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Citation for published version (APA):

Lempp, H., Tang, C., Heavey, E., Bristowe, K., Allan, H., Lawrence, V., Santana Suarez, B., Williams, R., Hinton, L., Gillett, K., & Arber, A. (Accepted/In press). The use of metaphors by service users with diverse long-term conditions: a secondary qualitative data analysis.: Metaphor analysis and long term conditions. *Qualitative Research in Medicine and Healthcare*.

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

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Key words: illness experience, long term conditions, metaphors, secondary data analysis.

Authors' contributions:

HL: proposed the idea and coordinated the writing of the paper, contributed transcribed interviews (Myositis, Fibromyalgia) for data analysis, co-conducted the data analysis, contributed to the writing and editing of the paper. CT: led the data analysis and edited the paper. EH: contributed to the first stage of the data analysis, co-wrote the Discussion section and edited the paper. KB: co-wrote the Background section and edited the paper. HA: co-wrote the Background section and edited the paper. VL: contributed transcribed interviews (dementia), contributed to the first stage of the data

analysis, and edited the paper. BS: contributed to the first stage of the data analysis and edited the paper. RW: contributed to the first stage of the data analysis, co-wrote the Discussion section and edited the paper. LH: contributed transcribed interviews (neonatal surgery) for data analysis and edited the paper. KG: edited the paper. AA: contributed transcribed interviews for data analysis (pleural Mesothelioma), co-wrote the Background and Discussion sections, edited and coordinated the submission of the paper.

Conflict of interest statement: The authors declare no conflict of interests.

Funding Statement: No funding was received for the study.

Ethical committee statement

All primary studies had received ethical approval prior to being conducted and all patients provided written informed consent. For the secondary data analysis, the first author (HL) sought a Research Ethics Subcommittee approval from King's College, London. Research Ethics approval (RESCMR-16/17-4211) was received. The King's College London Research Ethics Committee ensures research is carried out safely with considered consent and respect for the autonomy and privacy of research participants, and in accordance with the ethical principles set out in the Declaration of Helsinki and other relevant guidelines.

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 their life and delivering person-centred care to support them. 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 undertook a secondary qualitative data analysis of 25 interviews, comparing the metaphors used by patients and parents of patients with five long-term conditions. The analysis shows how similar metaphors can be used in empowering and disempowering ways as patients strive to accept the illness in their daily lives, and how metaphor use depends on the manifestation, diagnosis, and treatment of individual conditions. There are implications for how metaphorical expressions are 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/multi-morbidities . 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, e.g., HIV. It is estimated that 15 million people in the UK, a quarter of the population, live with a long-term condition (Nuffield Trust, 2021b) (Nuffield Trust, 2021b) (; and 14.2 million people, or one in four adults, are facing multimorbidity, the presence of more than two long-term conditions in England (Stafford et al., 2018) . Healthcare for those with lifelong conditions account for a considerable cost to the NHS amounting to 50% of General Practitioners' (family doctors) appointments, 70% of inpatient bed days (Coulter et al., 2013), and 70% of healthcare spending (Nuffield Trust, 2021b) .

Against this background, how lifelong conditions impact on health care systems, each of the illnesses included in this study can manifest themselves in different ways. For example, Dementia represents a significant burden for the ageing UK population and health services. In 2019, 850,000 people in the UK were living with Dementia (approximately 1 in every 14 adults over 65); this is expected to increase to 1,500,000 by 2040 (Wittenberg et al., 2019) . There is an increased prevalence of musculoskeletal problems in the ageing UK population. Many are associated with difficult symptoms amongst 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 ones such as fibromyalgia, characterised 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 with unpredictable trajectories and outcomes. Children who undergo early and complex surgery, for example for exomphalos (an abdominal wall defect, where 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, stomas and stoma care needs, neurodevelopmental- and potentially other difficulties such as restricted mobility (Page et al., 2020) . Neonatal deaths have steadily decreased over the past decades from 6.3 infant deaths and 4.2 neonatal deaths per 1000 live births in 1993, to 4 infant deaths and 2.9 neonatal deaths per 1000 live births in 2019 (Nuffield Trust, 2021a) .

Empathetic and effective communication between patients with long term conditions and healthcare professionals have therefore become an essential part of healthcare staff education across their curricula.

Metaphors of illness and long-term conditions

Metaphor and figurative language perform a vital function in giving patients and caregivers the tools to communicate their experiences and to highlight aspects of those narratives (Lakoff & Johnson, 1980), including the management of their LTCs and daily life (Cameron, 2003; Masukume & Zumla, 2012; Pena & Andrade-Filho, 2010);(Cameron, 2003) .

The use of metaphors in medicine serves 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 analyse feelings and emotions (Lanceley & Clark, 2013) as well as describing the abstract nature of pain, and the complex interplay of symptom experience over time (Charmaz, 1993) .

Lakoff and Johnson defined '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 a patient shares the illness experience is beneficial to understanding how patients make sense of their illness and negotiate a new sense of self (Charmaz, 1983). The use of metaphors in relation to cancer, death, dying, and bereavement is well studied (Southall, 2013), for instance metaphors involving 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 the “Military” and Journey metaphors frequently described in relation to the experience of having cancer (Lanceley & Clark, 2013; Semino et al., 2018; Sonntag, 1978). Within this literature, there have been calls for the abandonment of “Military” or “War” metaphors on the basis that they have negative implications for cancer patients (Miller, 2010), as well as for other types of illness (George et al., 2016). Systematic linguistic investigations of metaphor use only partly support such a claim, however. Firstly, while the prevalence of War/Military and Journey metaphors in patient data attest to their importance for conceptualising and expressing experience of illness, linguistic analysis raises issues with how we categorise these metaphors from a practice perspective. For instance, not all metaphors that construct the illness (or other aspect 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 is while such metaphors may be unhelpful and potentially harmful for some people, for others they may be motivating and empowering (Reisfield & Wilson, 2004; Semino et al., 2017). For instance, exploring the contexts of the Violence and Journey metaphors used by cancer patients indicates that “Violence metaphors are not always negative and Journey ones are not always a better alternative” (Demjén & Semino, 2016, p.395).

It follows that systematic linguistic enquiry is required to define how metaphorical language is shaped by the individual and what this tells us about their relationship with their illness (Semino et al., 2018; Skelton et al., 2002) . In the current study, by adopting a discourse-based approach to metaphor identification (Cameron et al., 2009) , we aimed to capture both metaphoric forms and how they were used by patients in the context of individual interviews. This approach allowed us to draw inferences about what the metaphors expressed, e.g. negative or positive emotion, and their implications for the patient, e.g. if the metaphor was potentially empowering or disempowering. Our work contributes to the existing body of work in two ways. Firstly, by exploring contexts of use across a range of long-term illnesses, occurring at different points in the lifespan, we were able to identify whether and how conventional metaphors of Journey and Violence were relevant for 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 experience.

Materials and Methods

Five qualitative one-to-one interview data sets (see Table 1 below) were analysed. They were made available for this study by four social researchers (XX-XX) to identify metaphor use in discourse about the condition. While the sample was opportunistic, it provided access to rare data from patients with LTCs with different patterns of diagnosis, aetiologies and trajectories. The analysis was carried out in collaboration with an applied linguist working in health communication (XX), and four independent researchers (XX--XX), including one Patient

Researcher Partner (XX). This multi-layered approach by different academics and patient research partner allowed a deep analysis of metaphor use in the data. allowing us to combine a linguistic approach to metaphor identification and analysis with social insights from the researchers who had been focusing on the respective conditions and from patient experience. Given that metaphors are a linguistic phenomenon that cannot be fully captured using other qualitative approaches, such as thematic or content analysis, the inclusion of a linguist in the team allowed us to sensitise our analysis to critical aspects of metaphor identification, such as semantic categorisation (e.g. the relationship between Violence and War as concepts).

[Insert Table 1: Summary of the primary data sets from 5 qualitative interview studies here]

The team undertook a supplementary and amplified qualitative secondary data analysis, which consisted of an in-depth analysis of emergent phenomena from 5 randomly selected interviews from each data set (x5) (Heaton, 2008) . The interviews were all conducted by experienced researchers. Interview length varied considerably (30-210 minutes), with a mean of c.70 minutes per interview. This variation reflects the different foci of the interviews (e.g. Myosotis interviews 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 perceived, e.g. patients from the Fibromyalgia study saw the interviews as an opportunity to voice concerns they felt had been unheard by clinical staff. All primary studies had received ethical approval prior to being conducted and all patients provided informed consent.

For the secondary data analysis, a Research Ethics Subcommittee application was submitted and a formal approval RESCMR-16/17-4211 was received, 9.3.2017.

Approach to metaphor identification and analysis

The process of identifying and coding the metaphors across the data set drew on Cameron et al.'s (2009) discourse dynamics approach. Metaphors were identified based on the '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 (contemporary) meaning in other contexts than the one in which they are applied (Pragglejaz Group, 2007) . The analysis proceeded by grouping these terms according to semantic fields (e.g., Journey, Violence) based on a comparison between their basic meaning and their use in context by six researchers (XX-XX). In this instance, as *knocked about* evokes the notion of a physical attack, its use was categorised under the Violence vehicle.

These categorisations were then checked by a seventh coder (XX). Metaphors were examined across the whole dataset to ensure consistent identification. Disagreements about whether the use of terms were metaphorical were verified against meanings listed in the Oxford English Dictionary and, when applicable (e.g., for tests of conventionality), their occurrence in the British National Corpus (a digitally available, stratified sample of contemporary British English of over 100 million words). The metaphoricity of *knocked about* 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 the vehicle terms in discourse, using a recursive process of 'principled flexibility' (Cameron & Maslen, 2010, p.126) . The analysis was thus neither entirely inductive (bottom up), or deductive (entirely top down). It was one that assumes that "a dynamic perspective on the relation between thinking and speaking 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) .

The 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 (e.g., 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 to investigate how participants drew upon the same and different metaphoric vehicles and what these framings can tell health and social care professionals about their perceived agency in living with and communicating about their condition (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 (XX) who then checked these with a second coder (XX). 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, e.g. 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 (e.g., 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 the metaphorical vehicles 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 is experienced. As will be unpacked in the following sections, collectively, these metaphors expressed three different aspects of life with a LTC. Metaphors of uncertainty represented the psychological impact of a sudden diagnosis or poor prognosis for patients with Mesothelioma and for parents whose baby required neonatal surgery. Metaphors of acceptance reflected a need to accommodate the acute mental and bodily impacts of a LTC within the daily life of patients with Fibromyalgia, Myositis and Dementia. The final section focuses on metaphors of resistance. Here, the authors will discuss how Violence metaphors frame a LTC as an invasive and overpowering force and how resistance to this force was either represented as a lonely struggle, or, in more empowering metaphors, as part of an alliance (e.g. with health professionals).

[Insert Table 2: Proportional representation of Vehicle groupings across the conditions here]

Metaphors of uncertainty

Journey metaphors draw on a schema that “provides 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 - alongside other metaphorical vehicles - expressed the deep-seated uncertainty that accompanies the diagnosis of a LTC. Parents reflecting on the

prospect of neonatal surgery conceptualised the period of the pregnancy following the initial diagnosis as a difficult journey:

We were about to *embark on* such a difficult time that we weren't sure what was going to happen. (Parent whose baby required neonatal surgery 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 4)

For example, 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 the Journey's onset and speed of travel – as suggested in the following by “on a rollercoaster, boom, gone”:

So, our GP [family doctor] acted very quickly. (Parent whose baby required neonatal surgery 3)

He worked very, he *went straightaway*, yeh and *from then on*, I mean, I was just *on a rollercoaster, boom, gone*. (Participant with pleural Mesothelioma 5)

In contrast to the parent in the example above, where the feeling of uncertainty relates to the journey's destination and path, here it is expressed by the patient's lack of agency over its progression. It is the doctor who initiates the Journey by moving "straightaway" and it is also notable how the mode of transport is one that is not usually operated or controlled by the traveller – a rollercoaster (as in the example above), a "train", or merely going "with the flow", suggesting a journey on water. Parents also used metaphors that expressed a lack of control over their journeys. Talk about the need to "just ride it" appeared to verbalise a sense of powerlessness in the face of diagnosis. Experiences of Mesothelioma diagnosis were also conveyed by using Violence metaphors – diagnosis was a surprise attack that (e.g.) "slightly out of the blue...hit you". These metaphors revealed how an unexpected diagnosis can leave patients in an uncertain space - robbed of agency in between the 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 destabilising.

Following diagnosis, the possibility of treatment for pleural Mesothelioma appeared to provide patients with a sense of progression. While this cancer that affects the lining of the lungs is incurable, a range of treatment options exist that can help control symptoms and lead to short-term remission. 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 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 be positively laden in the sense that being “on the treadmill” (perhaps drawing on the positive function of treadmills to improve fitness), and being moved in a particular direction, is outlined here as 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 that framed 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 the changes the illness had brought to their embodied worlds.

Metaphors of acceptance

LTCs often involve the onset of debilitating bodily changes in terms of how symptoms manifest. The pain and profound fatigue caused by Fibromyalgia 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 data extract, 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 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 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 counselling 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". What emerges from these metaphors is that 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. 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 the day-to-day manifestation and their management of the acute pain and muscle fatigue associated with the diagnosis. Participants conceptualised 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 conceptualisations were integrated into the schema of the Journey metaphor 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 10)

In this example, the participant likens their management of their symptoms to a challenging journey. The feeling of tiredness is compared to being “made of lead”, while their metaphorical journey is characterised as “uphill with a handbrake on”. 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 their progress on their 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 our selection of patients living with Fibromyalgia and Myositis, the use of these metaphors reflect 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 recovery as a destination.

The 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 can 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 9)

Statements such as “it’s gone, it leaves you” built on this conceptualisation 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. In the following example, the participant is describing what they derived was wrong in a short vignette describing a man experiencing 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 10)

Other Movement based metaphors cast the mind as an entity that was travelling. One patient, for instance, worried “how *far* am I *going*... am I *getting off* my brain or what” and another

about the prospect of “fretting myself away or thinking myself away”. By thinking, the patient’s mind travelled a path that led from their current sense of self – thinking was thus not just a matter of being unable to control thoughts but involved a loss of identity. Collectively, these metaphors highlight the powerlessness felt by these patients as their disease increasingly manifests. An alternative perspective was offered by uses of the highly conventional Life as a Journey metaphor. Life as a Journey explains our everyday experience as a journey with death as the final destination (Demjén et al., 2016) . One person, for instance, explained their illness as “you slowing down”. This metaphor frames their illness within the wider context of their life’s Journey – as a loss in momentum that happens as they approach the Journey’s end. 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 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 appeared to draw on an association between the Journey of the illness and old age as the final part of life’s Journey. In contrast to the Movement metaphors used to talk about the manifestation of their condition, these metaphors express a degree of acceptance of what is an incurable, gradually worsening condition on the part of the patient.

Metaphors of resistance

Metaphors that frame cancer patients’ experience of illness as a violent confrontation have been found to both express and reinforce negative feelings about living with the disease as well as

highlighting their agency in being able to manage their condition (Semino et al., 2017) . The majority of Violence metaphors in our data place the patient in a disempowered position. These were sometimes focused on the physical manifestations of these diseases. Some patients living with Myositis in our sample, 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 1)

For patients diagnosed with pleural Mesothelioma, it was the procedures applied for the diagnosis and treatment that 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 5)

For other patients, the primary impact of their confrontation appeared to be psychological. This is well 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 7)

Here the individual outlines the pain caused by the disease as “a killer” – but then a Movement metaphor that describes pain as an assailant that “comes” and “goes away” conveys the unpredictable nature of its attacks – which is then represented as an assault on the mind (“all the pains sort of does your mind”).

There was a congruency between the Violence metaphors used to represent the agency of the patients in their mental struggle with their condition and their Journey metaphors. Just at the metaphorical journeys of the patients with Fibromyalgia were directionless or without motion, their battles centred on the idea that they were being overcome. 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, the people 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, e.g.

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, then 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 9)

It is notable that participants affected by the other two LTCs (neonatal surgery and dementia) in our analysis rarely talked about their experiences as a violent confrontation. The parental narrative of neonatal surgery is qualitatively different 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. The 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, but more part of the journey to be taken in life.

The ones who did use Violence as a vehicle represented the bodily and mental impacts of the disease as an at times overwhelming force. Resisting this force was often described as a lonely struggle. In the extract below, the 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 12)

Finding the will to “carry on” in their journeys is equated with persisting in their fight (“won’t give in”), but both journey and fight are undertaken alone. A parallel can be found in the Violence metaphors used by the patients diagnosed with pleural Mesothelioma. Strategies that they had more control over – 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 agency in terms of adaptation, the feeling of being alone in the struggle can also be debilitating. For instance, the metaphors that reported

treatments and procedures as part of a physical assault suggests these were perceived as measures they were subjected to rather than as part of an alliance with medical practitioners.

A final contrasting example is a novel 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 10)

Here the participant uses language that frames the CK count as moving along an undulating path (bring down, gets into, takes off, 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, these metaphors support the overarching framing of “chasing the dragon”. The patient’s novel expression of this idiomatic phrase, which tends to refer to a method of smoking opium (Strang et al., 2006) , talks about the attempts to monitor the CK count as a chase. Within this context, references to the CK count can be seen as metonymic - it is in fact the disease (animated 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 language here 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 help them live with, and manage a LTC. Metaphors enabled challenging bodily changes and illness experiences to be expressed, which can be hard to convey with factual language alone (Lakoff & Johnson, 1980; Stibbe, 1997) . Our analysis demonstrated the use of well-established metaphors, in particular 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 highlighted 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.

The empowering and disempowering uses of these metaphors revealed three dimensions of life with a LTC. Firstly, we saw how the uncertainty surrounding a diagnosis or negative prognosis can leave a patient feeling overwhelmed and without agency. Mesothelioma diagnosis, for instance, was conceptualised as both a sudden attack and a rapidly progressing journey, with the patient as a passenger with little control over its direction and destination. The disempowering focus of the 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 may reflect for them that 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 highlights how metaphors can draw on accepted communal values such as promise and transformation (Charteris-Black, 2004) . However, the use of the treadmill imagery 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 express the 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 condition, and individuals living with Dementia talk 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), for others, a difficult or treacherous one, with feelings of being weighed down or 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 that journey, a 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, our patients talk about 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, focussing on its physical effects (e.g., in Myositis) and/or its psychological impact (e.g., Fibromyalgia). In common with the Journey metaphor too, many of these Violence metaphors revealed a sense of disempowerment, as the participant is defeated or

physically attacked by the illness or by its treatment. However, 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, the Violence metaphors demonstrated agency and/or empowerment in the illness experience. We found that these metaphors provide a means to demonstrate how illness can be coped with. Myositis and Mesothelioma are rare conditions that cannot be cured and share similar symptoms, such as fatigue, pain, and low mood (Lilleker et al., 2017; Maguire et al., 2020) . Perhaps it is not surprising then that with a diagnosis of these conditions, patients stated more violent confrontation metaphors to describe the effect of their illness on them. Although viewing each disease as a violent confrontation may 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 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 a LTC can be conceptualised as animate and wilful and thus something that needs to be controlled – but critically, in this instance, as part of an alliance with health practitioners. The example both shows how patients can build on conventional conceptualisations in ways that are uniquely tailored to their own perspective and experience of the illness, and underlines how integrating health practitioners (and members of support networks) into metaphoric framings of illness in ways that suggest cooperation and support can serve agency construction.

(Giles, 2016) This exploration of metaphor use across diverse LTCs has important implications for practice. Metaphor and figurative language provide a window into the experience of the patient, 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 upon them, and changes in their symptoms, allowing for a fuller understanding of the patient experience. As such metaphor and figurative language provide rich material for health and social care professionals to mine within their interactions in order to understand the patient's unique experience. Our analysis showed that metaphor use varied within and between conditions and individuals, illustrating how each patient brings a unique experience, understanding and context to each consultation. Recognising 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 which recognises the importance of eliciting the patient's perspective, understanding them within their unique context, and reaching a shared understanding of their problems (Epstein & Street, 2007). Adopting interpersonal and person-centred communication strategies not only contribute to positive experiences of the consultation, but also improved patient satisfaction (King & Hoppe, 2013), can directly and indirectly affect person-centred outcomes (Street et al., 2009) and contribute to improved healthcare quality (Doyle et al., 2013).

In practical terms, we can make two overarching recommendations. Firstly, those supporting patients with a LTC need to reflect on their own use of metaphors – e.g. if using a particular type of Violence or Journey metaphor imposes a restrictive or disempowering frame in the context of a particular experience. Secondly, practitioners should develop sensitivity to metaphor use by patients. For instance, metaphors that frame the patient as being violently “taken over” by the condition (Myositis) or as becoming “lost” (Fibromyalgia) do not just need to be recognised but actively questioned. This might involve drawing upon the patient metaphor, e.g. talking about possible course of actions as ways of resisting the disease or refocusing the journey in terms of its pace or direction. Here, our data suggests it is important

to recognise how entrenched metaphors take on important meanings in accepting life with a LTC, e.g. the Life as a Journey metaphor for Dementia patients. Additionally, there is a need to explore novel, emergent and creative uses of metaphor – e.g. the notion of treatment as a “treadmill” (Mesothelioma), or “chasing the dragon” (Myositis). As our analysis highlights, such an exploration needs to consider that the same metaphorical vehicles (e.g. Violence and Journey), often in interaction with other types of metaphors, can represent and construct patient experience in ways that have positive or negative implications for the patient. These implications might not be immediately clear without questioning and exploring their meaning 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.

Conclusion

Metaphor use has been found to be therapeutic for the patient (Rucinska & Fondelli, 2022; Stine, 2005) . Exploration of the patients’ use of metaphor has the potential for a deeper understanding of the impact of the illness and allow for shared exploration of needs, coping and goals of care. Our findings revealed how patients use of metaphor point to different ways of coping with LTCs. Patients appeared to accept illness as part of their daily lives as well as resisting the impact of the illness on the self. Our findings highlight the value of paying attention to how patients use metaphors, particularly the ones that empower and disempower. Furthermore, the meanings and nuances of the illness experience, expressed through metaphor may invite further exploration by the clinician. Being aware of how patients use metaphor has the potential to open up a space for dialogue, to understand better what the patient is

experiencing in relation to the illness and has the potential to enhance person centred care if picked up and sensitively explored by the clinician.

Table1: Summary of the primary data sets from 5 qualitative interview studies

Condition/Title of study/number of patients*	Aim of the study	Research Committee approval	Ethics
<p>“Improving the quality of care for people with <i>dementia</i>: a cross cultural study.” Study conducted 2005-2007. Number of patients: 30 (M/F); purposive sample</p>	<p>To report the attitudes, experiences, and beliefs of people with dementia within the three largest ethnic groups in the UK</p>	<p>Joint SLAM / IOP NHS REC Ref No 055/03.</p>	
<p>“Patient’s experiences during the first three months a diagnosis of pleural <i>Mesothelioma</i>.” Study conducted: 2008-2009. Number of patients: 10 (M/F); theoretical sample</p>	<p>To explore patient’s experience during the first 3 months following a diagnosis of malignant pleural Mesothelioma.</p>	<p>NRES Surrey Research Ethics Committee Ref No 08/H1109/51 and University of Surrey Ethics Ref No EC/2008/52/FHMS.</p>	
<p>“EULAR* Classification Criteria for <i>Fibromyalgia</i>: patient interviews.” Study conducted: 2008. Number of patients: 12 (M/F); purposive sample</p>	<p>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.</p>	<p>Bromley Research Ethics Committee; REC No. 07/H0805/28.</p>	
<p>“The impact and characteristics of fatigue in patients with Idiopathic <i>Inflammatory Myopathy</i>: an</p>	<p>To find out how common and how important the symptom of fatigue is to patients with idiopathic</p>	<p>Southeast London Research Ethics Committee; Ref No. 08/H0809/59.</p>	

exploratory qualitative inflammatory myositis,
study.” including what factors are
Study conducted: 2011 associated with fatigue.
Number of patients: 13
(M/F); purposive sample

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)

** for this dataset, the acronym LTC does not apply completely, but we decided to use the abbreviation to refer to the entirety of the datasets for simplicity. The extracts of interviews 10 available on the website are illustrative accounts (to support the topic summaries written after rigorous thematic analysis from the interview transcripts).

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	2.0	0.0	0.0
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

References

- Alvesson, M., & Skoeldberg, K. (2000). *Reflexive methodology: new vistas for qualitative research*. Sage Publications.
- Cameron, L. (2003). *Metaphor in Educational Discourse*. Continuum.
- Cameron, L., & Maslen, R. (2010). *Metaphor Analysis: Research Practice in Applied Linguistics, Social Sciences and the Humanities*. Equinox.
- Cameron, L., Maslen, R., Todd, Z., Maule, J., Stratton, P., & Stanley, N. (2009). The discourse dynamics approach to metaphor and metaphor-led discourse analysis. *Metaphor and Symbol, 24*(2), 63-89.
- Charmaz, K. (1983). The Loss of Self: a fundamental form of suffering in the chronically ill. *Sociology of Health and Illness, 5*, 168-195. (IN FILE)
- Charmaz, K. (1993). *Good days, bad days: the self and chronic illness in time*. Rutgers University Press.
- Charteris-Black, J. (2004). *Corpus Approaches to Critical Metaphor Analysis*. Palgrave Macmillan.
- Coulter, A., Roberts, S., & Dixon, A. (2013). *Delivering better services for people with long term conditions*.
- Demjén, Z., & Semino, E. (2016). *Using metaphor in healthcare: Physical health*. Routledge.
- Demjén, Z., Semino, E., & Koller, V. (2016). Metaphors for 'good' and 'bad' deaths. A health professional view. *Metaphor and the Social World, 6*(6), 1-19.
- Doyle, C., Lennox, L., & Bell, D. (2013). A systematic review of evidence on the links between patient experience and clinical safety and effectiveness. *BMJ Open, 3*(1). <https://doi.org/10.1136/bmjopen-2012-001570>
- Epstein, R. M., & Street, R. L., Jr. (2007). *Patient-Centered Communication in Cancer Care: Promoting Healing and Reducing Suffering*.
- Fayaz, A., Croft, P., Langford, R. M., Donaldson, L. J., & Jones, G. T. (2016). Prevalence of chronic pain in the UK: a systematic review and meta-analysis of population studies. *BMJ Open, 6*(6), e010364. <https://doi.org/10.1136/bmjopen-2015-010364>
- Gazeley, D. J., & Cronin, M. E. (2011). Diagnosis and treatment of the idiopathic inflammatory myopathies. *Ther Adv Musculoskelet Dis, 3*(6), 315-324. <https://doi.org/10.1177/1759720X11415306>
- George, D. R., Whitehouse, E. R., & Whitehouse, P. J. (2016). Asking more of our metaphors: narrative strategies to end the war on Alzheimer's and humanize cognitive aging. *The American Journal of Bioethics, 16*(10), 22-24.
- Giles, H. (2016). *Communication Accommodation Theory: Negotiating Personal Relationships and Social Identities across Contexts*. (Vol. Cambridge). Cambridge University Press.
- Heaton, J. (2008). Secondary Analysis of Qualitative Data: An Overview. *Historical Social Research, 33*, 33-45.
- King, A., & Hoppe, R. B. (2013). "Best practice" for patient-centered communication: a narrative review. *J Grad Med Educ, 5*(3), 385-393. <https://doi.org/10.4300/JGME-D-13-00072.1>
- Lakoff, G., & Johnson, M. (1980). *Metaphors we live by*. University of Chicago Press.
- Lanceley, A., & Clark, J. M. (2013). Cancer in Other Words? The Role of Metaphor in Emotion Disclosure in Cancer Patients. *Br J Psychother, 29*(2), 182-201. <https://doi.org/10.1111/bjp.12023>
- Lilleker, J. B., Gordon, P., Lamb, J. A., Lempp, H., Cooper, R. G., Roberts, M. E., Jordan, P., Chinoy, H., Network, U. K. M., & Myositis, U. K. (2017). Patient-centred standards of care for adults with myositis. *BMC Rheumatol, 1*, 4. <https://doi.org/10.1186/s41927-017-0002-7>
- Maguire, R., Connaghan, J., Arber, A., Klepacz, N., Blyth, K. G., McPhelim, J., Murray, P., Rupani, H., Chauhan, A., Williams, P., McNaughton, L., Woods, K., & Moylan, A. (2020). Advanced Symptom Management System for Patients with Malignant Pleural Mesothelioma (ASyMSmeso): Mixed Methods Study. *Journal of medical Internet research, 22*(11), e19180. <https://doi.org/10.2196/19180>
- Masukume, G., & Zumla, A. (2012). Analogies and metaphors in clinical medicine. *Clin Med (Lond), 12*(1), 55-56. <https://doi.org/10.7861/clinmedicine.12-1-55>
- Miller, R. (2010). Speak Up: 8 Words & Phrases to Ban in Oncology! *Oncology Times, 32*(12), 20.

- Nuffield Trust. (2021a, 17.08.2023). *Stillbirths and neonatal and infant mortality*. Nuffield Trust. <https://www.nuffieldtrust.org.uk/resource/infant-and-neonatal-mortality#background>
- Nuffield Trust. (2021b, 15/11/2021). *Supporting patients to manage their long-term conditions*. Nuffield Trust. <https://www.nuffieldtrust.org.uk/resource/supporting-patients-to-manage-their-long-term-condition-s>
- Page, B. F., Hinton, L., Harrop, E., & Vincent, C. (2020). The challenges of caring for children who require complex medical care at home: 'The go between for everyone is the parent and as the parent that's an awful lot of responsibility'. *Health Expect*, 23(5), 1144-1154. <https://doi.org/10.1111/hex.13092>
- Pena, G. P., & Andrade-Filho, J. (2010). Analogies in medicine: valuable for learning, reasoning, remembering and naming. *Adv Health Sci Educ Theory Pract*, 15(4), 609-619. <https://doi.org/10.1007/s10459-008-9126-2>
- Pragglejaz Group. (2007). MIP: A method for identifying metaphorically used words in discourse. *Metaphor and Symbol*, 22(1), 1-39.
- Reisfield, G. M., & Wilson, G. R. (2004). Use of metaphor in the discourse on cancer. *J Clin Oncol*, 22(19), 4024-4027. <https://doi.org/10.1200/JCO.2004.03.136>
- Rucinska, Z., & Fondelli, T. (2022). Enacting Metaphors in Systemic Collaborative Therapy. *Front Psychol*, 13, 867235. <https://doi.org/10.3389/fpsyg.2022.867235>
- Semino, E., Demjen, Z., & Demmen, J. (2018). An Integrated Approach to Metaphor and Framing in Cognition, Discourse, and Practice, with an Application to Metaphors for Cancer. *Applied Linguistics*, 39(5), 625-645.
- Semino, E., Demjen, Z., Demmen, J., Koller, V., Payne, S., Hardie, A., & Rayson, P. (2017). The online use of Violence and Journey metaphors by patients with cancer, as compared with health professionals: a mixed methods study. *BMJ Support Palliat Care*, 7(1), 60-66. <https://doi.org/10.1136/bmjspcare-2014-000785>
- Skelton, J. R., Wearn, A. M., & Hobbs, R. (2002). A concordance-based study of metaphoric expressions used by general practitioners and patients in consultation. *British Journal of General Practice*, 52(475), 114-118.
- Sonntag, S. (1978). *Illness as metaphor*. Farrar, Straus and Giroux.
- Southall, D. (2013). The patient's use of metaphor within a palliative care setting: theory, function and efficacy. A narrative literature review. *Palliat Med*, 27(4), 304-313. <https://doi.org/10.1177/0269216312451948>
- Stafford, M., Steventon, A., Thorlby, R., Fisher, R., Turton, C., & Deeny, S. (2018). *Understanding the health care needs of people with multiple health conditions*.
- Stibbe, A. (1997). Fighting, warfare and the discourse of cancer. *South African Journal of Linguistics*, 15(2), 65-70.
- Stine, J. J. (2005). The use of metaphors in the service of the therapeutic alliance and therapeutic communication. *J Am Acad Psychoanal Dyn Psychiatry*, 33(3), 531-545. <https://doi.org/10.1521/jaap.2005.33.3.531>
- Strang, J., Griffiths, P., & Gossop, M. (2006). Heroin smoking by 'chasing the dragon': origins and history. *Addiction*, 92(6), 673-683.
- Street, R. L., Jr., Makoul, G., Arora, N. K., & Epstein, R. M. (2009). How does communication heal? Pathways linking clinician-patient communication to health outcomes. *Patient Educ Couns*, 74(3), 295-301. <https://doi.org/10.1016/j.pec.2008.11.015>
- Wittenberg, R., Hu, B., Barraza-Araiza, L., & Redhill, A. (2019). *Projections of older people with dementia and costs of dementia care in the United Kingdom 2019-2040*. https://www.alzheimers.org.uk/sites/default/files/2019-11/cpec_report_november_2019.pdf