



COMMENT



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# Exploration of the social and philosophical underpinning of ‘the patient’—what this means for people with a long-term condition

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Should healthcare professionals use the term ‘patient’? A patient is a social construct, in a biomedical model, in which each actor has their role to play. This model has been criticised as belonging to an era of medical hegemony and (mis)represents an individual seeking healthcare as one who is simply a passive participant and recipient of care. The ‘Language Matters’ campaign, for people living with diabetes, has sought to address the role of language in interactions between healthcare providers. A key point raised in the campaign is whether someone who feels well, but has ongoing healthcare input, should be referred to as a patient? In this article, we address the concept of a patient and how its use can belie a particular mindset (or ‘discourse’) in which power is established in a relationship and can lead to individuals being defined by their condition. However, for some linguistic communities (such as nurses and doctors), a patient may be considered less as one over whom they have dominion, but rather someone for whom they have specific responsibilities and duty of care. Drawing upon the philosophical theories of language—that the meaning and inference of a word is dependent on its use—we argue that the context in which use of the term patient occurs is crucial. Without more fundamental cultural disruption of the biomedical model, word substitution, in itself, will not change perception.

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## Introduction

The ‘language matters’ campaign for diabetes originated in Australia in 2011 (*Diabetes Australia. Position Statement. A new language for diabetes, 2011*) and has since been adopted in The United States of America, India, Latin America and the UK (“Language Matters Diabetes”, 2020; Cooper et al. 2018). It encourages positive interactions with people living with diabetes by raising awareness of the importance of the language we use, the information we convey and the effect that it has upon others. The campaign covers a range of verbal and non-verbal communicative scenarios (such as active listening and expression of empathy). One of the guidance points is to “avoid ‘patient’ with diabetes—it can imply that the person is not actively participating/passive” (Cooper et al. 2018).

Should healthcare professionals use the term ‘patient’? How this question has arisen, and the philosophical underpinning of the language used in healthcare are addressed in this article. We have drawn upon semantic philosophy (Frege, 1952; Quine, Van (1960); Wittgenstein, 1997) and social identity theory (Conrad, 2005; Goffman, 1959; Jamieson, 1975; Oyserman, 2007, 2009) to examine whether the concept of a ‘patient’ has a meaningful role for people living with a long-term condition.

Diabetes is traditionally considered as two subtypes. Type 1 diabetes (10% to 15% of cases) was classically a condition with onset in childhood/early adulthood but is now recognised to present well past middle age. People with type 1 diabetes use insulin daily, in the form of multiple injections or an insulin pump, and monitor blood glucose and adjust insulin doses according to carbohydrate intake, activity levels, results of blood glucose monitoring, stress and illness. Type 2 diabetes is often identified in mid- to older-age but it is now frequently seen in children (Shah and Nadeau, 2020). Three-quarters of individuals with type 2 diabetes take glucose lowering therapy (Zinman et al. 2015) and insulin is used in approximately 10% (Wilkinson et al. 2018). Diabetes is therefore an exemplar of a lifelong condition that is often symptom-free, but which can have significant complications if left untreated. However, the arguments as to whether it is valid or appropriate to refer to such individuals as ‘patients’ may equally apply to other lifelong conditions with potential for health complications, such as high blood pressure or high cholesterol.

## People should not be defined by their health or long-term conditions

The 20th century philosopher David Lewis put the view that a convention is a regularity in behaviour, sustained by a system of preferences and expectations among a population (Jamieson, 1975). Employing the language of game-theory, Lewis argued that conventions are established by “populations” in order to solve recurring “coordination problems”... obstacles facing two or more people, where the best outcome for each person can result only by the coordination of their actions (Lewis, 1969). Meaning in language is therefore a matter of convention—but conventions occur when alternatives are possible. In other words, there is nothing inherently right or wrong about the language solution, but its adoption facilitates communication. It is important to emphasise that the existence of a convention often creates reason for its self-perpetuation; for instance, the use of ‘you’ and the informal ‘thou’ were used up to the 17th century, at which time ‘thou’ dropped from favour as it became to be seen as impolite and has been replaced in most contexts by ‘you’, to this day.

Linguistic convention is a significant plank to *symbolic interactionism*—the insight that human social organization is based almost entirely on the use of meanings (Carter, Fuller (2016)). However, in the event of a coordination problem between speaker and listener (or writer and reader), change is required. Lewis’s

notion of convention (Lewis, 1969) allows for conventions that evolve gradually and tacitly as a side-effect of agents’ independent need to make their way in the social world. Lewis’s definition also allows that conventions could be instituted explicitly—epitomized by Language Matters publications.

One target of the Language Matters campaign relates to the speaker: they must break free of constrained thinking whereby use of ‘patient’ will influence the medicalisation of thought in relation to the individual (semantic determinism). To no longer have ‘patients’ is a profound cultural disrupter to the biomedical model.

## Social constructionism and the biomedical model

The biomedical model (Wade and Halligan, 2004) has its roots in the objectivist and positivist philosophy of science - there is only one reality and by carefully dividing and studying its parts, the whole can be understood. Clinical reasoning is underpinned by this objectivist understanding of reality... “the belief that the ultimate reality one is dealing with is biological ... medical professionals commonly assume that clinical reasoning is a form of implied natural science” (Wilson, 2000, pg 204). The role of the patient in this model is to suffer from the disease. The physician is a detached neutral observer and the patient is a passive and grateful recipient of care (McWhinney, 1989). Society has adopted this biomedical model, for which the patient has an important role. However, the word ‘patient’ itself is not important but rather the concept that society applies to the word. Some advocate using ‘person living with diabetes’ rather than ‘patient’. In this case, the referent would no longer be a specific object but rather a description. The term ‘person living with diabetes’ may be considered an individuum—an indivisible entity. Their representation now includes ‘diabetes’. They are defined by having diabetes in their life. PLWD (or PWD) is now used as short-hand for ‘person living with diabetes’ (Hartmann-Boyce et al. 2021; Tenderich et al. 2019). Is referring to someone as a PLWD any less impersonal than as a ‘patient’? The problem is not with the word—we must look to *uses* instead. This was a theme advanced by Ludwig Wittgenstein, who argued that there was not an a priori ‘essence’ of a word but that we should look instead at how we use words. In his work *Philosophical Investigations* (Wittgenstein, 1997), Wittgenstein argued that the limits of language utility are set by social convention—“meaning is use”. In other words, as long as a linguistic community uses a word in a particular way, it has that meaning. Hence, his advice to anyone debating the substance of an ontological claim would be to make sure that you are not using terms in a non-standard way. Taken out of their everyday contexts, words can mean anything and nothing.

Wittgenstein’s view of language as social practice is instructive for all of us who see to communicate clearly and effectively. We must think about the audience. A linguistic community within a hospital (for example) might be justified in using the term ‘patient’ to convey an individual for whom they have a responsibility of care. Conversely, it might be considered that (for example) dietary information leaflets, sent to someone’s house after hospital discharge, should not contain the word ‘patient’.

## A long-term condition as an identity

The second target of the Language Matters campaign are people living with diabetes. They are living their everyday lives, away from any medical domain. There is no justification for medical intrusion. For them, receipt of disapproving, judgemental, stigmatising, or critical language can negatively impact their self-esteem, self-efficacy, damage the therapeutic relationship, and cause diabetes distress (Cooper et al. 2018). The psychological toll this takes can be considerable. Labelling reduces a person to their

health condition and overlooks their individuality. The term “patient” may intentionally or unintentionally reinforce societal stigmas associated with health conditions. Hence by removing ‘patient’ from the lexicon, the Language Matters campaign aims to reduce the sensation of medicalisation over their otherwise ‘normal’ lives. From a phenomenological standpoint, the Language Matters campaign is implying that it is better to conceive of a ‘patient’ as a person who occupies a lived context.

**Person-centredness.** The centrality of the ‘person’ has formed the foundation for Person-Centred Care’ (McCormack and McCance, 2006). In this approach, the person living with a chronic illness actively participates to explore the management of their health and well-being within the context of their whole life and family situation. This is facilitated and supported by the health-care worker. As Hippocrates (allegedly) said ‘*it is more important to know what sort of person a disease has, than to know what sort of disease a person has*’.

The gain from this approach is that when people play a more collaborative role in managing their health and care, they are more likely to adhere to their treatment plans and less likely to use emergency hospital services (De Silva, 2011). In the last 50 years, the concept of ‘person-centredness’ has become established in approaches to the delivery of health care (Balint, 1969; Coulter and Oldham, 2016; Mead and Bower, 2000) and particularly within nursing (McCormack and McCance, 2006).

**Identity.** Identities are the traits and characteristics, social relations, roles, and social group memberships that define who one is (Oyserman, 2007, 2009). There can be occasions when someone’s identity, defined by the presence of diabetes, is considered advantageous and is utilised. For instance, ‘patient groups’ can provide peer support to their members and ‘patient advocacy groups’ may advise charities and professional groups of strategic priorities. Such groups will also consist of representatives drawn from people defined by other identities: doctors, statisticians, economists, etc. Despite the unique life-stories and myriad features to their identity, the individual is included because they have a lifelong condition. This reflects the complexity and contrast between personal and social identities. A person may not wish to be defined by having diabetes but a social identity—involving the knowledge that one is a member of a group (Jetten et al. (2012); Tajfel, 1981)—might embody the presence of diabetes. If changes in self-identity are imposed rather than chosen, individuals may experience a loss of autonomy and control over their narrative. This could lead to diabetes distress, as described above.

However, if it is correct to say that diabetes doesn’t define a personal identity, then what does define identity? The assumption of stability in identity is belied by the malleability, context sensitivity, and dynamic construction of the self as a mental construct. Identities are not the fixed markers people assume them to be but are instead dynamically constructed in the moment. The fluidity of identity underscores its adaptability and responsiveness to changing circumstances—this challenges the fixed notions that people may have of someone’s identity. We all have multiple roles as a co-worker, partner, and daughter or son, etc. Each of which are very different. Difficulties arise when we try to embody our multiple identities simultaneously. Erving Goffman argued, in *The Presentation of Self in Everyday Life*, that ‘Identity negotiation’ is the idea that each of our relationships is built on a sort of mutually-agreed-upon, identity-based code of conduct (Goffman, 1959). This sets expectations about how each person will behave with the other one. Hence, if a person with diabetes is discussing their care, in a healthcare consultation, it

might be considered that they are in the role of a patient. Once they leave that scene, they may then switch to another identity (Turner, 1995). Only in the moment are we being the healthcare professional/the patient. Difficulties arise when that moment is captured and transcribed, for the moment is over and yet the descriptor ‘patient’ remains.

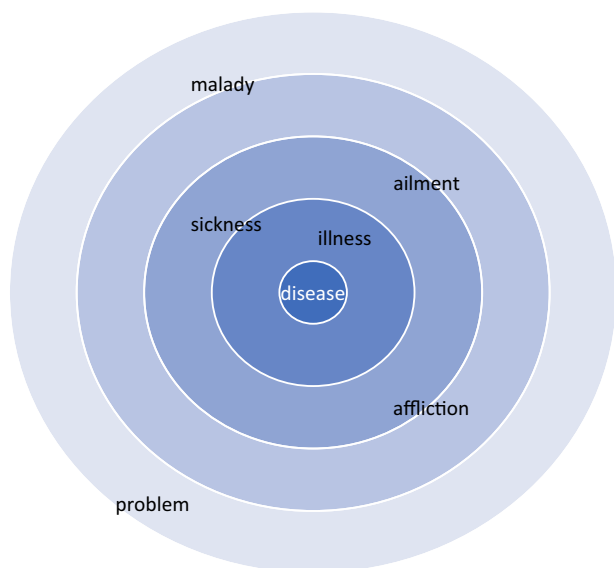
We will now progress from the sociological theories of meaning and social construction, to discuss the philosophical theories of language meaning.

### Word meaning

How then, do we determine the meaning of a word? One place to start is its etymology. The term ‘patient’, meaning “pertaining to a medical patient” arose in the late 14th century, and stems directly from Latin *patientem* “bearing, supporting, suffering, enduring, permitting”. It is this connotation of suffering and enduring that appears anachronistic: many individuals with diabetes can lead perfectly normal lives, whilst also having a condition that may be considered a ‘disease’ in certain classifications. But language changes over time, it adapts to suit the needs of its users. Some meanings disappear when no longer useful and others spread if they fit into a new environment (semantic change). Wittgenstein wrote that ‘language is a living phenomenon, and like most living things, there’s going to be change and variation’. Steadfast adherence to a definition over 600 years old is inconsistent with a living language.

Dictionary definitions can be helpful, but dictionaries are reactive—not proactive. Words and definitions are added once they become established in common parlance. Looking up a meaning in a dictionary may give an outdated definition. Words are, in fact, ‘word stories’ and their developments are captured in a dictionary, as they continue to unfold.

Word category membership may be describable using *necessary and sufficient conditions*. For example the word ‘bachelor’ has four necessary predicates [unmarried], [male], [adult], [human]. Taken together these constitute a *sufficient condition*. However, the all-or-nothing approach of inclusion or exclusion of the basic conceptual components of meaning (semantic features) for any lexical item, is not very close to reality. Meanings are separate to how we define the words that we are using. Wittgenstein argued that such (Aristotelian) categorisation doesn’t work. He gave the example as to whether it’s possible to define a ‘game’? This may be described as something to relieve boredom (but so is reading a book); competitive (but solitaire involves just one player); involves rules (but throwing and chasing a ball could be considered a game), etc. There are no *necessary* and *sufficient* conditions for a ‘game’. Even though it may be a struggle to come up with a definition of the word ‘game’, people can still know what the word ‘game’ means, through *family resemblance*. There is no one essential common feature but rather a series of overlapping similarities, where no one feature is common to all examples of a game. In the late 1970s, Eleanor Rosch developed *Prototype theory* which allows for words to have firstly, a fuzziness of category boundaries and secondly, degrees of representativity of category members (not the binary presence or absence of Aristotelian categories) (Rosch, 1977; Rosch, 1983). These two facts lead to graded category membership. The prototype is the ‘best’ example of the category. Membership of an individual in a category is determined by the perceived distance of resemblance of the individual to the prototype of the category (Fig. 1). Drawing on prototype theory, we considered whether a word could be found in the English language that sits between ‘patient’ and a (healthy) ‘person’ but found that there are none. Although not exhaustive, we have interviewed speakers of Asian languages including Cantonese, Hindi and Urdu; again finding no such word. Perhaps



**Fig. 1 Prototype theory.** The member fulfilling most features, to a higher degree, is closer to the prototype and at the centre of the category. All other members, less prototypical, are further away from the centre (graded membership). This example encompasses words used to denote a debilitating medical concern.

a difficulty with ‘patient’ is that it represents all those ‘outside of health’? Health has been defined as ‘a state of complete physical, mental and social well-being’ (World Health Organisation, 2005), which is very hard to achieve for a great many people. As a binary phenomenon, there are no alternatives from which to choose. This in-between zone, where people can be effectively well and yet never be considered cured has been termed the “postmodern experience of illness” (Frank, 1995) and has been the subject of discussion in those surviving a major illness, such as myocardial infarction, or cancer, but who have periodic clinical review thereafter. A word could be invented to fill this linguistic gap but as Wittgenstein outlined, it is not necessary. What is important is the way that we use words.

### Who decides on the meaning of a word? The speaker or the audience?

One dictionary reference of the word ‘patient’ is “a person who is receiving medical treatment from a doctor or hospital” (“Collins dictionary”, 2021). However, the sense that any of us conjures when thinking of ‘patient’ may vary enormously. This may include a term describing a perfectly healthy individual who is paying an invoice to a doctor for services rendered, to one who is critically ill and needing hourly attention in hospital. It is perhaps the latter extreme which is one that resonates and hence why it is felt to be inappropriate to use ‘patient’ in someone with a lifelong condition.

At issue is what the philosopher Gottlob Frege described in the late 19th century as the *sense* and *referent* of the word (Mendelsohn, 2005). The referent of a word is the object or concept that it’s meant to designate (for this example; a person with a long-term condition). The sense of a word is the way in which the words tie us to the object or concept. Frege had abandoned the view, common at the time, that a word gets its meaning in isolation, independently from all the rest of the words in a language. Instead, he advocated the context principle, according to which it is only within the context of an entire sentence that a word acquires its meaning.

Words can go wrong in lots of different ways and when it does, it usually comes down to the distinction between speaker meaning and audience meaning—or what a speaker intends, as opposed to what a listener understands. Regarding the word ‘patient’, what does the speaker intend and what does the audience infer? This will depend upon who the speaker is and the people comprising the audience. Why and how could the speakers or audience have changed in recent years?

**The speakers have changed.** Providers for mental health, such as psychologists, have historically used the term ‘client’ to denote recipients of their care. However a 2018 resolution by the American Psychological Association advocated use of the term ‘patient’, rather than ‘client’, in all of its publications, policies, and rules (American Psychological Society, 2018). Likewise, other allied healthcare providers—who increasingly have an extended role in case management and undertake tasks formerly restricted to doctors—have taken up the use of the term ‘patient’. As an example, within its Code of Ethics document, the Institute of Chiropractors and Podiatrists alternately uses the terms *client* and *patient* to describe users of their services (The Institute of Chiropractors and Podiatrists, 2021). For pharmacists, there has been debate as to whether or not they interact with ‘patients’, as exemplified by a publication for pharmacists with the subheading: ‘Transforming customers into patients’ (Guirguis, Johnson, and Emberley, 2014). Therefore, in many more interactions with healthcare, outside of the traditional setting of consultation with doctors and/or nurses, people living with diabetes might now find themselves referred to as ‘patient’.

**The audience has changed.** Within the framework of patient- or person-centred care, the representation of illness and disease is shifting from doctors to patients (Cliff, 2012). For example, communication about a patient used to be between healthcare workers, with the patient excluded. However, ‘The NHS Plan’ (2000) recommended that “patients should as of right receive copies of all correspondence between health professionals about their care” (The NHS Plan: A plan for investment. A plan for reform 2000). A ‘letter’ includes communication between different health professionals, for instance those from and to primary care doctors, hospital doctors, nurses, therapists and other healthcare professionals. In addition, in the UK, the Data Protection Act 2018 (section 45) now allows people the right to request a copy of their records (“Data Protection Act.” (2018)). The linguistic community has expanded. It is no longer solely between healthcare professionals. Communication is now being written directly to the patient with healthcare workers copied in, rather than the other way round (Department of Health and Social Care Policy paper. Government response to the independent inquiry report into the issues raised by former surgeon Ian Paterson. 2021).

### Possible implications if ‘patient’ is no longer used to denote those living with a lifelong condition

**For patients.** *Narrowing* is a form of semantic shift whereby a word’s meaning shifts from something general, to something more specific. For example, up to the 15th century, the term ‘girl’ was used to refer to a child of any sex, before morphing for use only for female children. If ‘patient’ is no longer applied to those with a lifelong illness [that doesn’t impact on their life], could that mean a narrowing of the term to only those hospitalised or significantly disadvantaged? Could pejoration of the term result, with ‘patient’ having the same negative interpretation as ‘invalid’, ‘diseased’, etc.?

Just as the term ‘patient’ may be an unwanted reminder when used outside of the healthcare environment, in the clinic setting it can be helpful; indeed, in most surveys of individuals who access healthcare settings, it has been the preferred term of reference (Costa et al. 2019). It assists the health care professional to remember the unique obligation they have to that individual, under all circumstances (Raphael and Emerson, 1991). For if they are not patients, what responsibility to them, would a doctor or nurse have? Alternative descriptors imply less ethical constraint on the person-to-person interaction—for instance, a ‘client’ suggests a more business-like arrangement. Use of the term ‘agents’ rather than ‘patients’ has been mooted (Costa et al. 2019). This highlights the agency (control) that a person would have over their life and decision making and perhaps deliberately, has less emphasis of the responsibility of the clinician towards the patient but a more equal-footing relationship. However, ‘agents’ has more than one sense. For instance, it can include a person who acts on behalf of another person; this is the opposite of someone taking control over their own life.

**For doctors and nurses.** The implication for doctors may be more immediate. A consensus statement on the Role of the Doctor, from the Academy of Medical Royal Colleges and other leaders of the medical profession, read “*Doctors as clinical scientists apply the principles and procedures of medicine to prevent, diagnose, care for and treat patients with illness, disease and injury and to maintain physical and mental health*” (The Consensus Statement on the Role of the Doctor, 2008). Therefore, to the medical establishment, the term ‘patient’ appears an existential necessity to be a doctor. Is there an institutional, conservative pressure exerted by the medical establishment to retain the term ‘patient’? This would seem unfounded; after all, in the UK surgeons lose the title ‘Dr’ and yet still care for patients. By contrast, after a four-month consultation exercise, with over 160,000 responses, the Royal College of Nursing defined nursing as “*the use of clinical judgment and the provision of care to enable people to promote, improve, maintain, or recover health or, when death is inevitable, to die peacefully*” (Waters 2003). ‘Patients’ do not feature but the definition deftly treats nursing as a mass noun - perhaps better representative of the multi-faceted nature of nursing throughout society.

## Conclusions

This essay has examined whether replacing one word with another changes the meaningfulness of the language used in the care of someone with a long-term condition. We have discussed how the concept of the role of a patient has been socially constructed and that challenging the use of the term ‘patient’ is a cultural disrupter. There are few (if any) existing alternatives to describe a person who is in receipt of chronic healthcare but otherwise feels well. Attempts at neologisms (such as ‘person living with diabetes’ or ‘PLWD’) run the risk of leading to no fundamental change in the perception of such individuals. A far more important consideration than the term used is *how* any such word (or phrase) is being used. Healthcare workers need to be helping the person with an illness, not an illness in possession of a person. Behaviour, not semantics must change. An individual is certainly more than their diagnosis.

## Data availability

Data sharing is not applicable to this research as no data were generated or analysed.

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### Author contributions

M.B.W., R.E. and D.C. contributed equally to the concept of the work, the original draft preparation and writing, as well as to subsequent review and editing.

### Ethical approval

Ethical approval was not required as the work is not research did not involve human participants.

### Informed consent

This work was not research and did not involve human participants and therefore no consent was required.

### Competing interests

The authors declare no competing interests.

### Additional information

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