The use of metaphors by service users with diverse long-term conditions: a secondary qualitative data analysis

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ABSTRACT

Long-term conditions and accompanied co-morbidities now affect about a quarter of the UK population. Enabling patients and caregivers to communicate their experience of illness in their own words is vital to developing a shared understanding of the condition and its impact on patients' and caregivers' lives and in delivering person-centred care. Studies of patient language show how metaphors provide insight into the physical and emotional world of the patient, but such studies are often limited by their focus on a single illness. The authors of this study undertook a secondary qualitative data analysis of 25 interviews, comparing the metaphors used by patients and parents of patients with five long-term conditions. Analysis shows how similar metaphors can be used in empowering and disempowering ways as patients strive to accept illness in their daily lives and how metaphor use depends on the manifestation, diagnosis, and treatment of individual conditions. The study concludes with implications for how metaphorical expressions can be attended to by healthcare professionals as part of shared care planning.

Introduction

Long-term conditions (LTCs) can broadly be defined as illnesses that cannot be cured and which may require pharmaceutical treatment and/or therapies to manage their symptoms and underlying disease processes including co-morbidities (co-occurring conditions) and multimorbidities. Lifelong conditions vary in nature and include physical non-communicable diseases such as diabetes, inflammatory arthritis, mental health conditions such as dementia, and certain infectious diseases, for example, HIV. It is estimated that 15 million people in England—a quarter of the population—live with a long-term condition (Nuffield Trust, 2021) and 14.2 million people—one in four adults—are facing multimorbidity, i.e., the presence of more than two long-term conditions (Stafford et al., 2018). Healthcare for those with lifelong conditions accounts for a considerable cost to the National Health Service (NHS) amounting to 50% of general practitioners' appointments, 70% of inpatient bed days (Coulter et al., 2013), and 70% of healthcare spending (Nuffield Trust, 2021).

Against this background of how lifelong conditions impact healthcare systems, each of the illnesses included in this study (dementia, myositis, mesothelioma, neonatal surgery, and fibromyalgia) can manifest themselves in different ways. For example, dementia represents a significant burden for the aging UK population and health services. In 2019, 850,000 people in the UK were living with dementia (approximately one in every 14 adults over 65 years of age); this is expected to increase to 1,500,000 by 2040 (Wittenberg et al., 2019). Similarly, there is an increased prevalence of musculoskeletal problems in the aging UK population, and many are associated with difficult symptoms among which pain is commonly reported. Indeed, estimates are as high as between one third and one half of the UK population living with chronic pain—approximately 28 million adults (Fayaz et al., 2016). While some conditions associated with chronic pain have a clear aetiology, other debilitating conditions such as fibromyalgia (characterized by pain and profound fatigue) or idiopathic inflammatory myopathy (associated with extreme fatigue and muscle weakness) have no known cause (Gazeley & Cronin, 2011).

Furthermore, more children and their families are living with the consequences of LTCs, including unpredictable trajectories and outcomes. Children who undergo early and complex surgery—for example, for exomphalos (an abdominal wall defect in which a child's abdomen does not develop fully while they are in the womb), experience such needs. Many children with LTCs have ongoing gastrointestinal problems, such as stoma care needs, neurodevelopmental needs, and other problems such as restricted mobility (Page et al., 2020). Empathetic and effective communication between patients with LTCs and healthcare professionals have, therefore, become an essential part of healthcare and staff education across their curricula.

Metaphors of illness and long-term conditions

Metaphorical and figurative language perform vital communicative functions by giving patients and caregivers tools to communicate their experiences (Lakoff & Johnson, 1980) and are often featured among narratives about patients' daily lives, including LTC management (Cameron, 2003; Masukume & Zumla, 2012; Pena & Andrade-Filho, 2010).

Specifically, metaphors serve to communicate a correspondence between two phenomena as a verbal shorthand, particularly when conveying something diffuse and abstract (Alvesson & Skoeldberg, 2000; Lakoff & Johnson, 1980), for example, to convey and analyze feelings and emotions (Lanceley & Clark, 2013) and to describe the abstract nature of pain and other symptom experiences over time (Charmaz, 1993).

Lakoff and Johnson identify that "the essence of metaphor is understanding and experiencing one kind of thing in terms of another" (1980, p.5). Metaphors permit and enable the expression of fears, conflicts, and anxieties, where overt acknowledgment may be too confronting. Therefore, studying and being aware of metaphor in how patients share illness experiences can be beneficial to understanding how patients make sense of illness and negotiate new senses of self in response to illness and medical care (Charmaz, 1983). The use of metaphors in relation to cancer, death, dying, and bereavement, for instance, is well studied (Southall, 2013), demonstrating how metaphors involve reflection on the nature of personhood (Charmaz, 1993), the natural world, and depictions of death "as a drift into sleep" (Southall, 2013, p.310).

In cancer research, particular attention has been paid to *military* and *journey* metaphors frequently described in relation to the experience of having cancer (Lanceley & Clark, 2013; Semino et al., 2018; Sontag, 1978). Within this literature, there have been calls for the abandonment of *military* or *war* metaphors because of potentially negative implications for cancer patients (Miller, 2010), as well as for other types of illness, for example, Alzheimer's disease (George et al., 2016). While the prevalence of *war/military* and *journey* metaphors in patient data attest to their importance for conceptualizing and expressing experiences of illness, linguistic analysis raises issues about how we can accurately and reliably categorize metaphors from a practice perspective.

For instance, not all metaphors that construct the illness (or other aspects of patient experience) as an opponent are best captured by the military metaphor. Semino et al., 2018 suggest *violence* as a more appropriate schematic concept. Another finding suggests that while such metaphors may be unhelpful and possibly harmful for some people, for others, they may be motivating and empowering (Reisfield & Wilson, 2004; Semino et al., 2017). Demjén & Semino (2016, p.395), for instance, write that "Violence metaphors are not always negative and Journey ones are not always a better alternative."

It follows that systematic linguistic inquiry is required to define how metaphorical language is shaped by the individual patient and what this tells us about their relationship with their illness (Semino et al., 2018; Skelton et al., 2002). In this study, by adopting a discourse-based approach to metaphor identification (Cameron et al., 2009), we intend to capture metaphoric forms and examine how they were used by patients in the context of interviews. This approach allowed us to draw inferences about what the metaphors expressed, for example, negative or positive emotion, and their implications for the patient, for instance, examining if the metaphor was potentially empowering or disempowering.

Our work contributes to the existing body of research in two ways. First, by exploring contexts of use across a range of long-term conditions occurring at different points in the lifespan, we were able to identify whether and how conventional metaphors of *journey* and *violence* were relevant to experiences of a particular condition. Secondly, our inductive, qualitative approach enabled us to identify how *journey* and *violence* metaphors were used alongside other metaphors, how these metaphors related to one another, and whether and how they indexed similar aspects of the illness experience.

Materials and Methods

Five qualitative, one-to-one interview data sets (see Table 1) were analyzed for the purpose of secondary analysis of previously reported data. The data were made available for this study by four social researchers (VL, AA, HL, LH) to identify metaphor use in discourse about multiple health conditions. While the samples were purposive (Coyne, 1997; Palys, 2008), they provided access to rare data from patients living with LTCs with different patterns of diagnosis, aetiologies, and trajectories. Analysis was carried out in collaboration with an applied linguist working in health communication (CT), and four independent researchers (HL, EH, VL, LH), including one patient researcher partner (RW). This multi-disciplinary approach—including a linguist, social researchers and a patient research partner—allowed a deep analysis of metaphor use in the data. Incorporating a linguist, allowed us to sensitize our analysis to critical aspects of metaphor identification such as semantic categorization (for example, relationships between *violence* and *war* as concepts).

The team undertook a supplementary and amplified, qualitative, secondary data analysis from five randomly selected interviews from each data set (Heaton, 2008; Heaton, 2004, p. 35-52). Interviews were all conducted by experienced researchers. Interview length varied considerably (30-210 minutes), with a mean of 70 minutes per interview. This variation reflects the different foci of the interviews (for example, myositis patients were asked specific questions about fatigue only), the nature of the condition itself (for instance, if a recent diagnosis was perceived as life changing), and how the interview was per-

Table 1. Summary of the primary data sets from five qualitative interview studies.

Condition/Title of study/number of patients*	Aim of the study	Research ethics Committee approval
"Improving the quality of care for people with *dementia*: A cross cultural study." Study conducted 2005-2007. Number of patients: 30 (M/F); purposive sample	To explore the attitudes, experiences, and beliefs of people with dementia and carers in relation to dementia	Joint SLAM / IOP NHS REC Ref No 055/03
"Patient's experiences during the first three months a diagnosis of *pleural mesothelioma*." Study conducted: 2008-2009. Number of patients: 10 (M/F); purposive sample	To explore patients' experiences during the first 3 months following a diagnosis of malignant pleural mesothelioma	NRES Surrey Research Ethics Committee Ref No 08/H1109/51 and University of Surrey Ethics Ref No EC/2008/52/FHMS
"EULAR* Classification Criteria for *fibromyalgia*: patient interviews." Study conducted: 2008. Number of patients: 12 (M/F); purposive sample	To report the subjective experiences of patients from diverse ethnic backgrounds who live with fibromyalgia syndrome with specific emphasis on how this long-term condition influences their everyday lives and their contact with primary and secondary care	Bromley Research Ethics Committee; REC No. 07/H0805/28
"The impact and characteristics of fatigue in patients with *idiopathic inflammatory myopathy*: an exploratory qualitative study." Study conducted: 2011 Number of patients: 14 (M/F); purposive sample	To find out how common and how important the symptom of fatigue is to patients with idiopathic inflammatory myositis, including what factors are associated with fatigue	Southeast London Research Ethics Committee; Ref No. 08/H0809/59
Available data (narratives of health and illness) on Healthtalk website about "Parent experiences of neonatal surgery. Study conducted: 2014 -2016. Number of patients: 44 (M/F) purposive sample; via snowballing"	To explore parents' experiences and perspectives of having a baby who needs early abdominal surgery, identify the questions and problems that matter to parents during and after their pregnancy and infant's surgery, and identify the long-term impact on parents and families	NRES Committee South Central- Berkshire, Ref No 12/SC/0495

*European Alliance of Associations for Rheumatology (EULAR).

ceived (for example, patients with fibromyalgia saw the interviews as an opportunity to voice concerns they felt had been unheard by clinical staff). All studies had received ethical approval prior to being conducted, and all patients provided informed consent. For secondary data analysis, a Research Ethics Subcommittee application was submitted, and formal approval was received.

Approach to metaphor identification and analysis

The process of identifying and coding metaphors across the data set drew on Cameron et al.'s (2009) discourse dynamics approach. Metaphors were identified based on "vehicle terms" in the transcribed data. Vehicle terms are individual words or phrases that stand out from the surrounding discourse as having a more basic meaning in other contexts than the one in which they are applied (Pragglejaz Group, 2007). Analysis proceeded by grouping these terms according to semantic fields (e.g., *journey* and *violence*) based on a comparison between their basic meaning and their use in context as conducted by six researchers (HL, AA, EH, RW, VL, BSS). For instance, because "knocked about" evokes the notion of a physical attack, its use was categorised under the *violence* vehicle.

The categorizations of these terms as metaphorical were then reviewed by a seventh coder (CT). Metaphors were examined across the whole dataset to ensure consistent identification. Disagreements about whether the use of terms was metaphorical were verified against meanings listed in the *Oxford English Dictionary* (2010) and, when applicable (for instance, for tests of conventionality), their occurrence in *The British National Corpus (2001)*—a stratified sample of contemporary British English, consisting of more than 100 million words. The categorization of "knocked about" as a metaphor rests on whether the phrase has a contemporary application to refer to a physical attack rather than a clinical procedure.

Though category assignment was informed by established metaphor theory (Lakoff & Johnson, 1980), the groupings themselves were allocated based on the use of vehicle terms in discourse using a recursive process of "principled flexibility" (Cameron & Maslen, 2010, p.126). The analysis allowed for deduction based on the theory that metaphors, as fundamental to human cognition, predict and structure uses of language, as well as induction, in terms of identifying the functions of metaphors in discourse. This approach was informed by "a dynamic perspective on the relation between thinking and speaking [that] leads us to see the words that people speak as fluid, tentative verbalizations of ideas that themselves may be fluid and tentative" (Cameron et al., 2009, p.68).

Metaphors were coded in Microsoft Excel for condition, participant vehicle (and vehicle terms), and topics for which they occurred—i.e., the domains represented in patient talk (for example, diagnosis, manifestation of symptoms, managing symptoms, etc.). This coding approach allowed us to examine which metaphors occurred for which topics as well as which vehicle terms were used by participants experiencing different conditions. The aim of the analysis was not to identify broad quantitative patterns, but rather, to investigate how participants drew upon the same and different metaphoric vehicles and what these framings can tell health and social care professionals about patients' perceived agency in living with and communicating about their respective conditions (Semino et al., 2018). Although the illness was the central point of comparison, coding by participant as well as condition allowed us to account for individual experiences of each illness. The codes were developed by one coder (CT) who then checked these with a second coder (HL). As advised by Cameron and colleagues (2009), vehicle groupings (such as *journey* and *violence*) were kept tentative and procedural until the very last stages of the analysis. Any vehicles or topics that occurred fewer than three times were assigned to a miscellaneous category ("MISC").

In the next phase of the analysis, the first coder worked collaboratively with the second coder to identify connections between metaphors based on their discursive function, for instance, whether their use expressed empowerment or disempowerment. This phase of the analysis enabled the identification and comparative analysis of established "systematic metaphors" (Cameron et al., 2009) identified in previous studies of illness (such as illness as a journey) across the different conditions.

Results

An overview of the main vehicle groupings shows that the dominant metaphors across the sample were the well-established *journey* metaphors and *violence* metaphors. The percentages in Table 2 are indicative of the relative prominence of metaphorical vehicles (e.g., *journey*, *violence*, and *movement*) to participants' experiences of LTCs, with the suggestion that the prominence of these metaphors is condition-dependent. It was typical, for instance, for participants to use *violence* metaphors to frame their experience of mesothelioma, but not for those with dementia. These differences suggest a qualitative relationship between the nature of a particular illness and the metaphors participants chose to frame their experience. These established metaphors were used alongside and often in interaction with other metaphorical vehicles, such as *weight*, *object*, and *movement* in ways that reflected how a given illness manifests and how diagnosis, treatment, management, and self-care are experienced.

As will be unpacked in the following sections, these metaphors expressed three different aspects of living with an LTC. Metaphors of uncertainty represented the psychological impact of a sudden diagnosis or poor prognosis for patients with mesothelioma and for parents whose babies required neonatal surgery. Metaphors of acceptance reflected a need to accommodate acute mental and bodily impacts of an LTC within the daily life of patients with fibromyalgia, myositis, and dementia. The final section focuses on metaphors of resistance in which violence metaphors frame an LTC as an invasive and overpowering force; resistance to this force was represented as a lonely struggle or, in more empowering metaphors, as part of an alliance with health professionals.

Metaphors of Uncertainty

Journey metaphors draw on a schema that "[provide] a way of metaphorically constructing goals as destination, ways of reaching goals as movement forwards, problems as obstacles to movement, and success or failure as reaching, or failing to reach, a destination" (Semino, 2008, p. 92). In our data, these metaphors, along with other metaphorical vehicles, expressed the deep-seated uncertainty that accompanies the diagnosis of an LTC. Parents reflecting on the prospect of neonatal surgery conceptualized the period of the pregnancy following the initial diagnosis as a difficult journey, for instance: "We were about to *embark on* (Note: Italics added here and below to emphasize use of specific metaphors.) such a difficult time that we weren't sure what was going to happen" (Parent whose baby required neonatal surgery, interview 3). The "difficult time" in this example is framed as a path on which the speaker is about to travel, a journey that has an uncertain destination—whether surgical procedures would be necessary or whether the pregnancy needed to be terminated or continued. Uncertainty surrounding the outcome of the surgery was also expressed by other metaphors. For instance, a parent, who had received a diagnosis with a poor chance of infant survival, compared the prognosis to a dark picture: "It was just so *doom* and *gloom* [the doctor] *painted* this *really dark picture*" (Parent whose baby required neonatal surgery, interview 4). Here, the darkness of the picture appears to reflect both the potentially negative outcome as well as the uncertainty surrounding the diagnosis itself.

Journey metaphors also expressed uncertainty by focusing on patients' movement along a path from diagnosis to treatment. As a condition that is often diagnosed late, the metaphors in the language used by pleural mesothelioma patients in our sample foregrounded the suddenness of a journey's onset and the speed of travel as suggested in the following by "on a roller coaster, boom, gone":

> Interviewer: So, your GP acted very quickly.
>
> Patient: He worked very, he *went straightaway*, yeah and from then on, I mean, I was just *on a roller coaster, boom, gone*. (Participant with pleural mesothelioma, interview 5)

In contrast to the parent, where the feeling of uncertainty relates to the journey's destination and path, in the example above, it is expressed by the patient's lack of agency over its progression. It is the doctor who initiates the journey. His reported actions in prompting the journey are represented as movement ("went straightaway"). It is also notable how the mode of transport is one that is not usually operated or controlled by the traveler: a roller coaster. Parents also used metaphors that expressed a lack of control over their journeys. Talk about the need to "just ride it" appeared to verbalize a sense of powerlessness in the face of diagnosis.

Experiences of mesothelioma diagnosis were also conveyed by using *violence* metaphors so that diagnosis was a surprise attack that "slightly out of the blue…hit you." These metaphors revealed how an unexpected diagnosis can leave patients in an uncertain space, robbed of agency amidst decisions being made about their health by the doctors responsible for their care. Just as the *journey* moves rapidly out of the patient's control, the attack is sudden and destabilizing.

Following diagnosis, the possibility of treatment for pleural mesothelioma appeared to provide patients with a sense of progression. While this cancer, affecting the lining of the lungs, is incurable, a range of treatment options exist that can help control symptoms and lead to short-term re-

Table 2. Proportional representation of vehicle groupings across the conditions.

Vehicle group	Myositis %	Dementia %	Mesothelioma %	Fibromyalgia %	Neonatal %
Journey	36.7	30.3	23.5	31.5	32.6
Violence	22.8	9.1	51.0	21.3	22.1
Movement	1.3	12.1	3.9	10.1	9.3
Container	7.6	6.1	3.9	15.7	16.3
Object	2.5	24.2	3.9	4.5	3.5
Weight	8.9	9.1	0.0	3.4	3.5
Painting	0.0	0.0	0.0	0.0	2.0
Machine	0.0	3.0	0.0	2.2	2.3
Chasing	12.7	0.0	0.0	0.0	0.0
MISC	7.6	6.1	11.8	11.2	10.5

mission. This potential for improvement in managing the conditions was framed as forward momentum. Talking about the prospect of chemotherapy, one patient stated:

> I mean, I know what I've got. I know the consequences [treatment], and I mean, up until now, I haven't had any treatment, and it's like, I sort of say to myself, well I've had no treatment yet. Perhaps when I have the treatment, things might improve like, you know. I'm not saying they are going to or for how long, but I think, also once *you get on the treadmill,* there's always *a bit of a light at the end of the tunnel,* but all the time I'm not having treatment, I feel in myself, well, you know, I can't wait to *get on the train* type thing. (Participant with pleural mesothelioma, interview 6)

Here, the participant uses a *movement* metaphor "get on the treadmill"—to refer to being treated for their condition and connects this with the *journey* metaphor by referring to "a bit of light at the end of the tunnel" which suggests a (hopeful) destination, even though treadmills do not move the traveller forward. The metaphor appears to have a positive connotation so that being "on the treadmill" (perhaps drawing on the positive function of treadmills to improve fitness) and being moved in a particular direction suggests a better alternative to the current situation where they are not being treated and, therefore, not moving (and thus "can't wait to get on the train").

For these patients, diagnosis has clearly created an uncertain frame of mind for which the possibility of treatment seems to offer some respite. The *light at the end of the tunnel* metaphor was one of the few *journey* metaphors framing an outcome as a hopeful destination. As suggested by the metaphors in the following section, for patients with LTCs with an unknown aetiology and for which treatment and control is more limited, uncertainty was sometimes displaced in our data by a need to accept changes the illness had brought to their lives.

Metaphors of acceptance

LTCs often involve the onset of debilitating bodily changes regarding how symptoms manifest. The pain and profound fatigue caused by fibromyalgia, for instance, cannot be explained by a clearly established cause; the disease is both challenging to diagnose and without a cure. Accordingly, the *journey* metaphors expressed by patients with fibromyalgia in our sample were different from those used by the mesothelioma patients. In the following examples, a correspondence between the complexities around diagnosing and treating the condition and a lack of direction in the journey were identified:

> … he [rheumatologist] told me that I've got fibromyalgia, which as I said, I haven't heard of in my life before. What he then did…. I mean, at the time, I did feel *a bit lost.* (Participant with fibromyalgia, interview 10)

> I don't know. I just got very ill after that [receiving the diagnosis] really, because just *going round in circles,* the money wasn't enough and things like that. (Participant with fibromyalgia, interview 7)

Treatments such as morphine and antidepressants were presented as roads the patient did not want to travel on, leaving them searching for ways "to steer…back." One participant mentioned counseling as a way of providing some control. Others talked of "pacing" themselves to get through the good days and bad days, or of exercise to "keep going." Without any clear path to recovery, patients focus on ways of controlling their journey, by (re-)directing or by maintaining its momentum. As the *object* metaphors for our sample of patients diagnosed with fibromyalgia revealed, the notion of steering their *journey* seemed to be a critical frame for accepting and managing life with the illness. For one participant, the dream of leaving her unsympathetic husband and living with her daughter is represented as an object she tried to "cling onto"—an orientation point for her *journey*.

Other metaphors framed the *patient* as the *object*, reflecting a sense of despair and hopelessness of life with the ailment. Some referred to being "discarded" by society because of their condition, or as one patient put it, "thrown on a scrap heap"—a potential endpoint for their *journey*, given its incurability and lack of treatment options. These metaphors show how in such a situation, developing a sense of agency is critical to learning to live with the condition and managing its impact on mental health.

Patients from our sample living with myositis used metaphors to focus on its day-to-day manifestation and their management of the acute pain and muscle fatigue associated with the diagnosis. Participants conceptualized tiredness as *weight* to describe the challenge of managing its impact on their ability to move. Fatigue would "build up in the legs," causing the muscles to get "heavy." In the following example, these conceptualizations were integrated into the schema of the *journey* when the participant referred to the consequences of carrying this heaviness as stalled movement:

> There are some days and some periods when I'm not quite as well. It gives me the impression that some days are like "*uphill with a handbrake on*," as if you're *made of lead*, everything *takes* that little bit more energy for you to do. On those days, I do less before I have to *come to the stage* where I *sit down* and say, "Right. I've got to *rest* now." On better days, like today…. Today is not a bad day, I can walk, if I stay nice and levelled on even ground. I can usually get a distance, but the slightest bit of uphill, and I usually *grind to a halt quite quickly* where

> I just have to have a rest. (Participant with myositis, interview 10)

As for others who live with fibromyalgia, the boundary between literal and metaphorical expressions that relate to movement can be fuzzy. The participant drifts between describing the metaphorical *journey* (living with myositis), literal journeys taken in daily life (e.g., describing their ability to walk a distance if the ground is level), and back again, with the metaphor *tiredness has weight* applying to both. The use of the word "handbrake" draws on the same metaphorical vehicle as suggested by "grind," representing impeded progress on the journey as that of a stalling vehicle. In both instances, the participant appears to be talking about both their metaphorical journey as a person with the condition and their literal ability to move about. For the patients living with fibromyalgia and myositis, the use of these metaphors reflects the incurability of the condition as well as the unknown aetiology, without a clear orientation as to the cause at the start of their journey or of recovery as a destination.

Participants with dementia in our sample used *object* and *movement* metaphors to talk about their experience of their condition. The impact of dementia on cognitive function can mean patients struggle to access and relate their thoughts to one another. This was reflected in how our patients talked about thoughts and memories as *possessions* they were trying to keep hold of in their minds:

> I have to keep trying to *put* it [memories about what needs to be done] *in* my brain all the time, but sometimes you *keep* it [memory], but not for long. (Participant with dementia, interview 9)

Statements such as "it's gone" and "it leaves you" built on this conceptualization by framing thoughts as objects moving out of the mind. Conversely, for another patient, thoughts were portrayed as becoming trapped in the mind, suggesting a constraint on movement as in the following description of memory loss and confusion:

> When you are worried the brain is so *blocked up* that they [patients] don't remember the right *things* [thoughts] that they should, they can't remember, too much *things going across* them, and they might need to perhaps take some pills for that. (Participant with dementia, interview 10)

Other *movement* based metaphors cast the mind as an entity that was traveling. One patient, for instance, worried "how *far* am I *going*… am I *getting off* my brain or what," and another wondered about the prospect of "fretting myself away or thinking myself away." The movement vehicles here frame the patient's mind as travelling on a path that leads from their current sense of self, leading to a loss of identity. Collectively, they highlight the powerlessness felt by patients as their illness increasingly manifests.

An alternative perspective was offered by uses of the *life as a journey* metaphor. *Life as a journey* explains our life experience as a journey with death as the destination (Demjén et al., 2016). One person, for instance, explained their illness as "you slowing down." Here, the concept of journey is represented as a loss in momentum that happens later in life. A similar metaphor was prompted after the interviewer asked another participant about their future: "Well, how old am I now? I must be 76 now. I think that's about right. There's not a lot of future. I suppose it [memory loss] will just *jog on* like this" (Participant with dementia, interview 9). In this instance, with only a short distance to go ("there's not a lot of future"), it is the experience of the illness that was said to "jog on."

Dementia as a condition without a cure tends to occur later in life; therefore, these metaphors normalize the *journey of the illness* by situating it within a natural phase at the end of the life course. In contrast to the *movement* metaphors used to talk about the manifestation of their condition, these metaphors appear to express a degree of acceptance of what is an incurable, gradually worsening condition on the part of the patient.

Metaphors of Resistance

Metaphors framing cancer patients' experience of illness as a violent confrontation have been found to both express and reinforce negative feelings about living with disease, while highlighting patients' agency in being able to manage their condition (Semino et al., 2017); however, the majority of *violence* metaphors in our data place the patient in a disempowered position. These metaphors sometimes focused on the physical manifestations of illness. Some patients living with myositis, for instance, focused on discomfort as a symptom, bestowing pain with a malevolent intent to cause harm: "The only thing I would say is that it [myositis] tends to give me this sort of *pulling* and *gnawing* [pain]; feels like *someone is trying* to *pull* my muscles *apart* and *explode* them" (Participant with myositis, Interview 1).

For patients diagnosed with pleural mesothelioma, the tests carried out prior to diagnosis and chemotherapy treatment were framed as the aggressor. For example, chemotherapy was described by one patient as a "killer," implying violence towards the participant rather than the illness. The pleural tap procedure used as a palliative treatment was also framed as a violent act:

> Researcher: And how were you feeling after that [your pleural tap last week]?
>
> Patient: Well, not too bad, I mean, all right. You get, you come out of hospital, you *are knocked about a bit,* ehm…. But that was really what it was [pleural tap]. But apart from that…everything was

> done so quickly, and you don't really know what's *hit you.* (Participant with pleural mesothelioma, interview 5)

For other patients, the primary impact of their confrontation appeared to be psychological. This is illustrated in the following extract from a patient who lives with fibromyalgia:

> I started to have joint flare ups. You know, my wrists first and then, my back was always playing up. My knees, you know. I am getting it a lot more now in my left side of my buttocks down into my left leg. It is like *a killer*, like a trapped nerve that *comes* when you don't expect it [sciatic pain], and it *goes away*. But you don't expect it, you know. You think…. You forget it's…. You forget…. You don't expect every time you tread on this leg. It is like really annoying, because it is just…. I think all the pains. I don't know if I jump from one thing to the other [very angry outburst]…. All the pains sort of *does your mind* [starts crying]. (Participant with fibromyalgia, interview 7)

Here, the individual outlines the pain caused by the disease as "a killer," while a *movement* metaphor describes pain as an assailant that "comes" and "goes away," conveying the unpredictable nature of its attacks which are then represented as an assault on the mind ("all the pains sort of does your mind").

Congruency occurs between the *violence* metaphors used to represent the lack of agency of the patients in their mental struggle with their condition and their *journey* metaphors. Just as the metaphorical journeys of the patients with fibromyalgia were directionless or without motion, their battles centered on the idea that those with fibromyalgia were overcoming the battles. Talking about the physical impact of the illness, a participant complained there were few remedies that "actually do fight the pain." Another, speaking on how their life as an obese person made the symptoms feel worse, felt "defeated." Similarly, patients with myositis explained their attempts to control symptoms as a battle for control over their daily lives, with the loss of agency equivalent to losing the fight and becoming dominated by their assailant:

> But now, I never really feel like doing that [going out in the evening socially]. I mean I *force* myself obviously. There are certain commitments you have to. But, I mean, I would prefer to just be at home in the evening. You know, relaxing there, than going out socially. It's a bit of an effort now…. I don't know. I just don't like to think of the condition *ruling* my life I think…. It bothers me that myositis *has taken over a bit.* (Participant with myositis, interview 9)

Notably, participants affected by the other two LTCs in our analysis (neonatal surgery and dementia) rarely talked about their experiences as a violent confrontation. The parents of children who required neonatal surgery talked about their experience in a different way from those with a long-term illness. The real "fight" is the battle for the child's life, which is fought by the child and the doctors rather than the parents. Indeed, the one instance of a *violence* metaphor in these interviews framed the child as the fighter. Patients diagnosed with dementia, on the other hand, expressed their experience of the disease as part of an inevitable "slowing down" towards the end of life and, thus, less of a fight to be won and more part of the journey to be taken in life.

Those who did use *violence* as a vehicle represented the bodily and mental effects of the disease as a force they had to resist alone. In the extract below, a patient with fibromyalgia draws on both *journey* and *violence* vehicles:

> I try to *carry on* as best I can, you know. I mean, I've got a washing machine. I put the washing in, you know, take it [washing] out, hang it up on airers. I keep, I don't, I won't *give in* to things, you know. I *keep on.* Even if I can't do it one day, I'll do it the next, you know. (Participant with fibromyalgia, interview 12)

Finding the will to "carry on" in their journeys is equated with persisting in their fight ("won't give in"), but both the journey and the fight are undertaken alone. A parallel can be found in *violence* metaphors used by the patients diagnosed with pleural mesothelioma. Strategies that patients had more control over, such as adjusting their diet and taking herbs, were talked about as weapons in the fight against the disease.

While feeling empowered to resist the impact of a medical condition on their daily life builds a sense of agency in terms of adaptation, the feeling of being alone in the struggle can also be debilitating. For instance, the metaphors that portrayed treatments and procedures as part of a physical assault suggest that these were perceived as measures patients were subjected to rather than as part of an alliance with medical practitioners.

A final contrasting example is a metaphor used by a myositis patient to outline the process of monitoring the creatinine kinase (CK) count as way of controlling the inflammation caused by the condition:

> For 10 days, we've been, so to say, "*chasing the dragon*." What they [medical staff] do is, they gave me a *high* dose of steroids *to bring* my CK count *down* into the normal range. Once it *gets* into the normal range, once they reduce the amount of steroids, you *get* then *to a point* where the amount of steroids *goes below a certain point* and the disease *takes off* again, the CK count *rises sharply*. So,

> we have to keep *chasing* this CK number all the time. (Participant with myositis, interview 10)

Here, the participant uses language that frames the CK count as moving along an undulating path ("bring down," "gets into," "takes off," and "rises sharply"). A key underlying conceptualisation is the metaphor *more is up*—the greater the CK count, the "higher" (elevated) the stress to muscle tissue or muscle injury there is. This account applies similarly to the steroid levels used to counterbalance this effect. The steroids are also represented as following this path ("goes below a certain point"). As such, this metaphor supports the overarching framing imagery of "chasing the dragon."

The patient's appropriation of this idiomatic phrase, which tends to refer to a method of smoking opium (Strang et al., 2006), imagines attempts to monitor the CK count as a chase. Within this context, references to the CK count can be seen as metonymic in reference to the disease (imagined as the metaphorical dragon) that is being chased. While the patient appears to be aware of the existence of the phrase and its idiomatic meaning, the metaphoric intent suggests reappropriation. The chasing element of the metaphor falls within the *journey* schema, but in contrast to some of the other metaphors discussed in this section, the doctor and participant are allied as travellers in the journey as companions in the chase after the disease.

Discussion

For many patients with LTCs, treatment options are limited, and they face restricted lives over which they have little control (Charmaz, 1993). In this secondary analysis of data about experiences of five heterogenous long-term conditions, the authors explored how metaphors are used by patients to communicate what it is like to be diagnosed, and, in turn, help them live with and manage their LTCs. Metaphors enabled challenging bodily changes and illness experiences to express meaning which can be hard to convey with factual language alone (Lakoff & Johnson, 1980; Stibbe, 1997). Our analysis demonstrated the use of well-established metaphors—most often, *journey* and *violence* metaphors—in varied illness experiences. Demjén & Semino (2016) demonstrated that *journey* and *violence* metaphors can be employed to express empowerment or disempowerment in the experience of cancer, a finding which our study supports and extends to the experiences of other long-term conditions. Our analysis also highlights how other metaphors, such as those drawing upon the vehicles of *object* and *weight*, have a relationship with these well-established metaphors and interact with them in the construction of such meanings.

Empowering and disempowering uses of these metaphors revealed three dimensions of life with an LTC. First, we saw how uncertainty surrounding a diagnosis or negative prognosis can leave a patient feeling overwhelmed and without agency. Mesothelioma diagnosis, for instance, was conceptualized as both a sudden attack and a rapidly progressing journey, with the patient as a passenger having little control over the journey's direction and destination. The disempowering focus of *journey* metaphors reflected the reality of living with a LTC with few effective treatments.

Only one patient with mesothelioma could see "a light at the end of the tunnel." This might reflect that, for them, following treatment, there is still hope and a direction to aim for, a more optimistic and potentially empowering use of the metaphor. The culturally valued theme of maintaining hope thus highlights how metaphors can draw on accepted communal values such as promise and transformation (Charteris-Black, 2004). However, the reference to a "treadmill" implies movement without any real progress towards a given destination, raising the possibility of never reaching the end of that tunnel.

Patients also used metaphors to describe debilitating mental and physical impacts of the condition on their daily lives. For instance, symptoms, such as tiredness were constructed as physically heavy burdens in myositis patients' day-to-day management of their symptoms, and individuals living with dementia spoke about their thoughts as possessions they struggled to hold onto.

The *journey* metaphor often framed these experiences in disempowering ways. For some, life with a long-term condition meant a directionless journey (fibromyalgia patients), whereas for others, it was difficult or treacherous, with feelings of being weighed down or enduring an uphill struggle (myositis patients). In contrast, a form of empowerment in the illness journey was expressed by participants with fibromyalgia who spoke of "pacing" themselves or rejecting certain (treatment) paths on their journey. While they did not necessarily know where they were going on their journey, they did have some control over how they made the journey in stark contrast to the patients with mesothelioma who were carried along by doctors planning their treatments. Likewise, the choice to "jog on" with dementia could be interpreted as a form of empowering acceptance of living with that illness.

Finally, predominantly using *violence* as a vehicle, patients described their illness as an ongoing struggle. Like *journey* metaphors, *violence* metaphors revealed distinct facets of individual LTCs. For example, participants used the metaphor to present themselves in conflict with their illness, focusing on its physical effects (e.g., myositis) and/or its psychological impact (e.g., fibromyalgia). In common with the *journey* metaphor, too, many *violence* metaphors revealed a sense of disempowerment, as the participant expressed defeat or physical attack by the illness or by its treatment.

Conversely, like the *journey* metaphor, the *violence* metaphor could express a sense of empowerment, a commitment to keeping fighting, or to choose one's weapons in the fight. In this way, *violence* metaphors demonstrated agency and/or empowerment in the illness experience. As such, these metaphors can provide a means of demonstrating how illness can be coped with.

Myositis and mesothelioma are rare conditions that cannot be cured, and they share similar symptoms such as fatigue, pain, and low mood (Lilleker et al., 2017; Maguire et al., 2020). Perhaps it is not surprising that with a diagnosis of these conditions, patients stated more violent confrontation metaphors to describe the effect of their illness. Although viewing each disease as a violent confrontation may figuratively place the patient in a vulnerable position, it could also be understood as a condition that can be coped with positively.

Similar to the findings of Semino, et al. (2017), we also found that these violence metaphors may be used in an empowering way. However, emerging strongly in our data was the notion that resisting the impacts of their condition was often framed as a lonely struggle wherein even treatments could be seen as a violent attack (as was the case for mesothelioma patients).

Agency negotiation was also evident in the employment of the novel metaphor *chasing the dragon,* which vividly illustrates how an LTC can be conceptualized as animate and wilful and, thus, something that needs to be controlled—albeit, crucially, in this instance, as part of an alliance with health practitioners. This example shows how patients can build on conventional conceptualizations in ways that are uniquely tailored to their own perspective and experience of the illness. By paying attention to the use of metaphoric expressions, health practitioners (and members of support networks) can understand the meanings attached to the metaphoric framings of illness in terms of the patient's agency construction.

Implications: Using metaphors in practice

This exploration of metaphor use across diverse LTCs has important implications for practice. Metaphor and figurative language provide a window into patients' experiences, allowing them to communicate intangible symptoms such as pain or fatigue that cannot be objectively measured in more direct terms. They also enable communication about the impact of the condition and changes in their symptoms, allowing for a fuller understanding of the patient experience. As such, figurative language provides rich material for health and social care professionals to mine within their interactions and to understand each patient's unique experience.

Our analysis reveals how metaphor use varies within and between conditions and individuals, illustrating how each patient brings their own experience, understanding, and context to each consultation. Recognizing and reflecting on the use of metaphors in consultations is, therefore, critical for developing shared understanding, building rapport, and supporting person-centred care delivery. This aligns with definitions of patient-centred communication, recognizing the importance of eliciting patients' perspectives, understanding patients within their specific contexts, and reaching a shared understanding of problems (Epstein & Street, 2007). Adopting interpersonal and person-centred communication strategies not only contributes to positive experiences of the consultation, but also improved patient satisfaction (King & Hoppe, 2013) and, ultimately, improved healthcare (Doyle et al., 2013).

In practical terms, we can make two overarching recommendations. First, providers supporting patients with LTCs need to reflect on their own use of metaphors. Using a particular type of *violence* or *journey* metaphor may impose a restrictive or disempowering frame in the context of a particular patient experience.

Second, practitioners should develop sensitivity to metaphor use by patients. For instance, metaphors that frame the patient as being violently "taken over" by the condition (as with myositis) or as becoming "lost" (fibromyalgia) not only need to be recognized, but actively engaged with. This might involve drawing upon the patient's use of metaphor when talking about possible courses of action as ways of resisting the disease or refocusing the journey in terms of its pace or direction.

Our data suggests that it is important to recognize how entrenched metaphors take on important meanings in accepting life with an LTC, as with the *life as a journey* metaphor for dementia patients. Additionally, there is a need to explore novel, emergent, and creative use of metaphor, as seen with the notion of treatment as a "treadmill" (mesothelioma) and "chasing the dragon" (myositis).

As our analysis highlights, such an exploration needs to consider that the same metaphorical vehicles, often in interaction with other types of metaphors, can represent and construct patients' experiences in ways that have positive or negative implications for the patients. These implications might not be immediately clear without questioning and exploring metaphors' meanings within a consultation. For instance, a metaphor that casts the patient in an empowering role might lead to unrealistic expectations about the effect of treatment and outcomes (Semino et al., 2018). In the case of LTCs, "useful" metaphoric framings tended to build patient agency in accepting and managing life with a given condition, ideally as part of an alliance with health professionals.

Conclusions

Our paper has several limitations. The sample size is small, and a limited number of patients with LTCs were included in our analysis; therefore, transferability of our findings is limited by the size of our sample and the lack of diversity of our participants.

In future research, an analysis of metaphor use could be developed to include studies with doctors, nurses, and allied health professionals caring for patients with LTCs to examine the kind of figurative language used and the purpose of metaphor use in practice. It would also be important to build a wider, more diverse sample for cross-condition comparison of metaphor use so that the effects of ethnicity and language background can be studied.

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