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Journey mapping long COVID: agency and social support for long-hauling

Journey mapping long COVID: Agency and social support for long-hauling

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ABSTRACT

Long COVID, also known as Post COVID-19 condition, is defined by the WHO as the continuation or development of new symptoms three months after the initial SARS-CoV-2 infection, with these symptoms lasting for at least two months with no other explanation. Despite many studies examining the causes and mechanisms of this disease, fewer studies have sought to understand the experience of those suffering from long COVID, or "long-haulers," This study contributes to the understanding of long-haulers (N = 14) by examining the role of agency and social support in shaping their journeys with long COVID. Drawing on a combination of interviews, questionnaires, and video diaries over a three-month period, journey mapping was used to document the participants' experiences, including symptoms, coping strategies, and lifestyle changes. Analysis of these journey maps resulted in a framework with four clusters demonstrating the importance of social support and patient agency shaping participants' Long COVID trajectory; the study contributes valuable insights into the daily lives and challenges individuals face with long COVID, informing the development of targeted support programs.

1. Introduction

Long COVID refers to the continuation or development of new symptoms three months after the initial SARS-CoV-2 infection (WHO, 2022). A complex, heterogeneous, multi-system disease, Long COVID can be disabling and fatal (Altmann et al., 2023; Al-Aly et al., 2021; Davis et al., 2023), with some evidence of its connection to the viral persistence of SARS-CoV-2 (e.g. Chen et al., 2023). Research has identified long COVID as a patient-made condition (Callard and Perego, 2021) and the first illness created through patients finding one another on Twitter and other social media in 2020 (Callard and Perego, 2021; Turner et al., 2023). Patient activists, much like in the history of AIDS or multiple sclerosis and ME/CFS, have had a very influential role in constructing what those conditions are and can do (Callard and Perego, 2021). Interest in the condition on online platforms was rapid before reaching more formal clinical and policy channels and ultimately being formally recognised by the WHO. Despite the number of people

experiencing this "emerging illness" (Roth and Gadebusch-Bondio, 2022, p.3), the causes and mechanisms are not fully understood, and there is no clear treatment for it (Davis et al., 2023).

Notably, the literature has shown the need for further understanding of the experiences of those with long COVID, also known as "long-haulers" (Callard and Perego, 2021, p.1), as they can provide insight into the physical, psychological, and social challenges these individuals face (Saunders et al., 2023). In particular, recent literature on these experiences has highlighted the need to better understand how these experiences might shape the care and support needs of long-haulers, especially when it comes to better understanding the ways long-haulers manage their symptoms (Skilbeck et al., 2023)and the support they receive (Lüscher et al., 2023; Luo et al., 2023). By carefully mapping the journeys (Joseph et al., 2020) of individuals with long COVID (N = 14, which is appropriate for this sort of deep dive into individual experiential journeys), we seek to improve our understanding of the lived experiences of individuals with long COVID and highlight the

importance of agency and social support in shaping the lived experience of sufferers.

2. Related work

2.1. Experiences of long COVID

The rapidly evolving literature on Long COVID highlights the length and multi-systemic impact of Long COVID symptoms on patients (Al-Ally et al. et al., 2023; Davis et al., 2023; Loft et al., 2022). Fatigue, respiratory difficulties, and cognitive dysfunction have been the predominant symptoms reported by patients with long-term sequelae (Davis et al., 2023). According to Altmann et al. (2023), a significant percentage of survivors report persistent symptoms associated with weakness, general malaise, fatigue, impaired concentration, and breathlessness, respectively. Al-Aly et al. (2021) identify incident sequelae in the respiratory system, as well as several other sequelae that include nervous system and neurocognitive disorders, mental health disorders, metabolic disorders, cardiovascular disorders, gastrointestinal disorders, malaise, fatigue, musculoskeletal pain and anaemia. Davis et al. (2023) found that the display of pathologies often overlaps, exacerbating management challenges.

While several studies have described the experiences of people with long-term sequelae following COVID-19, most of them are primarily quantitative accounts of symptoms (Loft et al., 2022). Symptoms can endure for years, especially if someone has recently developed myalgic encephalomyelitis/chronic fatigue syndrome or dysautonomia, which are expected to last a lifetime (Cortes Rivera et al., 2019). A recent study has proposed the need for a clearer focus on understanding long COVID as an embodied condition with heterogeneous biological, psychological, and social factors that interplay through complex relationships (Saunders et al., 2023). However, proposed healthcare interventions that address this condition are often siloed and lack a holistic perspective that addresses the relationality among symptoms and coping strategies (Ladds et al., 2021).

Despite the growing number of studies focusing on the lived experiences of individuals with long COVID (Hossain et al., 2023), there is a need to better understand the ways these experiences are shaped by the way they respond to symptoms (Skilbeck et al., 2023) and the support they receive (Lüscher et al., 2023; Luo et al., 2023). Long-haulers have reported a combination of physical and psychological feelings and experiences that affected their long-term wellbeing, often describing how "loneliness and a sense of self-hatred" was further exacerbated by their perceptions of a social stigma around expressing such mental distress (Hossain et al., 2023). Patients and advocacy groups representing patients have noted a lack of prompt assistance and inadequate acknowledgement of long COVID. This can be partly attributed to the limited knowledge and evidence regarding long COVID and healthcare systems struggling to cope with overwhelming demands. This insufficient provision of support has resulted in diminished trust and frustration with healthcare services, prompting individuals with long COVID to explore alternative avenues for support and treatment (Brown et al., 2022). Emerging studies have underlined the need for multilevel interventions to provide pathways to strengthen health and engage patients and caregivers in making decisions and developing resources (Hossain et al., 2023). Interventions however need to be carefully considered. While in some situations exercise, diet, and mental health interventions might provide a pathway for better coping with the chronic disease or reducing some symptoms (Davis et al., 2023), these interventions alone do not lead to recovering from a disease as severe and complex as Long Covid. Therefore, more nuanced research is needed to understand better the relationship between the long COVID experience and patients' coping strategies so that potential pathways for support can be devised.

2.2. Patient agency and social support

In this study, we seek to contribute to understanding the experience of long haulers by focusing on two dimensions of experience that deserve more attention. The first is *patient agency,* which refers to the set of skills ailing individuals display to better manage their symptoms "across the spectrum of participation in care, ranging from active participation in medical encounters and decision-making to self-care skills for managing everyday health-related activities." (Dahlberg et al., 2023, p.3). As explored in health literature, patient agency is interconnected with our life choices, and individuals can interpret their situation, make deliberate choices, engage in coping strategies, and attach subjective meaning to their actions (Mortimer and Staff, 2022). Having agency in healthcare means that ailing individuals have a sense of control and ownership over their health and wellbeing.

Within the context of long COVID, people are investing substantial effort in making sense of unusual and unpredictable symptoms (Turner et al., 2023), which in some instances has been met with medical gaslighting (Russell et al., 2022), which are "situations in which physicians dismiss a patient's account of their symptoms as unserious, perfectly normal, perhaps psychosomatic manifestations of stress" (Barnes, 2023, p.653). This has led many long haulers to stress their journey with multiple doctors and the importance of "finding the right GP" (Kingstone et al., 2020, p.1). Increased agency has been indicated to support sufferers of chronic conditions to manage their symptoms better, make informed decisions about their treatment options, and advocate for their needs (Lacy, 2016).

Within the context of long COVID, patient agency has been understudied, although its relevance has been highlighted in recent literature, especially as it relates to self-resilience, coping strategies, seeking support, and involvement in advocacy and research (Baz et al., 2021). Patient agency can potentially help reduce anxiety and stress associated with long COVID, as patients feel empowered and have greater control over their situation. In a study by Rushforth et al. (2021, p.7), those with long COVID who exercised agency felt empowered as they constructed "a shared account of rejection by the health system and a powerful call for action to fix the broken story." Many of these patients turned to advocating online as a way of reforming social discourses on long COVID. Long haulers have reported turning to a vast range of self-management practices, over-the-counter medicines, remedies, supplements, other therapies, and dietary changes to manage relapsing and remitting symptoms (Skilbeck et al., 2023). Many long COVID sufferers have turned to social media platforms like Facebook to seek guidance and find others sharing their self-management experiences (Rushforth et al., 2021). Despite these initial considerations about patient agency, more agentic and patient-centred approaches have been called to empower long haulers (Ladds et al., 2021).

The second dimension, social support, has been defined as "social interactions or relationships that provide individuals with actual assistance or with a feeling of attachment to a person or a group that is perceived as caring or loving" (Hobfoll and Stokes, 1988, p.499). Such support can strengthen the emotional and psychological resources needed to manage the illness (Dwarswaard et al., 2016). Support can come in many forms, including emotional support, practical assistance, and access to community resources. Support also includes the availability of healthcare providers and online communities.

As one systematic review of Long COVID experiences reveals, "insufficient social support is an important obstacle to the prevention and control of the epidemic" (Zheng et al., 2022, p.2). For individuals with Long-COVID, family has been shown to play a crucial role in supporting those with long COVID, with family members becoming informal carers, supporting self-care activities, providing emotional support and understanding what long COVID is (Humphreys et al., 2021). For long haulers, emotional support has been related to higher well-being and less distress (Lüscher et al., 2023).

Meanwhile, Ladds et al. (2021) documented how patients have

sought support and information in social media groups and immediate networks to feel less lonely. Online support groups have become a popular way for patients to gain emotional support, engage in information sharing, and raise awareness. For long haulers, social media support groups offer a means of sharing health-related information and a sense of shared identity and belonging, enabling retrospection of experiences, developing narratives, and becoming 'communities of practice' (Ladds et al., 2021). If used appropriately, online peer support groups can benefit patient wellbeing beyond simply filling gaps in long COVID care. Mullard et al. (2023) highlighted the importance of balancing different forms of peer support for long COVID sufferers.

Despite the significance of social support in helping manage chronic diseases, less is known about the role of social support in the patient experience of those experiencing long COVID. By taking a more holistic approach to understanding their experiences (Loft et al., 2022), this paper has sought to help patients feel more empowered to help manage their health and engage social support (e.g. feel more empowered to ask for clinical treatment and medical help despite potential pushbacks such as stigma or lack of access to care). To do so, it engages with experience journey mapping, a powerful technique to better understand how the experience of long haulers unfolds during a certain period. In the following sections, we aimed to 1) map individual patient journeys to gain insights into the lived experiences of individuals with long COVID and 2) examine the role of patient agency and social support network in shaping these experiential journeys.

3. Methods

The data presented in this paper is part of the larger multidisciplinary research collaboration focused on patient education of long-COVID and self-care strategies prior to or adjunct to multidisciplinary assessment and management of those suffering with long COVID within the Australian context (Australian Institute of Health and Welfare, 2022). Since 2021, Australia has grappled with a shortage of multidisciplinary long COVID services, struggling to meet increasing demand. This situation has impacted both primary healthcare providers and individuals suffering from long COVID, as they increasingly faced a critical lack of necessary support and education. In addition, there is restricted accessibility to public health resources (Luo et al., 2023). As a result, the National Health and Medical Research Council (NHMRC) issued a targeted call in September 2023 for urgent research focusing on identifying people's experience of Long Covid, including the impact on their physical and mental health and social and emotional wellbeing (www.nhmrc.gov.au). By mapping the experiences of people with long COVID, we sought to gather information about this emerging condition. In doing so, we help address this call and create knowledge that can inform a subsequent design of programs to support individuals to return to health. The study itself consisted of (i) an initial interview and a set of quantitative questionnaires; (ii) a series of 21 1–2 min video diaries and daily quantitative measures over a 3-month duration; and (iii) a repeat of the initial questionnaires alongside a final journey map review session. As participants were recruited from community settings across Australia, all engagement was remote, with both interviews conducted online and transcribed, while the longitudinal data was managed via Qualtrics. Participants were provided a daily link (via email or text) to surveys to complete and for uploading videos over the three-month period. The resulting datasets informed the creation of responding journey maps, visualising the quantitative changes and qualitative coding (see 3.2 Journey Mapping). These were shared with participants in the exit interview for review and feedback, alongside a final survey. RMIT research ethics committee provided ethics approval (no. 25621), and all participants provided verbal informed consent prior to enrolment in the study.

3.1. Data collection & sampling

The study focused on those with a confirmed COVID-19 diagnosis via a RAT or PCR test and focused on recruiting participants from the community who self-identified as suffering from long COVID (persistent symptoms for 12 weeks after initial infection) (WHO, 2022). In the case of long COVID, participants were not patients of a hospital or GP but those experiencing long COVID. The research was advertised on the university's intranet, via social media (the Australian Long COVID peer support Facebook group), and professional networks of researchers through an advertising flyer between August and September 2022. The eligibility criteria included: 1) individuals over 18 years of age, 2) born and residing in Australia, 3) experiencing persistent symptoms lasting more than eight weeks following a COVID-19 infection, 4) those symptoms have affected their work and daily life, 5) having access to a smartphone. Nineteen participants were initially recruited from the recruitment pool; however, after attrition, 14 individuals completed the entry and exit interviews alongside the daily recording. Not all participants were actively receiving healthcare services for Long COVID, and none were directly recruited from a clinic or medical centre.

Each eligible participant was invited to a 1-h online interview before and after the 3-month tracking of their experiences. Prior to the entry interview, a screening survey, the EQ-5D-5L Quality of Life Scale (Balestroni and Bertolotti, 2012), was completed by participants, which helped inform the topics of relevance. The semi-structured interview aimed to collect comprehensive information, including background details, preferred languages, habits, the influence of long COVID symptoms on physical activities, overall physical health and mental wellbeing, and aspects of social support and digital literacy. Post-entry interviews, participants were asked to record a three-month video diary (one week per month) to enable us to better understand critical moments of their long COVID experience over the three months. Each day of a recording week, they were provided with two 'prompt' diary questions (1. How are you feeling today? 2. How did you cope with your long COVID Symptoms?) and responded in two 2-min videos, complemented by the short form of the International Physical Activity Questionnaire (Craig et al., 2003). These components served to understand the 'need, think, feel, do' aspects of their experience, some of their coping behaviours that might involve changes in exercise and diet, and their search for information and support.

This qualitative and quantitative dataset was used to generate participant 'Journey Maps' (McCarthy et al., 2016), which capture insights into a patient's activities, interactions, feelings, and motivations throughout their health and care journey and can be used to help initiate and develop health care services from a patient perspective (He et al., 2021). A final exit interview session of 1 h was used as an opportunity to seek feedback from participants on the journey maps, hone in on inflexion points, and fill gaps in understanding how their experience has evolved during the three months.

3.2. Journey mapping

Journey mapping is an emerging process of documenting a participant's experience over time and creating a visual representation of it (Joseph et al., 2020). This method has been used effectively to study chronic diseases, helping scholars identify pain points and understand participant perspectives while creating a shared understanding, highlighting gaps in care, and improving patient engagement (McCarthy et al., 2016). As an analytical methodology, it allows researchers to attain a deeper comprehension of experiences, as it incorporates an appreciation that individual experiences are dynamic and evolving and that they commonly go through stages (Simonse et al., 2019). Supporting researchers to understand what individuals are thinking, feeling, and doing at different stages of their 'journey', mapping can lead to the creation of interventions that take into consideration patient experiences across a broader period and set specific metrics to identify whether

the intervention is changing the individual's experience or not. Within this study, the journey maps provided a format that ascertains thematically the symptoms, issues, and coping strategies long-haulers employed while conveying our learnings to participants from their three months of self-tracking. Researchers paid particular attention to inflexion points, which are the places where the sign of the curvature changes direction (Hayles, 2017). In our case, the inflexion points were moments in which the participant's journey (symptoms, cognitive stress, sleep) displayed a visible change in their direction, as evidenced on the map.

The authors developed the maps through an iterative process, working together over the self-recording period to determine what metrics and visuals would be needed. Two compositions were developed to communicate the journeys and findings. The first, a detailed thematic breakdown of the three-month period, documented daily 'Experiences' and 'Coping' strategies into colour-coded annotations (Fig. 1 – C, D, E), supported by quantitative 'Problem Tracking' (Fig. 1 – A), and a weekly summary (Fig. 1 – B). Additional 'inflexion points' (see Fig. 1 – F), as important moments on the journey, were also indicated by visualising problem tracking. The second composition provided a wider representation of the study period, with the weekly metrics – pain, anxiety, and issues with mobility, self-care, and performing usual activities (Fig. 2 – G) visualised over a further level of analysis of the thematic elements (Fig. 2 – H). This interpretation of annotations served to explore what themes were prominent or repetitive over this period and reflect on the intersections between experiences and coping, drawing dotted lines to loosely connect cross–theme connections (Fig. 2 – I) and solid lines to connect theme-based ones (Fig. 2 – J).

The analysis consisted of looking at the points of inflexion in problem tracking (e.g., a participant feels improvements in her cognitive function after a period of no improvement) and examining the different elements of their experiences during this change, the coping strategies and lifestyle choices that might have supported the change, and the social support they were receiving during this change. By moving back and forth from problem to experience to coping strategy in an iterative approach (Miles et al., 2014), the researchers could make inferences about patterns in the data (e.g., better understanding the role of patient agency in the context of an inflexion point).

4. Findings

The matrix (Fig. 3) captures agency and social support as guiding forces that can enable or limit a long-hauler's empowerment over their long COVID journey. In this context, agency refers to their ability to navigate an uncertain environment and a complex medical landscape with a range of symptoms and no known cure. Participants in this study exhibit agency through actively seeking engagement with multiple doctors or healthcare professionals, some by undertaking self-care through healthy behaviours like pacing physical activity and controlling their dietary intake. Social support refers to the social resources, guidance, and assistance healthcare providers, online groups, families, and significant others provide to patients. These supporting resources explain the context and conditions within which long-haulers operate. We documented explicit examples of this support, such as a spouse helping a participant put on their clothing, a manager helping a participant reduce their workdays, and those with more frequent and accessible support day to day through friends and family. Considering the number of individuals recruited from a Facebook support group, online communities and resources formed a significant form of social support for many highly isolated individuals.

Drawing on health and sociological notions of agency and structure when exploring healthy lifestyles, these two dimensions demonstrate how life choices and opportunities play a critical role in the outcomes for individuals and their health. In articulating the relationship between the agency, these individuals demonstrate and the social support they find in their environment, the matrix in Fig. 3 explores potential experiential

clusters.

4.1. Clusters

To capture how empowerment forms and changes for long-haulers, we formed four clusters to fill each matrix quadrant (Fig. 3). To clarify what we consider low to high agency and support, we described each quadrant as a cluster (Table 1) and provided study examples. Table 2 provides the schema of each participant in relation to the Agency/Support matrix. Each Cluster is further explained in the following sections.

4.1.1. Cluster #A (high agency – high support)

An individual with high agency and social support may be someone who can take action and make decisions to manage their health condition and has a strong network of people willing and able to provide support. Within the study, we identified participants #5, #7, #8 and #13 as those who have demonstrated to be experiencing a combination of high agency and support. Participants in this cluster demonstrated the benefits of increased control, autonomy and having rich resources available, experiencing improvements in their health condition or simply maintaining quality of life.

Across these individuals, we documented an ability to gain health advice effectively. Participants #5, #7, and # 8 could create and maintain strong relationships with healthcare professionals, while participant #13 engaged and managed several GPs, herbalists, and therapists. In the case of participant #5, an experience of agency was in regaining her work-life balance, as "*part of the long COVID strategy I've been doing, after chatting with my doctor was taking Friday's off. So, I spoke to my manager about this. And that was sorted*". The benefit of her capacity to move to a four-day week was evident in her journey map and problem tracking (Fig. 4), where the first two months saw a peak in the severity of problems on the third day of the week, a flatter, less severe graph is documented in month three where the additional day of rest improved overall health. The ability to navigate the healthcare system and their condition was also evident with participants #8 and #13, with participant #8 co-ordinating a difficult interstate visit for an experimental cardiologist trial. In contrast, participant #13 managed to access medicinal cannabis, which was associated with improvements in his symptoms.

There was also a contrast between those with existing and those building social supports, with participants such as #5 and #13 linking into strong existing support networks. In contrast, others had to seek out online communities to enable the high level of support they sought. Participant #5 detailed how utilising their support networks was a key strategy, indicating how those around helped her "… *getting out sometimes when you're not feeling the best, reminding yourself that there's life outside of not feeling good is really important … chatting to friends, we do a lot of group chats and making the effort to see people sometimes you're not able to you just really feeling done*". We see in Fig. 4 that moving to a four-day workweek and spending more time with her children is accompanied by a decline in overall symptom severity. Similarly, participant #7 found her online chat group to be a key source of support and help, while participant #8's church group provided social connection via Zoom. Notably, over the mapped period, most participants saw notable improvements in symptoms due to the combination of their agency and support.

4.1.2. Cluster #B (low agency – high support network)

An individual with low agency and high social support may not be actively making decisions or taking actions to manage their health condition but has a strong network of people willing and able to provide support. This was evident for participants #2, #6, and #12, who described limited agency when seeking medical advice, relying instead on the support of their partners and local networks of family and work colleagues.
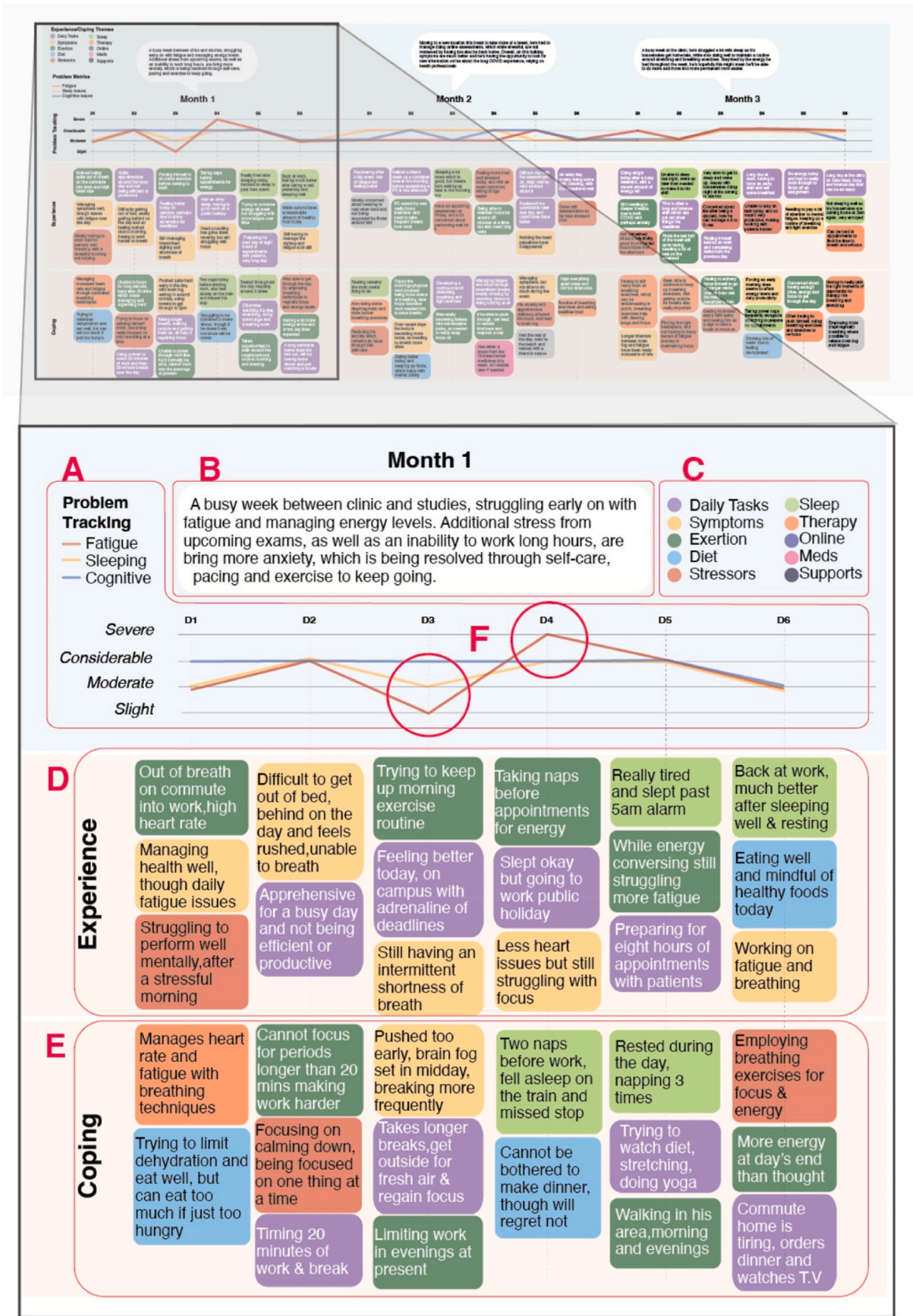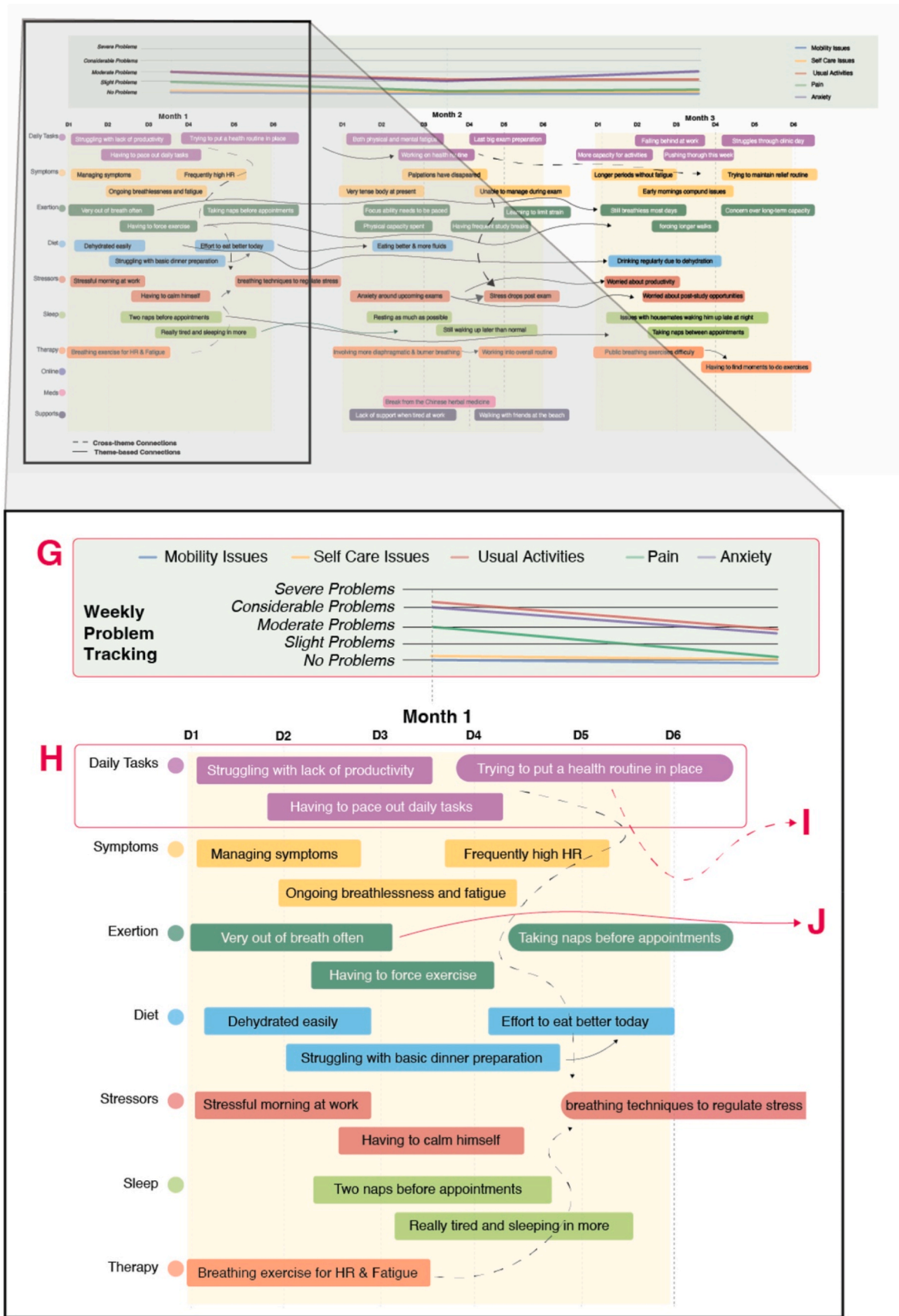
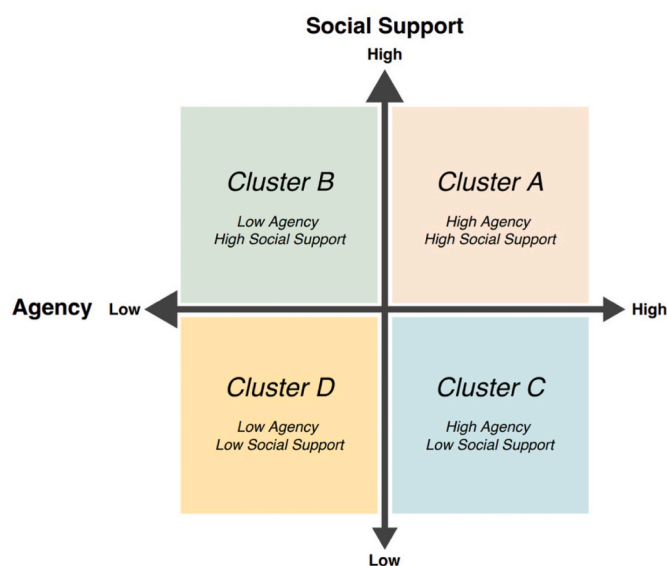**Fig. 1.** Daily tracking composition.

Fig. 2. Thematic connections composition.

Fig. 3. Patient agency & social support matrix.

Table 1
Cluster characteristics.

Cluster	Characteristic
Low Agency	An individual with low agency in long COVID has limited control or decision-making power over their own healthcare and health-related decisions. This could be due to a variety of factors, such as limited access to healthcare, lack of health literacy, socioeconomic status, or health conditions that impair their ability to make decisions about their health and wellbeing.
High Agency	An individual with high agency in a health condition has strong sense of control and decision-making power over their own healthcare and health-related decisions. They may reveal agency in their active involvement in and control of preventive health practices, healing processes, taking an active role in navigating the health system and online resources.
Low Support	An individual with low social support in long COVID is someone who lacks access to emotional, informational, and tangible support from family, friends, or other social networks while dealing with their disease. Social support can come in many forms, such as companionship, emotional support, instrumental support (e.g., help with transportation, chores), and informational support (e.g., advice, guidance).
High Support	An individual with high social support will often demonstrate a network of individuals, groups, and communities through which they engage and gain support. Informal or formal care, such as support groups to mental health, are also forms of social support services. Social Support provides physical, psychological, spiritual, emotional, and/or financial assistance.

Regarding their agency, participants faced physical limitations and financial burdens, such as participant #2, who described being "… *stuck in bed unable to move … things like Hydralyte and healthy food costs money, doctors costs money … that I don't have*". Like others in this cluster, her health-related situations were difficult to navigate, and she often felt "… *panicky and stressed and very concerned*". Participants would demonstrate small, temporary amounts of agency, such as participant #12, who sought to reduce a "*stressful day … listening to extremely calming music*". However, low levels of agency were also felt long-term in other aspects of life, with participant #12 noting that she felt "… *a bit stunted in regard to career choices at the moment … I just don't have the physical, emotional or even cognitive abilities*". Such reduced confidence and capability were a theme in this cluster, as #12 decided not to pursue a job opportunity due to her health when she would have previously.

Despite displaying lower agency, these participants could rely on a stronger social support network. In the case of participant #6, returning

Table 2
Participant characteristics.

No.	Age	Sex	Agency	Social Support	Biography
#1	47	M	High	Low	A middle-aged man living in the city, #1 continues to struggle with fatigue and lacks the level of social support and information he wants. Relying on online groups to gain new information though not an active member, he can take time off in the country to recuperate with weekly acupuncture.
#2	45	F	Low	High	Having worked as a teacher, #2 took extended time off work after fatigue and health conditions limited her mobility and energy, relying on her husband to act as her carergiver. Due to mixed responses from medical professionals, she has embraced a useful online community of long-haulers.
#3	33	M	High	Low	A young man struggling with fatigue, #3 works from home a few hours a day needing long periods of time off, and stressed by financial insecurity. Engaging multiple general practitioners (GPs) and a long COVID clinic, he has had disappointing results, relying on online forums for guidance.
#4	60	F	Low	Low	Only recently returned to work, #4 has been supporting her family with acute COVID-19, struggling to balance family and work. While friends have been supportive, she prioritises her husband's health and appointments, while struggling to keep active and eat well, with her pain and aches not being addressed by GP.
#5	42	F	High	High	A single mother, #5 works full-time while looking after her two daughters, making her fatigue an ongoing worry. In a good relationship with her GP, she manages her daily energy and symptoms effectively. Her manager supported fewer work days, and friends provide social and health-related support, with her overall wellbeing improving.
#6	55	F	Low	High	An older lady returning her workplace after getting acute COVID-19 there, #6 has struggled, with the passing of her mother, and limited her agency over her care. She relies on her colleagues support and a cardiopulmonary rehabilitation program.
#7	43	F	High	High	As a single mother returning to work, #7 has relied on an online community for support and guidance, including counselling sessions. Her workplace has been flexible with her migraines and fatigue, and has gained the medication she needs from her GP. She sees herself as an advocate for long COVID sufferers, as she works to improve her health.
#8	47	F	High	High	Living in the city centre, #8 has struggled with limited mobility and relies on an insurance scheme while unable to work. She has, however, been able to travel to take part in a cardiology trial interstate, and

(continued on next page)

Table 2 (*continued*)

No.	Age	Sex	Agency	Social Support	Biography
					socialises with her church group virtually. While she is susceptible to sickness, she has supported regular doctor visits.
#9	40	M	High	Low	Finalising his studies and working part-time, #9 struggles with fatigue, managing his energy levels and stress of upcoming exams. Unable to work longer hours places more financial stress on him, he copes through self-care such as diaphragmatic breathing, alongside advice through Medscape online, though rarely socialises.
#10	55	F	Low	Low	With a busy workload and severe chronic issues such as high blood pressure, fatigue, and brain fog, #10 relies on off-the-shelf pills and medication based on online recommendations. She is unable to get desired information, finds doctors unhelpful, and struggles to eat well and reaches out to friends.
#11	49	F	Low	Low	With severe symptoms and chronic fatigue, #11 documents how her illness has disabled her: alongside high cholesterol, brain fog and dysphonia, she is also wheelchair reliant, and bed bound most days. Having explored multiple avenues, such as brain and spine MRI and nerve testing, #11 has lost hope and isolated.
#12	46	F	Low	High	As a teacher returning to full time work, #12 struggles with pacing and daily tasks, seeking advice on Facebook groups and Google. With no support or guidance while her doctor is on leave, she focuses on diet while her husband cares for her. Worried about further infection, she limits socialising.
#13	49	M	High	High	A hospitality work returning after an infection, #13 manages constantly changing symptoms, from blocked sinuses to fatigue. He relies on advice from online forums and friends, actively requesting medication or further testing. He has also been able to source CBD oil to manage his sleeping and sinus issues, very successfully.
#14	27	F	Low	Low	Severely affected by long COVID, #14 works from home and has become extremely isolated and depressed by her chronic pain, insomnia, and evolving symptoms. Unable to get the support or help she wants, an inability to search for information or to see professionals, socialising is limited by her housebound routine.

to work and adjusting was well-supported by their colleagues and managers, yet this formed a fear of relying too heavily on others. For participant #2, her husband's immense support allowed her to reduce daily tasks and manage her energy. However, she also worried about asking her "*husband to prepare my meals for the day, the night before and pack them up. And in addition to all the cooking and cleaning and looking after me that he's doing, it feels like too much to ask*", suggesting the growing asymmetry in the relationship poses new concerns. Notably, while her workload reduced, the severity of her symptoms persisted across the three months (Fig. 5). We note that while social support improved, through her spouse caring and cooking for her grew, ongoing self-care and financial issues limited her agency. Berry and colleagues (2017) note that perceived asymmetry between patient autonomy and their ability to coordinate with their partner can lead to tensions and enforce barriers to their autonomy. Individuals in this cluster illustrated how their condition changed their relationships with those around them, often seeing high reliance and less ability to manage their health condition themselves.

4.1.3. Cluster #C (high agency – low support network)

An individual with high agency and low social support may be someone who can take action and make decisions to manage their health condition but lacks a strong network of people willing and able to provide support. Across participants #1, #3, and #9, we noted a high degree of self-confidence in their approach; however, when juxtaposed with the lack of support, these individuals displayed lower resilience than cluster #A individuals.

Participants #1 and #3 struggled with fatigue and actively pursued solutions and answers by scouring online forums for new ideas to share with their doctors. Both have moved through multiple doctors during their condition, with participant #1 positioning his doctors as a key source of information, often "*… contacting a doctor just to see if there's anything out there new*". Meanwhile, participant #3 had gone through several doctors to trial and tested various online medical advice, describing how he "*… had to work it out myself, work out which medication, (and) fired a few doctors to get it.*". Similarly, participant #9 demonstrated a high level of control over his health condition, relying less on medical professionals and more on his skillset as a therapist, employing breathing exercises while also exploring tools to manage his workload.

These participants did not demonstrate comprehensive social networks or support systems, with #1 and #9 busy with their occupations (#1 looking after children and partner working full-time, #9 working and studying to support a new career). Participant #3 noted how others had not contacted him, describing how "*most of my family haven't contacted me that much over the last five months. So I've really just been on my own 24/7, which does wear anyone down … I have seen friends occasionally, but I can't do anything*".

The benefit of exposure to more supportive environments was evident to participant #1, who noted how his time on the family farm saw "*… an increase in energy. I'm down at my folks' farm, and I've been doing a lot more walking, lifting, more physical things. And I seem to be Yeah, seem to have a bit more of a reservoir of energy*". As demonstrated in Fig. 6, while exercising control of his medicine management and routine, his spouse and children's reliance on him diminished his health, and his social support was further reduced by the isolation of moving into a new house and area. Reflecting how crucial in-person support was to improving wellbeing, rather than just having individuals around you, participant #3 and #9 documented how living in disruptive and isolating shared accommodation affected them. For example, participant #9 found he "*didn't have a good sleep because my housemates once again just came in at 2 a.m. So yeah, I was a little bit annoyed at that*".

These individuals with high agency and low support demonstrated skill in making decisions and taking action. However, all struggled with a combination of stress, anxiety, and despair that reduced their resilience over time. For example, participant #1 discussed how moving house has produced additional stress that was "*creating a bit of anxiety. I usually don't get anxiety so it's a bit unusual for me.*" Similarly, participant #9 also found his stress grow over this period, as he was managing his studies and a full caseload at work, while participant #3 relied on "*medication to keep my emotions in control right now*". Such experiences spoke to the increased stress and emotional toll of managing their symptoms and daily tasks, with a lack of support networks limiting their capacity to build resilience.
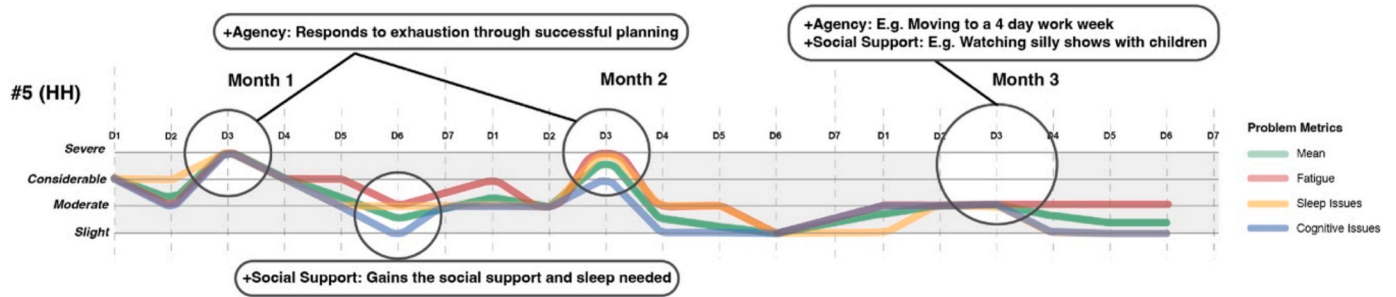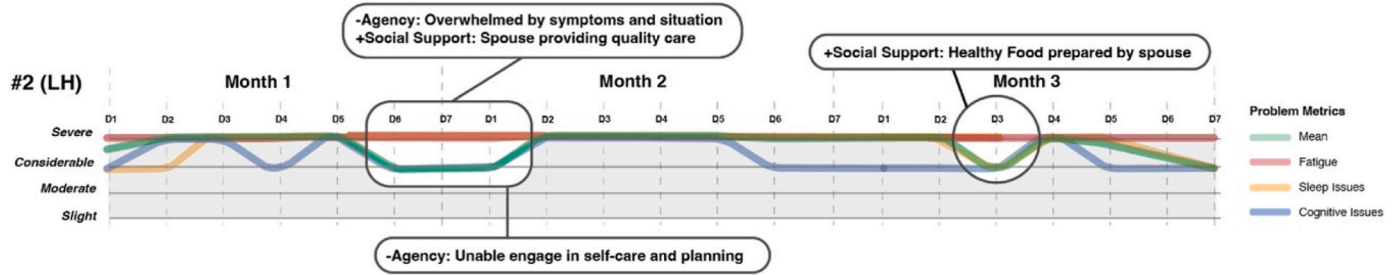
Fig. 4. Participant #5 daily tracking composition.

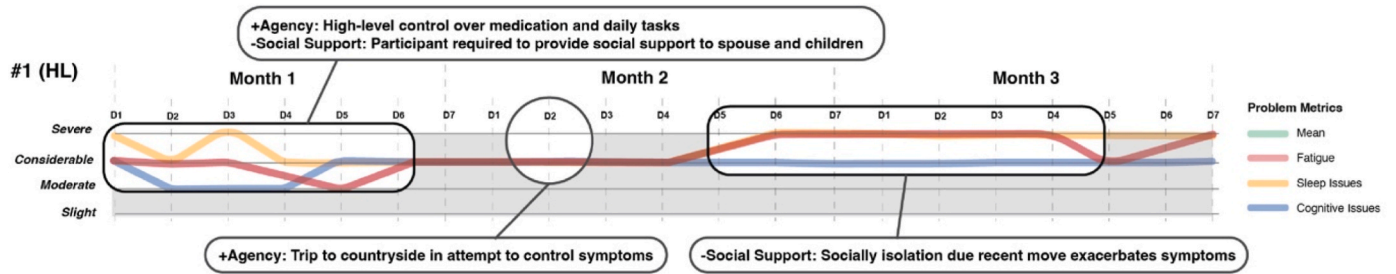**Fig. 5.** Participant #2 daily tracking composition.

Fig. 6. Participant #1 daily tracking composition.

4.1.4. Cluster #D (low agency – low support network)

An individual with low agency and low social support may have limited ability to take actions and make decisions to manage their health condition and also has a limited network of people willing and able to provide support. We documented how participants #4, #10, and #14 encountered a lack of options and limited knowledge and expertise from their general practitioners, which led many to further isolation over time.

In the case of participant #4, her agency was greatly reduced by prioritising others and her work over her own wellbeing. She noted how her workload was overwhelming, that she had "*so much work to do meetings, phone calls pulled in so many directions. No time to stop and think*

about anything else", illustrating how her lack of control limited what self-care she could do, such as going for walks or making a healthy lunch. Participant #10 also noted occupational barriers: " *... it's hard getting time off work to go and see a new doctor*". Both worried about employer perceptions and financial instability. Late in the study, participant #4 had to prioritise her partner's health over her own, unable to make timely decisions about her care, while managing his "*... anagram this Friday, a follow up to the mild heart attack ... so I'm trying to keep it all together at the moment for all of us, but it's not working for me*". We noted an increase in the severity of her condition during this period, over months 2 and 3 (Fig. 7), as spousal health issues disrupted her routine, and her wider family became even more reliant on her care to
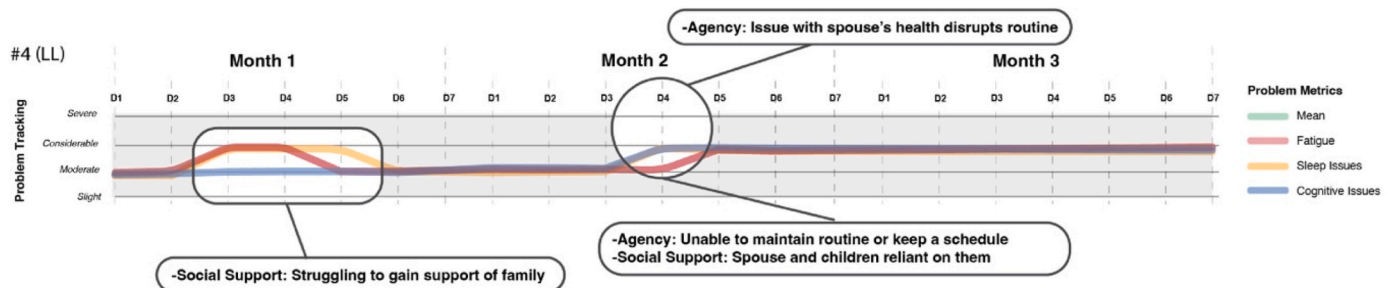

Fig. 7. Participant #4 daily tracking composition.

manage the situation, demonstrating how this combination of low agency and support impacted her ongoing care and wellbeing.

Concerning these participants' limited social support, it was evident that dwindling medical advice and pool of support affected those in this cluster. For example, participant #10 charted her difficulties in seeking out professionals that recognised her long-COVID symptoms, describing how she repeatedly faced scepticism. Even when she found strength to seek other healthcare professionals, she did not find them interested or empathetic. They were "just so dismissive". This lack of support further inhibited her agency in dealing with her symptoms and getting help. Participant #14 also found that the information she sought, that of medical information and expert opinions, was severely lacking and not improving due to "*an overall very, very poor understanding of the patho-physiology of the condition which is harming patients like me*". Like others in this cluster, she had reached the end of options available to her, and without future research, let alone potential interventions on the horizon, she had remained relatively static with her daily activities (resting frequently, staying inside) and problem-tracking (consistently severe).

Both participants #14 and #10 also lacked support from friends and family, with #10 actively limiting her interactions, having not "*reached out to my friends too much about it because I just feel like such a hypo-chondriac*". Also highlighting how symptoms shaped her relationship, participant #14 highlighted their toll on her personal relationships, that she does "*miss out on a lot of time with my partner this way as he gets up at a normal time in the morning and we are not able to spend that time together as I need to rest and sleep*". As a result, those in this cluster indicated larger worries about their long-term opportunities and quality of life, with participant #14 describing how "*long COVID has destroyed so many aspects of my life … and it's impossible to overstate the negative impact that it's had on all of us*". This reflected the very fixed nature of their wellbeing, remaining low and maintained there by a lack of options, support, or choices available to these individuals.

5. Discussion

This study enhances our understanding of long COVID in a group of long-haulers, focusing on how agency and social support influence their experiences. The analysis of these journey maps yielded a framework comprising four distinct clusters. These clusters highlight the significance of social support and patient agency, and their interaction, in influencing the experiential journey of long-haulers. The healthcare system can leverage patient agency and social insights by designing screening tools to rapidly assess the clusters long-haulers are in and develop tailored support programs and resources for each cluster, including patient education, self-care practices, and peer support groups. These resources would focus on leveraging agency and social support where they are high and addressing the specific challenges of low agency and social support, helping individuals transition to clusters with more agency and/or social support. For instance, high-support and high-agency participants were ready to perform an active role in their treatments and healthcare decisions, and they will use their support networks to help maintain new habits and routines. They might be suited to healthcare interventions that include the delivery of educational resources and coaching that helps them better understand key challenges of their condition and learn more about potential self-care practices and self-management tools (goal setting, action planning, and self-monitoring), as well as their risks and limitations. This could, for instance, and depending on the local context, take the form of self-assessment tools that, together with GP's orlientation, lead to a series of targeted online videos, explaining and demonstrating several coping strategies, exercise routines adequate to their condition, diet patterns, and mental health strategies that might be useful for this group.

This is consistent with expectations for managing chronic conditions (Dwarswaard et al., 2016) and more closely aligned with long COVID guidelines that seek to enable patients to be supported effectively and holistically in primary care (Greenhalgh et al., 2022). Such interventions could leverage their high level of social support by including family, friends, and work colleagues as both audience and subject matter of targeted educational videos, with information on how to support long haulers best. Programs can also include strategies on how individuals can make the most of peer support groups (Mullard et al., 2023) and online communities without creating additional risks to their condition (Russell et al., 2022). Indeed, some more active participants in the current study found they were empowered when the GPs were empathetic in their attempts to find ways to try coping practices safely that they learned about through online communities. However, consistent with guidelines for chronic diseases (Dwarswaard et al., 2016), patients should not independently handle self-management; they depend on healthcare professionals to guide them. A collaborative partnership between patients and professionals is essential to effectively combine and address support needs (Dwarswaard et al., 2016). Given the changing nature of these support requirements, it is vital to regularly evaluate what patients need and frequently assess patients' requirements.

In contrast, long-haulers in the low support and low agency cluster might need interventions that consider the limits on their autonomy and community-based resources. Such low agency means they are likely to have difficulty engaging in self-assessment, understanding their treatment options, advocating for themselves, navigating online solutions, or taking actions to manage their health. Responding interventions need to consider their fear or anxiety about healthcare (whether caused by low healthcare literacy or gaslighting), their level of health literacy, lack of access to information or resources, and low trust in healthcare providers. Their limited social support will make it challenging to manage daily tasks, adhere to a proposed intervention, gain assistance managing their symptoms, and access healthcare services. They can further exacerbate the risks of developing mental health issues such as anxiety and depression. Loft et al. (2022) found that many long COVID patients have a high degree of emotional stress, underscoring the need for psychoso-cial support or psychotherapy that enables long-haulers to develop personal and individualised coping strategies to deal with everyday emotional distress. Interventions might combine the delivery of educational materials with more targeted actions that address issues related to their social support and agency, such as peer support groups (Mullard et al., 2023) and group counselling to develop coping skills, improve self-esteem, and combat depression (Greenhalgh et al., 2022). They may also benefit from case management services to help them access community resources and treatments that can improve their overall experience of long COVID.

Our findings suggest that interventions for those in the high agency and low social support clusters should aim to improve social support levels while leveraging their level of agency. Unlike the low-agency participants, the ones in the high-agency cluster may be able to actively seek resources and follow prescribed instructions, especially when the roadmap to self-care, exercise, diet, and coping mechanisms are provided by the healthcare system. Thus, the emphasis should be on helping them find and monitoring their social support networks to help them adhere to these treatments. Healthcare providers can, for instance, refer patients to community resources, such as peer groups (Mullard et al., 2023), counselling services, and community organisations that provide social support for patients with specific conditions (Greenhalgh et al., 2022). Telehealth and remote support technologies can also connect patients with additional social support resources, such as virtual support groups and online communities, which is important to help overcome some of their mobility limitations. Being highly agentic, these long-haulers are likely to be able to take advantage of the resources provided and improve their level of social support, eventually moving to cluster A.

Finally, interventions in the low agency/high social support cluster should include the existing support network in the intervention program. For instance, educational resources can include information on ways in which the social support network can improve a long-haulers

journey. Participation in online communities might help mitigate issues usually exacerbated in low agency. Russell et al. (2022) found that individuals with long COVID often face challenging encounters when seeking acknowledgement and medical assistance from healthcare providers. Our research suggests that low agency is likely to increase these difficulties in navigating the system. However, consistent with this study, Russell et al. (2022) also found that their patient engagement in online communities plays a role in helping them navigate uncertainty. Support communities fulfil various purposes for individuals with chronic illnesses, such as exchanging knowledge, creating and affirming identity, providing mutual support and communication, advocating for themselves, and organising collective action (Kingod et al., 2017). So, participation in the right online communities might be a way to mitigate the effects of low agency. However, given their low agency, they might require tighter monitoring from healthcare professionals.

Overall, the study supports a person-centred approach that focuses care on the needs of individual, on the preferences and values that shape long-haulers' experience, and highlights the role of agency and social support in their journeys. One limitation is that there are significant variations in services and healthcare systems for long-haulers, and the availability of resources, waiting times, and other contextual factors can indeed impact the feasibility and effectiveness of proposed interventions (Hossain et al., 2023). Thus, it is important to allow for adaptability and flexibility in implementing proposed interventions (Ladds et al., 2021). With this in mind, the proposed clusters are well-positioned to guide healthcare practitioners in delivering supportive interventions that consider the lived experiences of patients with long COVID (Loft et al., 2022), ultimately improving their quality of life.

Credit author statement

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Data availability

The authors do not have permission to share data.

References

Altmann, D.M., Whettlock, E.M., Liu, S., et al., 2023. The immunology of long COVID. Nat. Rev. Immunol. 23, 618–634. https://doi.org/10.1038/s41577-023-00904-7.

Al-Aly, Z., Xie, Y., Bowe, B., 2021. High-dimensional characterization of post-acute sequelae of COVID-19. Nature 594, 259–264. https://doi.org/10.1038/s41586-021-03553-9.

Australian Institute of Health and Welfare, 2022. In: Long COVID in Australia – a Review of the Literature, Catalogue Number PHE 318. AIHW, Australian Government.

Balestroni, G., Bertolotti, G., 2012. EuroQol-5D (EQ-5D): an instrument for measuring quality of life". Monaldi Arch. Chest Dis. 78 (3) https://doi.org/10.4081/monaldi.2012.121.

Barnes, E., 2023. Trust, distrust, and 'medical gaslighting'. Phil. Q. 73 (3), 649–676. https://doi-org.ezproxy.is.ed.ac.uk/10.1093/pq/pqad035.

Baz, S., Chao, F., Carpentieri, J.D., Sheard, L., 2021. Understanding the Lived Experiences of Long Covid: A Rapid Literature Review. University College London, London. https://livrepository.liverpool.ac.uk/3169178/.

Callard, F., Perego, E., 2021. How and why patients made Long Covid. Soc. Sci. Med. 268, 113426 https://doi.org/10.1016/j.socscimed.2020.113426, 1982.

Chen, B., Julg, B., Mohandas, S., Bradfute, S.B., RECOVER Mechanistic Pathways Task Force, 2023. Viral persistence, reactivation, and mechanisms of long COVID. Elife 12, e86015. https://doi.org/10.7554/eLife.86015.

Cortes Rivera, M., Mastronardi, C., Silva-Aldana, C.T., Arcos-Burgos, M., Lidbury, B.A., 2019. Myalgic encephalomyelitis/chronic fatigue syndrome: a comprehensive review. Diagnostics 9 (3), 91. https://doi.org/10.3390/diagnostics9030091.

Craig, C.L., Marshall, A.L., Sjöström, M., Bauman, A.E., Booth, M.L., Ainsworth, B.E., Pratt, M., Ekelund, U., Yngve, A., Sallis, J.F., Oja, P., 2003. International physical activity questionnaire: 12-country reliability and validity. Med. Sci. Sports Exerc. 35 (8), 1381–1395. https://doi.org/10.1249/01.MSS.0000078924.61453.FB.

Dahlberg, M., Lek, M., Castillo, M.M., Bylund, A., Hasson, H., Riggare, S., Reinius, M., Wannheden, C., 2023. Objectives and outcomes of patient-driven innovations published in peer-reviewed journals: a qualitative analysis of publications included in a scoping review. BMJ Open 13 (6), e071363.

Davis, H.E., McCorkell, L., Vogel, J.M., Topol, E.J., 2023. Long COVID: major findings, mechanisms and recommendations. Nat. Rev. Microbiol. 21, 133–146. https://doi.org/10.1038/s41579-022-00846-2.

Dwarswaard, J., Bakker, E.J., van Staa, A., Boeije, H.R., 2016. Self-management support from the perspective of patients with a chronic condition: a thematic synthesis of qualitative studies. Health Expect. 19 (2), 194–208.

Greenhalgh, T., Sivan, M., Delaney, B., Evans, R., Milne, R., 2022. Long covid—an update for primary care. bmj 378.

Hayles, N.K., 2017. Unthought: the Power of the Cognitive Nonconscious. University of Chicago Press.

He, Q., Du, F., Simonse, L.W.L., 2021. A patient journey map to improve the home isolation experience of persons with mild COVID-19: design research for service touchpoints of artificial intelligence in eHealth [original paper]. JMIR Med Inform 9 (4), e23238. https://doi.org/10.2196/23238.

Hobfoll, S.E., Stokes, J.P., 1988. The process and mechanics of social support. In: Duck, S., Hay, D.F., Hobfoll, S.E., Ickes, W., Montgomery, B.M. (Eds.), Handbook of Personal Relationships: Theory, Research and Interventions. John Wiley & Sons, Hoboken, NJ, pp. 497–517.

Hossain, M.M., Das, J., Rahman, F., Nesa, F., Hossain, P., Islam, A.M.K., et al., 2023. Living with "Long Covid": a systematic review and meta-synthesis of qualitative evidence. PLoS One 18 (2), e0281884. https://doi.org/10.1371/journal.pone.028188.

Joseph, A.L., Kushniruk, A.W., Borycki, E.M., 2020. Patient journey mapping: current practices, challenges and future opportunities in healthcare. Knowledge Management & E-Learning 12 (4), 387–404.

Kingstone, T., Taylor, A.K., O'Donnell, C.A., Atherton, H., Blane, D.N., Chew-Graham, C. A., 2020. Finding the 'right' GP: a qualitative study of the experiences of people with long-COVID. BJGP open 4 (5). https://doi.org/10.3399/bjgpopen20X101143 bjgpopen20X101143.

Kingod, N., Cleal, B., Wahlberg, A., Husted, G.R., 2017. Online peer-to-peer communities in the daily lives of people with chronic illness: a qualitative systematic review. Qual. Health Res. 27 (1), 89–99.

Lacy, A., 2016. Chapter 2 - Patient Emotions and Patient Education Technology. Emotions, Technology, and Health. S. Y. Tettegah and Y. E. Garcia. Academic Press, San Diego, pp. 23–39.

Ladds, E., Rushforth, A., Wieringa, S., Taylor, S., Rayner, C., Husain, L., Greenhalgh, T., 2021. Developing services for Long Covid: lessons from a study of wounded healers. Clin. Med. 21 (1), 59–65. https://doi.org/10.7861/clinmed.2020-0962.

Loft, M.I., Foged, E.M., Koreska, M., 2022. An unexpected journey: the lived experiences of patients with long-term cognitive sequelae after recovering from COVID-19. Qual. Health Res. 32 (8–9), 1356–1369. https://doi.org/10.1177/10497323221099467.

Lüscher, J., Scholz, U., Bierbauer, W., 2023. Social support, distress and well-being in individuals experiencing Long-COVID: a cross-sectional survey study. BMJ Open. https://doi.org/10.1136/bmjopen-2022-067166.

Luo, S., Zheng, Z., Bird, S.R., Plebanski, M., Figueiredo, B., Jessup, R., Stelmach, W., Robinson, J.A., Xenos, S., Olasoji, M., Wan, D.W.L., Sheahan, J., Itsiopoulos, C., 2023. An overview of long COVID support services in Australia and international clinical guidelines, with a proposed care model in a global context. Publ. Health Rev. 44, 1606084 https://doi.org/10.3389/phrs.2023.1606084.

McCarthy, S., O'Raghallaigh, P., Woodworth, S., Lin Lim, Y., Kenny, L.C., Adam, F., 2016. An integrated patient journey mapping tool for embedding quality in healthcare service reform. J. Decis. Syst. 25 (Suppl. 1), 354–368. https://doi.org/10.1080/12460125.2016.1187394.

Miles, M.B., Huberman, A.M., Saldana, J., 2014. Qualitative Data Analysis: A Methods Sourcebook. Sage, London.

Mortimer, J.T., Staff, J., 2022. Agency and subjective health from early adulthood to mid-life: evidence from the prospective Youth Development Study. Discov Soc Sci Health 2 (2). https://doi.org/10.1007/s44155-022-00006-0.

Mullard, J.C., Kawalek, J., Parkin, A., Rayner, C., Mir, G., Sivan, M., Greenhalgh, T., 2023. Towards Evidence-Based and Inclusive Models of Peer Support for Long Covid: A Hermeneutic Systematic Review. Social Science & Medicine, 115669.

Roth, P.H., Gadebusch-Bondio, M., 2022. The contested meaning of "long COVID"–Patients, doctors, and the politics of subjective evidence. Soc. Sci. Med. 292, 114619.

Rushforth, A., Ladds, E., Wieringa, S., Taylor, S., Husain, L., Greenhalgh, T., 2021. Long Covid - the illness narratives. Soc. Sci. Med. 286, 114326 https://doi.org/10.1016/j.socscimed.2021.114326, 1982.

Russell, D., Spence, N.J., Chase, J.D., Schwartz, T., Tumminello, C.M., Bouldin, E., 2022. Support amid uncertainty: long Covid illness experiences and the role of online communities. SSM. Qualitative research in health 2, 100177. https://doi.org/10.1016/j.ssmqr.2022.100177.

Saunders, C., Sperling, S., Bendstrup, E., 2023. A new paradigm is needed to explain Long Covid. The Lancet. Respir. Med. 11 (2), e12–e13. https://doi.org/10.1016/S2213-2600(22)00501-X.

Skilbeck, L., Spanton, C., Paton, M., 2023. Patients' lived experience and reflections on Long Covid: an interpretive phenomenological analysis within an integrated adult primary care psychology NHS service. Journal of patient-reported outcomes 7 (1), 30. https://doi.org/10.1186/s41687-023-00570-2.

Simonse, L., Albayrak, A., Starre, S., 2019. Patient journey method for integrated service design. Design for Health 3 (1), 82–97. https://doi.org/10.1080/24735132.2019.1582741.

Turner, M., Beckwith, H., Spratt, T., Vallejos, E.P., Coughlan, B., 2023. The #longcovid revolution: a reflexive thematic analysis. Soc. Sci. Med. 333, 116130 https://doi.org/10.1016/j.socscimed.2023.116130, 1982.

WHO, 2022. Post COVID-19 Condition (Long Covid). https://www.who.int/europe/news-room/fact-sheets/item/post-covid-19-condition.

Zheng, X., Qian, M., Ye, X., Zhang, M., Zhan, C., Li, H., Luo, T., 2022. Implications for long COVID: a systematic review and meta-aggregation of experience of patients diagnosed with COVID-19. J. Clin. Nurs. https://doi.org/10.1111/jocn.16537, 10.1111/jocn.16537. Advance online publication.