruited participants who were already part of an evaluation of the social prescribing intervention (Wildman et al., 2019; Moffatt et al., 2019). We invited 90 individuals who had previously completed a health-related quality of life (EQ-5D-5L) questionnaire to participate in a telephone interview about their experiences of the pandemic. Twenty-nine of these expressed an interest in the study and agreed to participate. Participants were sent an information sheet and consent form and given time to consider any questions. Informed consent was verbally audio recorded. We also conducted semi-structured interviews with people who were existing participants of the afore-mentioned client ethnography (Gibson et al., 2021). Fifteen of the 19 ethnography participants agreed to participate in a final semi-structured interview for the ethnography that focused on their experiences of the pandemic. Original recruitment procedures for the ethnography participants are published elsewhere (Gibson et al., 2021).

All names used in this paper are pseudonyms and any identifiable personal details have been omitted in quotes presented. Ethical approval for all interviews was gained from Durham University Ethics Committee.

2.3. Data collection

Data reported here were collected via 44 semi-structured interviews: 29 semi-structured interviews with participants who had previously completed the EQ-5D-5L questionnaire and 15 semi-structured interviews with participants who were part of the client ethnography. All interviews were conducted between 11th May and 13th July 2020. The 29 semi-structured interviews with the EQ-5D-5L questionnaire participants were conducted by experienced sociologists and anthropologists KG, SLM, SM, and TP using an interview guide which covered participants' and households' health and shielding status; COVID-19 symptoms; impact of COVID-19 on daily life, employment, health, and relationships; and support sought, provided or received. The 15 semi-structured interviews with the client ethnography participants were conducted by KG and included the topics described above. All interviews were audio recorded and lasted between 20 and 120 min with an average of 50 min.

2.4. Data analysis

Interviews were transcribed professionally and checked by the team for inaccuracies. The transcripts were read by all authors allowing for immersion, familiarity and conversation recall. Thematic analysis was then used to identify patterns in the data relevant to the research questions (Braun and Clarke, 2006). SLM and JMW annotated the transcripts and led the initial descriptive thematic data coding process, including checking independently coded transcripts. Nvivo 12 was used to manage the data. The descriptive coding framework was developed inductively by SLM and JMW to reduce the data and then used to create a descriptive thematic account. SLM conducted further data reduction to make sense of the data, which included the creation of narrative case summaries for each participant (Richie et al., 2003). The comparison across these summaries led to the formulation of latent or analytic themes relating to the research question. Authors met regularly to discuss the emerging themes and developed the final analysis iteratively. This thematic case approach enabled a tracing of people's experiences of the pandemic to their illness trajectories and social circumstances. We have chosen to use extended narratives in the findings section below because many of our participants had strong wishes to share their stories and because this presentation method enables clear and transparent showcasing of how experiences are embedded within the complexities and contexts of people's lives.

3. Findings

This section presents analysis of *how* people were managing to different degrees via three analytic themes: deploying social, digital and financial capital to self-manage; relying on tactics to make life 'habitable'; and experiencing 'zones of impossibility'. Each theme begins with a narrative, followed by further examples and analysis, and focuses on how and why people accessed or used such resources and 'tactics' to self-manage and cope, and what enabled and prevented coping.

3.1. Demographics and health status

Table 1 shows participants' (n = 44) sociodemographic characteristics. Most were aged over 50, over one third were retired and nearly two thirds were homeowners. Over half claimed some form of benefit, often health-related. Nearly one third were unemployed, often due to ill health, and nearly two thirds reported an annual household income of less than £20,000 (equivalent to \$27,400 or €22,800). All but six participants experienced multi-morbidity; most participants reported

Table 1
Participant demographics.

	N = 44 (%)
Gender	
Male	19 (43)
Female	25 (57)
Age	
40-49	6 (13.5)
50-59	11 (25)
60-69	17 (39)
70+	10 (21.5)
Ethnicity^a	
White British	38 (86)
Bangladeshi/Pakistani/Asian Punjabi	6 (14)
Income	
<10K	13 (29.5)
10-20K	14 (32)
21-30K	6 (13.5)
31-40K	3 (7)
>40K	4 (9)
Prefer not to say	4 (9)
Employment status	
Full-time (FT) employment	4 (9)
Part-time (PT) employment	8 (18)
Furloughed	2 (4.5)
Unemployed	13 (29.5)
Retired	17 (39)
Benefits claimed^b	
None	19 (43)
Attendance or carers allowance	5 (11)
Child tax credits/child benefit	2 (4.5)
DLA/PIP, ESA, LCW	12 (27)
Universal Credit	9 (20.5)
Household Structure	
Lives alone	12 (27)
Lives with partner	17 (39)
Lives with family <18 yrs	10 (22)
Lives with family >18 yrs	4 (9)
Multigenerational household	1 (2)
Housing Status	
Owned	26 (59)
Rental (Private or social housing)	17 (39)
Other	1 (2)
IMD Decile of home address	
1-2 (most deprived)	20 (43)
3-4	5 (11)
5-6	9 (20.5)
7-8	4 (9)
9-10 (least deprived)	6 (13.5)

^a The ethnic diversity of the sample is similar to the population of Newcastle-upon-Tyne, with 88% of the population being White British and Asian/British Asian ethnic groups comprising the majority of the minority ethnic groups (UK Census Data, 2011).

^b Attendance allowance is available for people of pension age or older who have a physical or mental disability severe enough that they need someone to help look after them; carers allowance is available for people who care for someone at least 35 h a week and that person gets certain benefits; child tax credit and child benefit is available to a person who is responsible for raising a child (up to age 16, or age 20 if that child is in full time education or training); PIP (Personal Independence Payment) is replacing DLA (Disability living allowance) and is for disabled people aged between 16 and pension age; ESA (Employment Support Allowance) is available for people who have a disability or health condition that affects how much they can work; Universal credit (UC) is available for people on a low income, out of work or unable to work; LCW is an additional element of UC for people who have limited capacity to work due to a health condition or disability.

having long-term conditions including various combinations of T2D, cardiovascular disease, respiratory conditions such as asthma or chronic obstructive pulmonary disease (COPD), anxiety or depression. A small number reported less common conditions, including multiple sclerosis and epilepsy. Nine participants reported receiving official advice to shield. Those shielding tended to live in more deprived areas and spanned all age groups. Whilst the relationship between the participants

and the social prescribing intervention is not the primary focus of this paper; it is important to point out that the participants had variable engagement with the intervention and contact with their link workers both before and during the pandemic. Some reported regular or irregular contact with their link workers during the pandemic, yet most had not had any contact, including some who said they did not recall a link worker, and others who said they had been 'signed off' previously.

In the following analysis qualitative data are linked to useful participant demographic information in the following way: [pseudonym name-age group-gender (F/M)- employment status-index of multiple deprivation (IMD) decile-household structure-number of conditions].

3.2. Deploying social, digital and financial capital to self-manage and cope

One way people managed was by drawing on a range of resources and forms of capital. A combination of multiple accessible resources and well-managed or less complex conditions meant that some people, often those in higher social positions (defined by IMD and level of education), including Graham below, continued to successfully self-manage their LTCs and remain physically and mentally well during restrictions.

Narrative 1: Graham

Graham is a "comfortably well-off" retired professional. He lives with a single condition, T2D, which he had managed well since diagnosis with the support of his wife: "*we've been doing the dietary thing together ... which has been a great help for us both*" and "*We've got some weights, hand-held weights ... we were doing them pre-lockdown anyway*". Since lockdown he was "*continuing to lose weight*" and did not report any issues with his condition.

Graham and his wife had support for errands from one of his adult children who lived locally and "volunteered" to collect prescriptions and do the "*big shop*" for them. Although his other adult child had "*kept away*" for 2 months, at the start of June they had all begun spending time together "*in the garden while two metres apart*".

Graham lived in a pleasant neighbourhood that enabled exercise and sociability. Graham and his wife were "*quite happy*" living in a "*nice area*" with "*nice friends, neighbours and what have you*" who were "*all keeping in contact with each other*" whilst "*maintaining the social distancing, standing at the end of drives*". He was also able to walk his dog outside on the "*loads of walkways*" and "*green fields*" in the area and "*have a chat with other dog walkers*". He said he had "*convivial chats*" with his link worker but had told them, "*don't bother getting a (gym) referral from the City Council*". He explained he was "*doing plenty of exercise*" by himself and preferred the referral to be used by someone with "*greater need*".

He explained how he had been actively engaging in reciprocity with neighbours who had recently moved in: "*I've been cutting their grass for them because they don't have a lawnmower, so I've been doing that for them and, obviously, they've reciprocated by providing us with some food and what have you*".

Graham owns his own home and said that activities within his house and garden kept him and his wife busy: "*We've got a nice home ... we've been pottering around in the house ... We've done some decorating. We've got a nice little bit of garden at the back, so we've been out, looking after the garden*".

When Graham retired, he took up photography. He takes the camera out with him on dog walks, but during the lockdown he was drawing on his digital literacy to adapt his hobby in the house to keep busy:

"I'm a member of a couple of Facebook groups in relation to photography, and they have weekly challenges for you to do things on lockdown. So

doing photography in and around the house, macro photography and things. It's like a little bit of a competition ... it gave me something to do."

Graham's technological competence had enabled him to adopt new ways of keeping in touch with friends:

... pre-lockdown, we [friendship group] had a WhatsApp group which we used to contact each other. We've always kept in regular contact with each other ... We've set up- Every Tuesday, we have a Zoom conference and put the world to rights ... So, obviously, with the Zoom thing, it was just a decision we made. "Oh, well, we'll embrace this new technology" ... it's not the same ... it can be a little bit sort of frustrating at times when you're not in each other's company ... but otherwise, everything's hunky-dory [good] really

(Graham-60-69-M-retired-IMD 9-lives with partner-1)

Graham's overall experience was positive although he, like many, looked forward to being physically close to people again. Graham said, "*you've just got to get on with it*", and as such had actively continued previous routines by drawing on resources he had at hand. He was one of many retired participants who had developed interests and activities close to or around their homes and consequently experienced relatively manageable disruptions from the lockdown. Many, like Graham, who appeared to be coping reasonably well during the lockdown tended to have few financial or other difficulties, or pain and significant struggles associated with their conditions.

The digital literacy that kept Graham socially connected was also adopted by other participants to good effect to produce new forms of sociality, often facilitating more frequent interaction, which made life under lockdown more manageable. In this way, digital connectivity acted as a form of cultural capital and, even in the absence of other forms of capital/accessible resources, became a valuable means by which to ensure social connections. For instance, Sarah who lived alone in an area of higher socio-economic deprivation, was able to deploy her digital cultural capital (or digital 'know-how') in order to maintain increased contact with her son and his partner since lockdown, albeit remotely:

My son comes online every day and talks, well, every evening. And he talks to me with his fiancée. So life for me is quite nice, actually, compared to some people (Sarah-60-69-F-retired-IMD 1-lives alone-3)

For others, digital connectivity enabled them to cope with other difficulties. For instance, Jerry could "*barely walk*" due to a deteriorating muscular disease and had no access to the specialist gym he previously used (*not a referral via social prescribing*) during the lockdown. His means of coping was telephoning friends and remote schooling his teenage granddaughter, which he was enjoying:

[I'm] teaching my granddaughter everything that my elder daughter wants me to teach her which is basically everything except art. Art is a difficult thing to teach over the phone but we do about four hours a day with lots of breaks ... she will be starting, what you call them GCSE ... come September. So she doesn't want to be behind ... I am keeping in close contact with elder daughter because I am still teaching my granddaughter through the system, I have to discuss tutoring her and where she is behind and which bits she deserves extra pocket money for and stuff like that.

For Jerry, who was educated to postgraduate level, access to digital resources became a means of maintaining his relationship with his granddaughter, which in turn helped him deal with the "frustration" of the pandemic's effect on his "*ability to interact directly with people*". It also shaped the effects of the 'vital conjuncture' of COVID-19 on his wider family, as the remote interactions between Jerry and his granddaughter became an opportunity for him to equip her with cultural capital/educational resources, thus minimising the disruptive effects of school closures on her education.

Having a local social network and living in a friendly neighbourhood was also a valuable resource people drew on and often acted as key

support throughout the pandemic. Martha explained how what many called ‘neighbourhood spirit’ was an important resource for feeling safe:

Well, there is always somebody if things were really bad that I could go just three doors away or next door and get help. So, that is quite reassuring. So, I have never felt vulnerable or really, really anxious because I am thinking, “Well, there is always somebody I could go to.” (Martha-70-75-F-retired-IMD-1-lives with partner-2)

Many others recalled developing stronger friendships with neighbours since the ‘lockdown’, including helping/being helped with errands. Nonetheless, many continued to grapple with the uncertainty of the pandemic: ‘I think it’s very difficult to imagine the future at the present time’ (Janet-70-75-F-retired-IMD-8-lives alone-1).

In this section, we see that lockdown could become a ‘zone of possibility’ (Johnson-Hanks, 2002), where people with access to resources were able to continue managing LTCs as they previously had done and/or cope with the restrictions on daily life, even developing valued new skills or building stronger relationships with family and friends. Within these zones of possibility possible futures remained relatively secure in the face of the unknown long-term impact of the pandemic at a time before vaccinations had been produced and were even reconfigured in potentially positive ways. Literatures suggests that the extent to which chronic illness produces a biographical disruption differs according to people’s prior experiences of adversity, their age and socioeconomic background in very inconsistent ways (Cluley et al., 2021). However, following Johnson-Hanks (2016), we argue that, in the case of the pandemic, access to resources shaped people’s experiences by influencing the extent to which the vital conjuncture could become a ‘zone of possibility’. As the example of Jerry suggests, those with the highest levels of education appeared better equipped to create new ‘zones of possibility’. Our findings echo O’Donnell’s (2020) findings from life history interviews with people with T2D, which showed those of higher socio-economic status (SES) were more able to deploy resources, including social support, to successfully self-manage their T2D. Similarly, Franklin et al. (2019) highlight that possibilities for self-management of LTCs are often shaped by individuals’ abilities to draw on forms of economic, social and cultural capital. This included buying gym memberships, engaging in recreational physical activities and mobilising social networks to assist with self-management. Crucially, we find that at the ‘vital conjuncture’ of the lockdown, resources which enabled the maintenance and, for some, the development of social connections, had a key impact on health and wellbeing and allowed people to continue to work implicitly towards a future; Graham’s new technical skills and Jerry’s contribution to his granddaughter’s education are valued partly because of their future value. Furthermore, and especially for those in more advantaged social positions, digital capital and local social capital were a prerequisite to fostering social connections which in turn allowed people to transcend the physical boundaries of lockdown.

3.3. Etching out ‘tactics’ to make life ‘habitable’

In the absence of resources, or if resources were limited, some people’s response to the ‘vital conjuncture’ of lockdown was to more explicitly etch out ‘tactics’. This allowed them to ‘use, manipulate, and divert’ (de Certeau, 1984:30) the negative effects of lockdown in order to make their lives ‘habitable’. That is, contrary to the people above, who created ‘zones of possibility’, these participants were using tactics that shaped their experience of the ‘vital conjuncture’. Those who particularly relied on ‘tactics’ were those living in less advantaged circumstances, or those experiencing more complex health issues or life circumstances. Some ‘bent rules’ to gain social support, engaged in forms of sociality (digital or local) and cared for others as part of caring for themselves. Others negotiated being outside and mobile in ways that felt safe and helped with managing their conditions and mental

wellbeing. For example, Brian, who was not digitally connected, had limited household space and health conditions that affected him on a day-to-day basis, used certain ‘tactics’ to make his life habitable:

Narrative 2: Brian

Brian is a retired manual worker who had two LTCs that caused breathing difficulties. He lives with his partner in a rented one-bedroom flat, which has a private outside area. He has a nearby allotment that he continued to enjoy through the pandemic, although he had to rely on friends to do most of the heavy work. He also explained that he is “surrounded by fields” so occasionally walks there. Brian said he thought his health had worsened over the last few years because he had focused on caring for his partner. Despite his worsening health conditions, Brian’s rhetoric during the pandemic was of ‘getting on with it’:

I don’t like to have to depend on anybody else ... I look at it this way, there are a load of people worse off than me. Let them [the social prescribing service] concentrate on them and I’ll just get away with it.

Brian noted that the local shop was doing deliveries but that he would often pop over there himself instead “because I like to get a little bit of exercise”, and he enjoyed seeing familiar people around the area. Brian did not have access to a car, so to retain his mobility and keep a check on his bank account (he did not use online banking) he travelled to the city centre by negotiating public transport in a way that minimised his risk of infection. He explained how he always caught a particular bus that never had anybody on it but stated, “I won’t catch it if it’s a [name of bus company] bus because I know there are a lot of people on there.”

Brian was not digitally connected, owning only an old laptop and TV, and was frustrated by the national track and trace service depending on a smartphone app. He explained he was generally not one for ringing people and preferred to “socialise in person”; however, throughout the lockdown he regularly called a family member who lived alone and was struggling. He and his partner also continued to cook for a neighbour who lived alone:

We always do him a Sunday lunch ... Yes, we did it before lockdown and just carried on doing it except now when he comes to the door you’ve got to get your arm out and he’s got his arm out, stretch for the bag.

He also explained how he had previously been referred via social prescribing to an exercise course for COPD at the hospital, which he took up once and then had maintained using an exercise DVD, albeit inconsistently:

So I just do the exercise in the house. I’ve got the DVD showing us [me] how to do them and what have you. Sometimes I can’t even be bothered doing that either. (Laughter)

(Brian-70-75-M-retired-IMD-5-lives with partner-2)

Brian was caring for others and his own wellbeing by maintaining some routines and being as mobile as he could. He, like others, continued to “get on with it” regardless of circumstances. Many participants said they were “keeping busy”, and some explained how caring for others, “keeps you going” because they were “concentrating” on someone or something else. Pollak (2018) notes how in a Native American community with a high prevalence of diabetes, care-of-others was often prioritised over care-of-self, and yet here care-of-others appeared to be important for some people’s own wellbeing.

Others who were managing under similarly difficult circumstances reported etching out their “own rules” due to care needs and their own or others’ wellbeing. For example, Rosalind explained how and why she negotiated seeing her local family members during the earliest part of lockdown by using private garden spaces:

They come and they sit out in the garden, and we sit in the house and talk through the back door. We have all kept our distances. That has kept my husband going ... Yes, they are saying you should not do that, but the end of the day, if you have got somebody who is just diagnosed with [progressive illness] - He wanted to see the family, so that is what we have been doing. Then I disinfect everything when they go. (Rosalind- 70-75-F-retired-IMD-2-lives with partner-3)

Rosalind was negotiating and balancing risks of COVID-19 infection and her husband's deteriorating condition. For others, this means of managing took the form of creating their own protective tactics (e.g. Jessica), or 'bending the rules' for necessary child care responsibilities (e.g. Kate):

The changes in messages recently ['stay alert'], we weren't too happy about that ... we've just stuck to what the original messages ['stay at home'] were, for now We had a discussion about it with the girls, and I think we almost felt that it was a time to be more aware than we were previously, because more people would be out and about. (Jessica-40-45-F-full-time employment- IMD-5-lives with family-4)

It's been quite hard. Predominantly, I suppose, because he [son] probably shouldn't have been going [to his grandparents' house] but I had no other option. (Kate-40-45-F-part-time employment-IMD-1-lives with child-1)

Kate explained that it was important she continue working, whereas Jessica, whose family had two incomes, decided her self-employed husband who worked in a person-facing role would cease work to ensure the safety of the nuclear family, all of whom had health conditions.

For others, learning to 'see' family via video calls was an attempt to make life habitable during traumatic loss of physical contact. For example, Amanda, who experienced great difficulties with multiple health issues and bereavement, attributed her worsening mental health to missing physical contact with nearby family:

Yeah I think WhatsApp [has] been really good for me ... so I can see people and I can ring them and talk to them whenever my girls [daughters] put me on it (Amanda-50-59-F-unemployed-IMD-5-lives alone-6)

This was the only tactic available to Amanda for coping with the distress of shielding and being isolated from her family. She also did not recall any contact with a link worker prior to or during the pandemic. The development of this tactic was relational: her daughters encouraged and set it up for her. Yet, Amanda continued to have a difficult experience living without the regular in-person family contact she was used to.

A reduction in movement and exercise was a concern for many in relation to their conditions. Some attempted to replace gym routines or create alternative and safe means of exercise. For instance, Martin explained how he felt worse without his regular gym classes (not linked to social prescribing) but creatively attempted to replace it:

I am struggling I sit on a little bench in the garage and I have got hand weights, which I swing about, just for my breathing, exercising on my chest and stuff like that ... You know, I used to go around the block but I was starting to see one or two people, so I thought, "Right, I'll just start to walk up and down the street a couple of times a day just to try ... " I seize up if I don't move. You have got to keep exercising. (Martin-70-75-M-retired-IMD-6-lives with partner-3)

Remaining mobile was also problematic for those without regular car access. Martha and Brian used largely empty buses to travel to town, whereas others who relied on buses were very frightened of using them. Eddie, who was living in poor housing, using food banks and experiencing difficulties with increased anxiety during the lockdown, explained the importance of his friend who drove them to "beautiful" places:

Just going out to the countryside and getting away from city life, you know, and these dodgy neighbours if you like ... Yes, just get out and enjoy the quietness. I really enjoy that kind of thing (Eddie-50-59-M-unemployed-IMD 1-lives alone-2)

For Eddie, tactically utilising his limited social network to make trips acted as an escape from his daily reality of living in poverty and helped him cope with day-to-day anxieties associated with having chronic conditions during the pandemic. The only other resource he could access was occasional food bank vouchers through the social prescribing intervention and the temporary increase of £20 (equivalent to €22 or \$27 USD) in the key state benefit for people of working age (Universal Credit) received during the pandemic:

It might not sound a lot but when you're on the Universal Credit thing it's a lot. It does help a bit, it affords you to put a bit more on the electric and gas and things, and a little bit extra food.

Drawing on Guell (2012:525), we suggest that during lockdown some people relied on tactics firstly to make COVID-19 restrictions "habitable to their lives" whilst managing and ensuring their own and others' safety and wellbeing, and secondly, to develop new or adapted ways to self-manage their LTCs under such restrictions. For many, the former involved finding ways to care for others, being mobile in ways that felt safe and enjoyable, and/or accessing in-person family support. For some, these 'tactics' were relational as actions were taken with family members or friends. Hall (2019) similarly explain how people experiencing effects of UK austerity drew on kinship and intergenerational ties during health crises. Following de Certeau, one could suggest that some people's 'tactics', rather than confronting and opposing the COVID-19 restrictions, sometimes took place in "blindspots" of gardens, allotments, or doorsteps in ways that did not hinder the rationale of the restrictions (Highmore, 2002:159). The Turkish Berliners who participated in Guell's study were shown to be creative in how they accessed self-care advice and translated it to fit with their everyday lives and familial relationships. Some of our participants, like Guell's (2012:526), managed their LTCs by adapting methods they previously used to self-manage their conditions (e.g. walking or exercising in the garage), whereas as we shall see, others struggled to do so.

3.4. Experiencing 'zones of impossibility'

A lack of access to resources and coping practices often combined with deprived social circumstances, difficult health issues and major disruptions in employment or daily life. This meant that some people struggled to self-manage their conditions and cope with living under social distancing restrictions. Those shielding and living alone or in deprived circumstances often experienced few or no possibilities to self-manage and cope. Attempts to etch out 'tactics' were often impossible or unsuccessful, and only contingent events occasionally helped. This sense of impossibility sometimes extended to people's potential or imagined futures. Take for example, Reena, who was shielding with multiple serious physical LTCs exacerbated by anxiety:

Narrative 3: Reena

Reena experienced huge disruptions to her daily life in terms of work and resources for managing her physical and mental health. She recalled having previously made dramatic improvements to her health and wellbeing following support and information about local activities from her link worker but said her "whole life" had now changed. She explained how shielding and the cessation of various formal activities she had joined led to severe social isolation:

I also used to go to the swimming baths for myself at least twice a week, and I used to go to the circuit class at my local gym. I also enjoyed the tai chi classes at the community centre. There was also the walking group ... I

was always in and out, in and out busy. From being cooped in after my heart attack and frightened to go out, I built up a life for myself, in and out all the time. Now I'm right back to square one again You just get forgotten, don't you? You just feel like you just disappear. That's how I feel. I've just disappeared. Even my employer, I've had one text in three months nearly asking me how I am.

Reena said she had seen one friend on her driveway twice in two months of shielding. She was unable to imagine any future or being able to return to her face-to-face frontline work and feared being forced into early retirement due to her health problems:

I can't see how it is going to get back to normal for me and my life, my job, my going out, my social, like going swimming or going to a class. I can't see how it will get better really ... I hope to get to visit my family ... I used to go on the train, but I don't know if that will happen.

Her poor mental health was worsened by a sense of vulnerability to COVID-19 mortality and her perception of a bleak employment future. This meant it was difficult for her to motivate herself to do her indoor hobbies:

It's really, really hard actually, to keep upbeat for me. Although I have so many hobbies ... that I could do ... But I'm finding it harder and harder to motivate myself. I think it's partly being on my own and partly not feeling it to do things, and the fear I have of going out ... You know, I just got over all of that and here we are again, frightened to go out again because there is something terrible out there.

Despite the major disruptions she experienced and a lack of access to multiple resources that others had, she considered others “worse off” than herself and said she was nervous about contacting a new link worker who she had not heard from since the pandemic started:

You've just got to put up with it I think, and get on with it. But occasionally I have thought, “Gosh. If I feel like this, I can't imagine when people” - It is awful. It's really hard But there are a lot worse off than me ... That's what I tell myself For me I hope this isn't a permanent thing.. (Reena-60-69-F-Part-time employed-IMD-2-lives alone-4-shielding advised).

Reena experienced a radical change in her present life and potential futures during the period of disruption and uncertainty associated with the pandemic. Reena lived alone and did not have children or any family locally, and many friends she knew through her employment were still working in frontline roles. Similarly, Morgan and Burholt (2020) show how older adults in Wales experienced loneliness as a disrupted sense of self. Some, like Reena, experienced an ongoing disconnect between their past and current selves (Morgan and Burholt, 2020). Reena's attempt to ‘get on with it’ appeared the only means available to her to cope. But imagining others in more desperate situations than herself may serve to render her, in her own eyes, illegitimate for formal support. The abrupt cessation of formal groups and gyms, access to which had often been facilitated through social prescribing, was damaging to Reena and several others who consequently found themselves “back to square one”.

Poor housing directly affected the ability of others to cope. For instance, Derrick, who had multiple worsening health issues, lived alone in a “tiny” one-bedroom flat in a “horrible” area, and was “bored” and “lonely”. Prior to lockdown he described how he would walk into town (using his walking stick) for exercise, meet friends and his partner, and go to shops, cafés and gigs. During the lockdown, aside from going to his 2-day per week front line job, he said:

I'm stuck on the 18th floor and I can't do anything, it's quite depressing, because all I can do is look out of the window. You can only watch so much telly, watch so many DVDs, read so many newspapers. But, like I say, what else can you do? I just comfort eat. That's all got to stop. It's going to have to stop actually, because I'll just make myself worse ... I say, just cope with it [loneliness, boredom, and health issues] and hopefully it

will pass ... I'll just take one day at a time, that's all you can do. (Derrick-60-69-PT-IMD 1-lives alone-4)

Derrick expressed desires for a “fresh start” and had asked the council to relocate him months previously but had “heard nothing back”. He was in contact with the social prescribing intervention but said “there's not much they can do” at the current time. He said he knew his new eating habits (often high sugar foods) would negatively affect his T2D, but the lack of control over his living arrangements, where he experienced frequent anti-social behaviour, a lack of support for errands, and social isolation from his partner who lived elsewhere, hindered positive practices. He appeared to be using ‘small pleasures’ (high sugar foods) to care for himself during hardship (Zivkovic et al., 2015) and his articulation of only being able to “take one day at a time” show the ‘short horizon’ (Warin et al., 2015) he was living in.

Financial challenges, fears of COVID-19 infection and digital illiteracy/inaccessibility also affected how some coped. For instance, Sadia lived in a multi-generational household with her children, received Universal Credit and experienced difficulties paying household bills. Her daughter, who translated in the interview, said that their family experienced reduced social connection with their community due to government restrictions and fears of the virus, which made their experience even worse:

Everybody is quarantined so we haven't really helped each other, we've been sticking to the guidelines ... She's scared to go out in case the coronavirus is still about. (Sadia-40-45-unemployed-IMD 2- lives with family-3)

The combination of a lack of resources and ‘tactics’ available to people like Reena, Derrick and Sadia created ‘zones of impossibility’ where “just coping” or “getting on with it” often led to deteriorating physical and mental health.

However, some experienced chance events or changed circumstances, which created time-spaces for possibilities. For example, Carol (40-49-F-unemployed-IMD-1-lives alone-4- shielding advised) explained a chance meeting with a neighbour led to less social isolation. Others had formal support, such as Gill, who had multiple complex health issues and severe depression in connection with a traumatic bereavement when her partner died during lockdown. Support offered by her social prescribing link worker over a course of several months became vital:

She [link worker] has given me so much encouragement and she tried to get me to see a positive side of things ... I don't want to be spending my days crying ... all I hope for is that I can get some normality coming back into my life (Gill- 60-69-F-unemployed-IMD1-lives alone-5- shielding advised)

For a person who was socially isolated, lacked access to resources and was not in a position to employ ‘tactics’, this formal support became central to her perceiving some form of potential future.

At the ‘vital juncture’ of lockdown, several people experienced ‘zones of impossibility’ in which ‘boundaries’ (the contexts in which people live) circumscribed expressions of agency, limiting the future-making element within the ‘vital juncture’ (Johnson-Hanks, 2002; Evans, 2002). The idea of ‘bounded agency’, described by Evans (2002), recognises that “agency is a socially situated process, shaped by the experiences of the past, the chances present in the current moment and the perceptions of possible futures” (Evans, 2002:262). For some of our participants, during the pandemic the ‘boundaries’ shrank, perceptions of the present and future became bleak, and people's abilities to exert agency and utilise ‘tactics’ was diminished. This was particularly so for those who were both shielding and living alone. For a few, chances, whether a positive regular contact with a link worker or new social support from a neighbour, led to an opportunity to regain some hope for the future. These contingent events highlight the precarious nature of some people's lives, and the value of formal and informal support during crises.

4. Conclusions

We have conceptualised the COVID-19 pandemic and associated lockdown measures as a ‘vital conjuncture’, albeit dilated in scale and time from the original concept (Johnson-Hanks, 2002, 2016). Johnson-Hanks (2016:7) reflects that “there is considerable variation in the types of people who find themselves confronting different kinds of structured zones of uncertainty”. Although most people found themselves in a period of uncertainty where futures were difficult to imagine and dependent on the spread of the virus, our analysis highlights divergent experiences and inequalities amongst people with LTCs. Those who had well-managed or less complex health conditions were also often in more advantaged social positions, able to deploy resources and forms of capital, and lived more stable lives. Those experiencing more difficult life circumstances or less advantaged social positions sometimes had worse health (which sometimes meant shielding) and were less able to deploy capital to cope with the lockdown. Whilst some etched out coping ‘tactics’ others, often those who experienced the compounding effects of shielding, social isolation, poor health status, and complex deprived circumstances, struggled to do so. For these people, priorities were often focused on getting through the present distress found in zones of *impossibility*, and as such any support offered to manage LTCs needs to be mindful of this.

We reveal how people with LTCs managed to cope during and immediately after the UK’s first national lockdown: by deploying social, financial and digital capital or by etching out ‘tactical engagements’ to make their lives habitable. For many, access to pleasant outdoor spaces (private or public) for physical activity or mobility, and social interaction (in-person and digital), were key for managing their health, well-being and daily lives. Many had private gardens which afforded daily movement and distanced sociability. Those who lived in flats or lacked accessible outdoor space struggled significantly. Many in disadvantaged urban areas across England live without access to greenspaces (Marmot et al., 2020). Moreover, being digitally literate or able to embrace online social connectivity was key for coping with life under lockdown.

(In)abilities to deploy resources and ‘tactics’ produced divergent experiences amongst our participants during the first phases of the COVID-19 pandemic. However, many, regardless of social position or circumstances, expressed the importance of ‘getting on with it’, a discourse of simultaneous collective resilience and self-responsibility. Those who experienced significant struggles often said others were “*worse off*” than themselves, and felt they had to “*get on with it*” and “*just cope*”. This suggests people are attempting resilience at detrimental costs to themselves as the collective resilience and self-responsibility rhetoric can act to delegitimise dependency on health and social services, including social prescribing, in a time of crisis (Peacock et al., 2014).

Our study was itself limited by social distancing restrictions; interviews took place via telephone, and as such we were unable to access the finer details of daily self-management afforded by participant observation and lengthy fieldwork. Our ‘snapshot’ of people’s experiences early in the pandemic featured a lockdown with pleasant weather. Subsequently the UK saw two further lockdowns and North East England experienced some of the highest rates of COVID-19 in the UK and saw prolonged stringent restrictions into 2021. Our participants who were ‘just coping’ in the short term likely experienced worse struggles with managing their health in the longer term.

This study focused on people with LTCs and their experiences of coping during the pandemic and the associated withdrawal of services, some of which had been delivered via social prescribing. Yet our findings have implications beyond this unprecedented time-period. They provide broader understandings of how people with chronic ill-health manage during periods of uncertainty and disruption to everyday life, and how this intersects with social position and (lack of) access to resources. Through drawing on experiences across the socioeconomic gradient, and highlighting inequalities, we contribute to knowledge

regarding how and why practices that aid coping during crises and self-management of LTCs, health and wellbeing are possible for some but not for others.

Credit author statement

Stephanie Morris: Writing – original draft, Formal analysis, Investigation, Data curation, Tessa M. Pollard: Writing – review & editing, Investigation, Funding acquisition, Methodology, Conceptualisation, Supervision, Suzanne Moffatt: Writing – review & editing, Investigation, Funding acquisition, Methodology, Conceptualisation, Supervision, Kate Gibson: Writing – review & editing, Investigation, Josephine M Wildman: Writing – review & editing, Formal analysis, Data curation.

Acknowledgements

We would like to thank the social prescribing intervention and the participants who generously contributed their time to this research. We also acknowledge the following study team members: Bethan Griffiths, John Wildman, Nicola O’Brien, and Allison Lawson who successfully recruited participants. This study is funded by the National Institute for Health Research (NIHR) Public Health Research Programme, Community Groups and Health Promotion (project reference 16/122/33). The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

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