Presenting complaint: use of language that disempowers patients

Caitríona Cox and Zoë Fritz argue that outdated medical language that casts doubt, belittles, or blames patients jeopardises the therapeutic relationship and is overdue for change

Caitríona Cox, Zoë Fritz

Language is important. It is a vehicle for sharing knowledge and understanding, and by means of which we can express and communicate our values to others. In a medical context, language does more than transfer information between patients and healthcare providers—it has the potential to shape therapeutic relationships.\(^1\)\(^2\) Indeed, specific word choices and phrases affect how patients view their health and illness,\(^3\) reflect healthcare workers’ perceptions of their patients,\(^4\)\(^5\) and influence medical care and treatments offered.\(^5\)\(^6\) Language in medical narratives also shapes how trainees think, talk, and act, perpetuating any ingrained biases.\(^8\)

In the UK, guidance by the UK National Institute for Health and Care Excellence (NICE) on shared decision making focuses on the importance of communicating risks, benefits, and consequences of interventions to patients.\(^9\) Yet some language used either to communicate directly with patients, or when discussing patient care with other healthcare professionals, might inadvertently disempower patients.\(^10\) Although the derogatory slang that was historically used is now nearly universally recognised as unacceptable,\(^11\) language that is belittling, doubting, or blaming continues to be commonly used in everyday clinical practice, both verbally and in written notes.\(^12\)\(^15\)

Drawing on existing research, we describe how such language, while often taken for granted, can insidiously affect the therapeutic relationship and suggest how it could be changed to foster a relationship focused on shared understanding and collective goals. It is difficult to establish a comprehensive list of all potentially damaging language. We present examples that we or patients we spoke to have experienced, or which have been described in the literature, but there are likely to be many other phrases—including in languages other than English—that should be reconsidered.

Language that belittles patients

Some language used in clinical practice implicitly casts doubt on patients’ experiences or infers a degree of petulance. One such term—presenting complaint—is so central to the patient-doctor encounter that many will have stopped hearing the words for what they are. Complain has negative connotations, and use of “problem” or “concern” instead has been suggested as more sympathetic.\(^8\)\(^16\) But not all patients have symptoms that are causing concern.\(^3\) A patient may, for example, be seeking to understand the cause of an untroublesome lump. It would be more neutral to refer to a patient’s reason for engaging with healthcare (which could include diagnosing or treating a symptom, managing a condition, proactively planning for life changes, or preventing future complications).

In medical documentation, doctors sometimes use language that questions the authenticity of a patient’s symptoms.\(^15\) For example, they often translate the reported absence of symptoms or experiences as the patient “denying” symptoms—for example, “patient denies fever, chills, or night sweats.” To deny is to refuse to admit the truth or existence of something, and the term can hint at untrustworthiness. In a study examining reactions to outpatient notes, patients responded negatively to language that questioned the validity of their experiences. One patient stated: “I did not deny these things. I said I didn’t feel them. Completely different. Language matters.”\(^16\) Similarly, writing, “patient claims pain is 10/10” instead of “patient experiencing 10/10 pain” implies a degree of disbelief. Other phrases that cast doubt on the validity of the patient’s experience have also been criticised.\(^5\)\(^8\)\(^16\)\(^17\)

It is, of course, sometimes appropriate for a clinician to exercise some scepticism about a patient’s account (for example, when a patient asserts that they have not taken any illicit substances but a urine toxicology screen gives positive results). But the terms denies and claims are widely used in situations where there is no reasonable basis for such doubt, probably out of (bad) habit rather than any disbelief. By contrast, physician observations are usually described as “note,” “observe,” or “find.”\(^17\) Clinicians record their (somewhat subjective) perception of the presence or absence of signs on examination yet it is rarely documented as, “Dr claimed to hear diastolic murmur.”

Language that emphasises the patient as passive or childlike

Much of the language used in clinical medicine inappropriately renders the patient the object of the doctor’s action, conferring passivity to the patient while emphasising the doctor’s position of power.\(^14\) For example, doctors “take” a history, or “send” patients home.

This is particularly prominent in the narratives surrounding conditions such as diabetes. There is an authoritarianism, for example, in talking about patients (not) being “allowed” certain foods by their doctors.\(^18\)\(^19\) Although patients can find such language upsetting or frustrating,\(^20\) some also adopt a childlike narrative, describing the effect of being “naughty” or “good” on their blood sugars, or recounting being “scolded” by healthcare professionals.\(^18\)
The terms “compliance” and “non-compliance” (in relation to taking medication) are also authoritarian, suggesting that patients must obediently comply with the doctor’s recommendations. Patients too have objected: “Being described as ‘non-compliant’ is awful and does not reflect the fact that everyone is doing their best.” Concordance and adherence have been suggested as alternatives; these seek to reconceptualise the doctor-patient relationship as a partnership, with treatment decisions the result of a collaboration towards a shared goal.

Language that blames patients

Another problematic category of language is which implicitly places the blame on patients for poor outcomes. This has also been explored in the context of diabetes, where commonly used language is often moralistic, tacitly placing the blame on the patient for poor outcomes. The term “poorly controlled diabetic” can be stigmatising and make patients feel judged. More generally, talking about glucose control has been highlighted as unhelpful. Although it may be useful to conceptualise patients as capable of exerting a positive influence over their health, it is important to be realistic about the nature of diabetes and acknowledge the challenges in its management. Many patients will have difficult to manage disease for complex reasons beyond their control. It may be better to acknowledge that patients can never truly control their blood glucose concentrations by using terms such as influence. Use of “poorly controlled” is also damaging in other conditions such as epilepsy, where describing patients as having poorly controlled seizures is correlated with worsened stigma.

Treatment failure is another example of patient blaming language. Here doctors assign patients responsibility for something over which they have no control: “the patient failed immunotherapy” rather than “immunotherapy failed the patient.” In obstetrics, clinicians refer to “failure to progress” and “poor maternal effort.” These linguistic shifts implicitly suggest that the patient is the cause of the failure (perhaps even because of a lack of will or effort), rather than the limitations of the treatment or the doctor. We should move away from language which implies (however subtly) that the patient is personally responsible for a non-favourable outcome.

What’s in a word?

Language that belittles, infantilises, or blames patients runs counter to the collaborative relationships we are trying to foster through initiatives such as shared decision making. Patterns of language that connote objectivity and credibility to physician findings while questioning the reliability of patients’ experiences hint at an ongoing lack of respect for patients—a poor foundation for power sharing in therapeutic relationships. Critics of word replacement as part of political correctness argue that by focusing on—and trying to change—the words we use, as opposed to the intent or context, we fail to bring about meaningful change. However, written and verbal communication can shape the therapeutic relationship by subtly altering the way both doctors and patients conceptualise and interpret it.

The negative effect of stigmatising language on the attitudes of healthcare professionals towards patients is well studied in the context of chronic pain and sickle cell disease. For example, a US vignette study compared the wording “substance abuser” with “having a substance use disorder,” finding that when substance abuser was used, healthcare workers more strongly agreed that the patient was personally culpable and that punitive measures should be taken. Another study compared neutral language with language implying patient responsibility (not tolerating oxygen mask v refuses oxygen mask), showed that the non-neutral term was associated with negative attitudes towards the patient and less prescribing of analgesic medication. There is also evidence that specific words used by clinicians can affect how patients feel about their doctors, thus directly influencing the therapeutic relationship. For example, participants in one study rated terms such as “fat” and “obese” as undesirable and blaming, with 19% reporting they would avoid future medical appointments if made to feel stigmatised about their weight by their doctor.

Furthermore, terms that disparage or confer passivity on patients leave little room for considering the reasons for a patient’s actions. Language should be reframed to explicitly relay a patient’s individual situation—for example, we might write “barriers to adherence include cost and polypharmacy in the setting of recent job loss” instead of simply, “patient is non-compliant.” By prompting doctors to name barriers, the nature of the conversation between patient and doctor might be changed, opening lines of communication for collective problem solving. As others have argued, using the right language “is not a matter of political correctness; it affects the core of our interactions.”

Because changing language can act as a catalyst for changing the way doctors think or approach patient care, reflecting on and updating the words we use might be considered part of a broader movement to support and promote a collaborative doctor-patient relationship. This has already been suggested in obstetrics and diabetes care. Engagement with patient groups is important to get changes right: what language do patients prefer, and what language do they find alienating or upsetting? It may be helpful for healthcare professionals to make small changes to their vocabulary (table 1).

### Table 1 | Suggested changes to terminology

<table>
<thead>
<tr>
<th>Problematic term</th>
<th>Suggested replacement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Denies chest pain</td>
<td>Reports no chest pain</td>
</tr>
<tr>
<td>Patient claims pain is x/10</td>
<td>Patient reports pain is x/10</td>
</tr>
<tr>
<td>Compliance</td>
<td>Barriers to adherence</td>
</tr>
<tr>
<td>Presenting complaint</td>
<td>Reason for attendance</td>
</tr>
<tr>
<td>Patient failed on x</td>
<td>X was not effective for the patient</td>
</tr>
<tr>
<td>Patient refused x</td>
<td>Patient declined x</td>
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</tbody>
</table>

Areas for future research

Much of the evidence presented here highlights the effect of language on the attitudes and perceptions of patients and doctors. Whether these perceptions or resulting shifts in therapeutic relationships translate into meaningful differences in patient outcomes, however, is not yet known. For example, although several
studies have shown that patients respond negatively to patronising or patient blaming language in diabetes, it is not clear whether using more empowering language will change clinical outcomes (eg, a lower glycated haemoglobin concentration or avoidance of complications).

The direct and indirect pathways by which doctor-patient communication might improve health outcomes have been explored; there is some evidence for the doctor-patient relationship having a beneficial effect on objective health measures outcomes. The large number of potential confounding factors make it difficult to robustly isolate the effect that language changes might have on disease progression or management. We should start by working with colleagues from health communication research to map out the effect of language on patient and clinician perceptions, and of those perceptions on outcomes—both desired and unintended.

There is also a need for research examining the effectiveness of interventions to change language, for example, in medical education. There is evidence to suggest that interventions to improve communication skills can have an enduring effect, but little research has specifically investigated interventions to change language as suggested here.

Time for change

Much of the language highlighted here is deeply ingrained in medical practice and is used unthinkingly by clinicians. However, we believe that it is now outdated. There is widespread acknowledgment of the need for collaborative doctor-patient relationships that pool the expertise of patients and health professionals to agree management. Patients do not like many of these commonly used phrases, and some are associated with problematic changes in the attitudes of healthcare workers.

Although evidence that language affects longer term health outcomes would strengthen the case for making alterations, the potential effect on the attitudes of patients and doctors is still important. Changing language to facilitate trust, balance power, and support shared decision making is unlikely to harm patients and should be viewed as a positive step in promoting a healthy therapeutic relationship.

Electronic health records have been suggested as a tool for making space for patient focused narratives, and there is a growing movement for increased patient access to their notes. The language used in medical narratives therefore has the potential to affect patients in new ways. We encourage all to reflect on the words and phrases currently used in practice, in particular considering whether they hamper or help to establish a genuinely collaborative therapeutic relationship.

Key messages

- Some commonly used language in healthcare confers petulance on patients, renders them passive, or blames them for poor outcomes
- Such language negatively affects patient-provider relationships and is outdated
- Research is needed to explore the impact that such language could have on patient outcomes
- Clinicians should consider how their language affects attitudes and change as necessary

Provided comments on the suggestions for change and offered further examples of language which could be modified.

Public and patient involvement: A group of 10 participants was consulted to gather opinions on the suggested changes to language discussed here. Many of the examples resorted with participants, who felt strongly that this was a topic worthy of discussion. Participants provided written feedback (including suggestions for other changes in language), which was synthesised by the authors.

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Contributors and sources. ZF is a consultant physician in acute medicine at Addenbrooke’s Hospital. Her research is focused on identifying areas of clinical practice that raise ethical questions and applying rigorous empirical and ethical analysis to explore the issues and find effective solutions. CC is working with ZF on ethical issues surrounding the communication of diagnostic uncertainty. ZF and CC, together conceived this article. CC produced the first draft and ZF was closely involved in further drafts, they drew on patient focused research in a range of settings to explore the issues in the article. A PPI group