Language matters: a UK perspective

How to cite:


For guidance on citations see FAQs.

© [not recorded]

Version: Accepted Manuscript

Link(s) to article on publisher’s website:
http://dx.doi.org/doi:10.1111/dme.13801

Copyright and Moral Rights for the articles on this site are retained by the individual authors and/or other copyright owners. For more information on Open Research Online’s data policy on reuse of materials please consult the policies page.

oro.open.ac.uk
Language matters; a UK perspective

<table>
<thead>
<tr>
<th>Journal</th>
<th>Diabetic Medicine</th>
</tr>
</thead>
<tbody>
<tr>
<td>Manuscript ID</td>
<td>DME-2018-00223.R2</td>
</tr>
<tr>
<td>Manuscript Type</td>
<td>Review</td>
</tr>
<tr>
<td>Date Submitted by the Author</td>
<td>01-Aug-2018</td>
</tr>
<tr>
<td>Complete List of Authors</td>
<td>Lloyd, Cathy E; The Open University, Faculty of Health &amp; Social Care; Wilson, Anthea; Greenfields, Powys; Whicher, Clare; Southern Health NHS Foundation Trust, Moor Green Hospital; Holt, Richard; University of Southampton, Human Development and Health Academic Unit; Kar, Partha; NHS England, Diabetes; Portsmouth Hospitals NHS Trust, Diabetes and Endocrinology</td>
</tr>
<tr>
<td>Keywords</td>
<td>health care delivery, psychological aspects</td>
</tr>
</tbody>
</table>
Language matters; a UK perspective.

CE Lloyd¹, A Wilson², RIG Holt³, C Whicher⁴, P Kar⁵, On behalf of the Language Matters Group.

¹School of Health, Wellbeing and Social Care, The Open University, UK, ²Montgomery, Powys, UK, ³Human Development and Health Academic Unit, Faculty of Medicine, University of Southampton, UK, ⁴Southern Health NHS Foundation Trust, Southampton, UK, ⁵NHS Trust, NHS England.

Address for correspondence:

Professor CE Lloyd
School of Health, Wellbeing and Social Care
Faculty of Wellbeing, Education and Language Studies
The Open University
Walton Hall
Milton Keynes
MK7 6AA

Tel: 01908 654283
email: Cathy.Lloyd@open.ac.uk

Word count 3867 (excluding abstract, tables and references)

Funding sources:

This review was supported by a small grant from NHS England.
Novelty statement

- This paper reviews existing evidence on the use of language in clinical encounters
- Poor language practices can lead to stigma, lack of engagement with self-management, low satisfaction with care and poor clinical outcomes
- Research has demonstrated the importance of good communication skills and that appropriate use of language can benefit psychosocial wellbeing and support optimal diabetes self-management
- Our review has directly informed the publication of a UK Position Statement on Language Matters

Key words: Language, type 2 diabetes, type 1 diabetes, psychosocial aspects
Abstract

Awareness of the importance of language in clinical encounters is mostly lacking or located within broader discussions on communication.

A scoping study was conducted to review the existing research which could increase our understanding of the role language plays as well as identify gaps in knowledge and inform the development of a position statement on language in diabetes care.

Evidence shows that although carefully chosen language can have a positive effect, there is a potential negative impact of language on people’s experiences of diabetes care. The use of stigmatising and discriminatory words during communication between health care practitioners and people with diabetes can lead to disengagement with health services as well as sub-optimal diabetes self-management. Clinical encounters can be compromised where language barriers exist or where there is limited understanding of cultural differences which may impact on diabetes self-management. What little empirical evidence there is shows that training can improve language and communication skills.

This review raises a number of questions which are being addressed by the NHS England Language Matters Group who have developed a set of recommendations to support the use of appropriate language in clinical encounters.
Introduction

Communicating impactful messages about health often rests on the assumption that the advice given will translate into changes in behaviour, for example stopping smoking or increasing physical activity. However, the profound often negative impact of language on how those messages are received during clinical encounters is largely ignored [1]. Good communication between the health professionals in the multi-disciplinary team is also vital and has been found to effect opportunities for optimal care. Conversely, poor communication and can negatively impact on outcomes [2]. Whilst huge strides have been made in the move towards more person-centred care, communication skills still need to be addressed in order to facilitate this [3]. This is especially true for people with diabetes where messages about self-management are numerous and ongoing throughout that person’s lifetime.

In recent times the language used for communication between health care professionals and people with diabetes has come under scrutiny [4]. Indeed a number of professional bodies, including the American Diabetes Association and Diabetes Australia, have made recommendations on how language should be used [5, 6]. Apart from the Diabetes UK recommendations for journalists, little has been done to explore the specific language needs of people with diabetes living in the UK. In addition to the indigenous population, there are a range of minority ethnic groups whose language needs are often not met [4, 5].

NHS England, in partnership Diabetes UK, has established a working group of people with diabetes, academic and professional groups and independent organisations, to address how refining the use of language can lead to better clinical outcomes and quality of life for people with diabetes. This paper reports findings from a scoping review of the existing evidence of the use of language in healthcare which can inform the everyday practice of health care professionals to optimise outcomes for people with diabetes.

Methods

A scoping review of the literature was conducted by one of the authors (AW) in order to identify published literature on the use of language in relation to clinical encounters between people with diabetes and health care professionals. The search was performed using The Open University library search engine, which includes databases Medline, Cinahl,
PubMed central, PsycARTICLES, Science Direct, Academic Search Complete, Communication & Mass Media Complete™ and Education Research Complete. Priority was given to papers that directly discussed interactions between healthcare professionals and patients in consultations (considering communication skills, disease management and/or outcomes/patient experience). Papers were included if they included applied key concepts to the language/communication elements of the ‘doctor-patient’ relationship, e.g. stigma, empowerment, cultural competence, patient satisfaction, clinical empathy or person-centred practice / person-first language and discussed patient opinions, attitudes, experiences of the communication. Papers were rejected if they: 1) did not directly address language in the context of diabetes or similar long-term condition management, 2) only discussed the challenges of a foreign language or 3) did not discuss the patient’s perspective: experiences, attitudes, etc.

In order to identify recent papers which were most relevant to current diabetes care practice, papers were limited to those published after 2000, with the exception of two papers (identified in later publications); one published in 1997 as it was one of only a few which included a discussion on patient outcomes [6] and one which took a broader focus on public perceptions regarding person-first terminology [7]. Search terms are shown in Table 1. Papers were selected by one author (AW) complemented with further selections on cultural competence by another (CW) and overseen by the first author (CL). Only articles published in English were considered. A total of 68 peer reviewed articles were selected from approximately 1500 search results by scanning titles and subject data, and reading abstracts. Our search indicated 5 broad although somewhat overlapping topic areas, which will be discussed in turn below: (1) the use of negative terms and their impact, (2) the experience of stigma, (3) culturally appropriate language, (4) existing interventions to address the use of language and improve communication in clinical encounters and (5) training opportunities to support these.

**Negative terms**

Research has demonstrated that negative terms, such as ‘uncontrolled’, ‘non-compliant’ or
‘non-adherent’ are often used in diabetes care, can lead to a disconnect between the person with diabetes and the clinician and have a significant impact on health outcomes [7-10]. For example, in one qualitative study in women with diabetes, communication with their health care professional was found to be the most important factor affecting diabetes self-management, with autonomy perceived by the health provider as ‘non-compliance’ [11]. Ideas about ‘non-compliance’ and ‘adherence’ are still prevalent, and indeed on searching the literature we found a substantial number of studies still using this term, perhaps reflecting the lack of clarity about what would be appropriate language. Terms assumed to have a negative connotations however, may not always be identified as such by all. Indeed different stakeholders, be it individuals with diabetes or health care professionals, may have preferences for person-first (‘I am a person with diabetes’) or disease-first (‘a diabetic’) language. Some people may simply apply the adjective ‘diabetic’ to themselves or another person. Although many people with diabetes may accept the label ‘diabetic’ unquestioningly, health care professionals have a responsibility to use language that respects the wishes of the person they are supporting in their diabetes self-management. This, along with the use of third-person language (‘person with diabetes’) should be recognised as having an important influence on clinical encounters [12]. There are arguments both for and against using person-first language (see Table 2). Stereotypes and generalisations can be addressed by using person-first language and may reduce the stigma experienced by having diabetes, however the opposite has also been posited; as Collier argues, trying to hide a word in a sentence might emphasis stigma [13].

The relationship between providers and people with diabetes (regardless of socio-economic status, ethnicity or culture) is a key component of satisfaction as well as influencing self-management of diabetes [12, 14]. An early study employing video observations [16] has offered useful insights into person-centred diabetes care and patient satisfaction. The authors found that in consultations rated as extremely satisfactory, the doctor was less irritated and more interested, which are indicators of respectful communication, a key component of person-centred care [16]. Doctors also expressed fewer concerns and patients asked for clarification less frequently. These features of ‘satisfactory’ consultations indicate patients’ potential sensitivity to negative communication. It was also noted that doctors tended to be more patient-centred during the diagnostic phase, although investing
less in the relationship after the initial consultation, focussing more on biomedical outcomes and less on psychosocial problems, most often associated with challenges with diabetes self-management. The competing priorities of people with diabetes and health care professionals has also been demonstrated in other studies [15, 16]. However, this scoping review has only included articles published in English; the use of particular terms that may be seen as negative or inappropriate in the UK may not be perceived as such in other countries or indeed reported in the literature.

**Stigma**

Studies in the USA and Australia have described the potential negative impact of language on peoples’ experiences of diabetes care and perceived stigma [5, 7, 8]. Stigma has been defined by Thomas et al [17] as ‘an attribute or label (such as a particular diagnosis) that links individuals to negative social stereotypes.’ (p352). Research has shown how negative language such as apportioning blame, stereotyping (such as portrayals in the media) and judgemental remarks have all been found to increase stigma [8, 18]. Stigmatising attitudes, reinforced by stereotypes and prejudices, can lead to discriminatory behaviour or ‘unconscious bias’ where practitioners often give themselves away in their body language and clinical decisions in consultations [19]. Feelings of shame or of being judged, and the experience of stigma are likely to lead to lack of engagement with health services and can increase the chance of developing diabetes-related distress, which is directly linked to poor diabetes self-management [20 -22]. Research which aims to identify the sources and experience of stigma are still few and far between and, albeit informative, have relied on small qualitative studies. However, recently new ways to measure stigma using questionnaires such as the Diabetes Stigma Assessment Scale developed in Australia is likely to advance this field [23].

**Culturally appropriate communication**

Issues around communication and the language used have pointed to the need for greater cultural competence in clinical encounters. However, most research has focussed on the need for interpreters or translation services rather than the use of appropriate language per
Cultural competence can be defined as the ‘knowledge, attitudes and skills required to provide good quality care to ethnically diverse patient populations’ [24]. Care can be compromised due to different beliefs, language barriers and educational backgrounds [24 - 26]. For example, Greenhalgh et al. [26] found that Bangladeshis did not have a comparable word for ‘exercise’. Lloyd et al. [25] identified descriptions of depression and worries about their diabetes that were particular to Pakistani and Bangladeshi people with diabetes, with somatic symptoms of depression commonly described, for example a ‘feeling of heaviness in the heart’, a lot of pressure in the head’. Using terms to identify symptoms of depression that have been recommended by the National Institute of Health and Care Excellence (NICE) therefore, may mean that many of those who need psychological treatment may be missed.

**Interventions to address language and communication barriers**

Over a number of years, a person-centred approach to care, which recognises the importance of the relationship between the health care professional and the patient in improving health outcomes, has been strongly advocated [12, 27]. A patient-centred model of care has been described as the “empowered autonomy” of patients as equal and active partners in care, contributing experiential knowledge to the decision-making process of care’ [12]. This approach has implications for communication (the broad focus of most research in this area) as well as the specific language used to support a positive relationship between the person with diabetes and health care practitioners. Indeed, two recent reviews have highlighted the importance of communication style, giving reassurance and enhancing people’s expectations through the provision of positive information about treatment [27, 28]. Overall, one consistent finding has been that the adoption of a warm, friendly and reassuring manner is more effective than consultations that were more formal and did not offer this. Being reassured that diabetes can be managed successfully and provided with a clear plan of action have been found to reduce diabetes-related distress [21]. Other research supports these findings and has reported the positive effects of an open attitude and empathy on wellbeing, including minority ethnic groups [24, 29 - 31]. Structured interventions tailored to the needs of minority ethnic groups which integrate elements of language, culture, religion, and health literacy skills have been found to have a positive impact on outcomes identified as important by the person with diabetes, although less
evidence for an impact on glycaemic control or other health measures has been reported [29].

A small body of literature has considered the potential for addressing stigma, mainly through attempts to increase the information available online, regarding people’s experiences of diabetes [17]. These included user-generated content and sharing experiences through blogs or tweet chats. However, recently messages about losing weight or healthy eating, obesity and diabetes have shifted the focus to the individual, identifying them as the person responsible for their health and ignoring the socio-economic context within which they live [18, 25]. This has profound implications for the provision of care; if communication is suboptimal then any knowledge or understanding of social circumstances and their impact on self-management is may not be obtained and care is likely to be compromised. With the move towards person-centred care and the person with diabetes as the focus, clearly the wishes of the person with diabetes in this regard are paramount. Studies have confirmed this and pointed out that there may be contradictions and idiosyncrasies between the person with diabetes and the health care practitioner such that negatively framed advice could spur people into action whilst for others it would not (33). The message here is that health care practitioners, through practising practice person-centred care, need to discover what will motivate each individual patient.

Further evidence supporting the need to tailor interactions for the individual have been reported by Svenningsson et al. (2011). In their qualitative study, participants had type 2 diabetes and were either normal weight or obese. An authoritarian approach from health care professionals resulted in the person with diabetes developing strategies to remain in control of the situation, such as being awkward, confrontational, asserting their rights or seeking help from other care providers. In another study, messages which focused on the long-term gains in people who were more future-oriented resulted in improved medication taking [35]. However, in a study which aimed to frame messages in a culturally appropriate manner in order to promote physical activity in British South Asians (although most did not have diabetes) found no effect on physical activity levels [9]. The evidence, therefore, remains equivocal.
One important systematic review of studies evaluating the impact of culturally competent diabetes care concluded that diabetes education interventions, including using different media to support the language needs of some minority ethnic groups could produce a positive impact on outcomes [29]. However, there remain challenges in identifying the most relevant impacts of diabetes education; most studies have relied on clinical factors to assess impact, and while quality of life, satisfaction and psychological wellbeing have often been ignored. Indeed, ways for practitioners to easily identify relevant cultural characteristics and link them with culturally sensitive communication still need to be developed further. There are still serious challenges to be addressed with regard to specific terminology and assumptions made about a person’s ethnicity or cultural background, based on either appearance or language.

Training and recommendations

Research suggests that patient-provider communication is the most important factor affecting diabetes self-management and promotes a person-centred approach to care [11, 36]. However, there remains a lack of training opportunities where the language used in clinical encounters which support the person with diabetes in order to optimise their self-management is specifically addressed. Where opportunities do exist, training in communication skills has been found to significantly improve the patient-centred practice of physicians [36], at least in the short term as well as increase knowledge and awareness of the needs of different people with diabetes such as those from minority ethnic groups or people with learning difficulties [30, 37].

Research studies have suggested ways to improve communication or reduce stigma, however evidence which evaluates training of health care professionals in the use of appropriate language is rare. Fisher and colleagues note that there are a range of programmes aimed at improving person-centred diabetes care but that these rely on the ability of the clinician to engage with and motivate the person with diabetes to make changes in how they manage their condition [27]. They recommend a new framework for developing a more empathic, collaborative environment for supportive clinical encounters. This is supported by other specialists in the field who recommend an empowerment
approach to self-management of diabetes which recognises the importance of appropriate questions which influence clinical encounters [38].

**Conclusion**

Empirical evidence has identified the potentially negative impact of language on the experience of diabetes care, the positive impact of carefully chosen language, and the importance of improving communication between health care practitioners and people with diabetes. The use of stigmatising and discriminatory words impacts on those interactions and can lead to disengagement with health services. More person-centred care, clinical empathy and supporting greater empowerment are vital in order to therefore have the potential to promote better health outcomes, although more work is needed to demonstrate this. Health care professionals’ relationships with individuals from minority ethnic groups may be compromised where language barriers exist or where understanding of cultural differences is limited. Evidence does show, however, that these communication barriers can be overcome with appropriate training in cultural competence. A limitation of this review is the exclusion of any publications not written in English. However, we would suggest that research in this field can most likely be translated to other countries’ practices albeit with the caveat that there might be some terms that do not hold similarly negative connotations as they do in the UK or Australia, for example. This review raises a number of questions which are being addressed by the Language Matters Group who have developed a set of recommendations to support the use of appropriate language in clinical encounters.

**Key recommendations:**

- Be aware that language has enormous power which can have both positive and negative effects on people living with diabetes
- Become alert to the language used around you and recognise when it has a negative impact
- Seek to be more empathetic and person-centred in practice
- Seek to be less authoritarian, disapproving or stereotyping
- Aim to be culturally competent (for example explore individuals’ cultural beliefs about diabetes) and aware of the importance of health literacy
• Support others to be aware of their language and encourage them to make changes in a non-judgemental way

Acknowledgements

Our grateful thanks go to Diabetes UK, NHS England and the Juvenile Diabetes Research Foundation for their support.
The Language Matters Group

Partha Kar, NHS England.

Anne Cooper, Person with Type 1 diabetes

Naresh Kanumilli, Greater Manchester Strategic Clinical Network

Jill Hill, Co-Chair, TREND-UK

Richard IG Holt, University of Southampton

Daniel Howarth, Diabetes UK

Cathy E Lloyd, The Open University

Dinesh Nagi, Association of British Clinical Diabetologists

Sarita Naik, University College Hospital

Jen Nash, Positive Diabetes

Helena Nelson, Juvenile Diabetes Research Foundation

Katharine Owen, Oxford Centre for Diabetes

Bob Swindell, Diabetes UK and parkrun Outreach (Diabetes)

Rosie Walker, Successful Diabetes

Clare Whicher, YDEF representative

Emma Wilmot, Derby Teaching Hospitals

Competing interests: None
Table 1: Search terms used for the review.

<table>
<thead>
<tr>
<th>Search Terms</th>
</tr>
</thead>
<tbody>
<tr>
<td>(doctor-patient relationship*) AND (cultural competence) OR communication</td>
</tr>
<tr>
<td>Diabetes AND stigma AND communication</td>
</tr>
<tr>
<td>(patient satisfaction) AND (doctor-patient relationship) AND language AND (cultural competence)</td>
</tr>
<tr>
<td>nurse-patient communication AND diabetes</td>
</tr>
<tr>
<td>diabetes AND language AND empower*</td>
</tr>
<tr>
<td>stigma AND diabetes AND patient-centered OR patient-centred AND language OR communication</td>
</tr>
<tr>
<td>person first language</td>
</tr>
<tr>
<td>diabetes AND (health professional communication)</td>
</tr>
<tr>
<td>diabetes AND (patient-provider relationship*)</td>
</tr>
<tr>
<td>diabetes AND (patient-provider communication)</td>
</tr>
<tr>
<td>Doctor-patient relationship* AND strengths-based language</td>
</tr>
</tbody>
</table>
Table 2: Arguments for and against promoting person-first language

<table>
<thead>
<tr>
<th>Arguments for</th>
<th>Arguments against</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Non-disabling language presents the 'person' before the disability. A focus on people first puts the emphasis on the individual, not the functional limitation (Lynch and Thuli (1994).</td>
<td>• In some research (e.g. Bickford (2004), people with visual impairments preferred disability-first language</td>
</tr>
<tr>
<td>• Person-first language is beneficial not just from a semantic viewpoint, but as a method of changing attitudes (Lynch and Thuli, 1994).</td>
<td>• 'Claiming disability' means valuing disability, that the disabled person chooses his or her identity. The person-first approach subtly implies that there is something inherently negative about disability and that use of constructions such as “with a disability” or “with diabetes” unnecessarily dissociates the disability from the person (Dunn and Andrews, 2015).</td>
</tr>
<tr>
<td>• By focusing on person-first language, it may be possible to eliminate stereotypes, negative assumptions, and generalisations by respectfully addressing the whole individual (Dickinson et al., 2017)</td>
<td>• Many people with diabetes are surprised to learn that the word “diabetic” is now considered taboo (Collier, 2012b)</td>
</tr>
<tr>
<td>• Identity-first language can depersonalise (e.g. the spinal injury in bed x) (Dunn and Andrews, 2015).</td>
<td>• By calling attention to a person as having some type of marred identity, person-first language may do the exact opposite of what it purports to do by ‘signalling shame’ instead of true equality. This could be remedied by either referring to all persons, both those with and without impairments, with person-first language, or embracing identity-first language for everyone (Gernsbacher, 2017).</td>
</tr>
<tr>
<td>• Identity-first language creates a cultural stigma against people with obesity, which in turn leads to a range of negative psychological and physical health outcomes (Armstrong et al., 2017).</td>
<td>• The growing popularity of person-first language might be a symptom of society’s failure to address a much bigger issue – how to improve the lives of people so often ignored in a world that doesn’t always embrace physical or mental diversity (Collier, 2012c)</td>
</tr>
<tr>
<td>• The point of person-first language is not to divorce “disability” from “person,” but rather to think of disabilities like another human trait, such as gender or ethnicity (Collier, 2012c)</td>
<td>• The “euphemism treadmill.” Over time, lexical euphemisms have a tendency to take on the stigma of the words they replace, so new euphemisms are coined to take their place. “Lame” becomes “crippled,” which becomes “handicapped,” which becomes “disabled,” which becomes “differently abled,” and so on (Collier, 2012a).</td>
</tr>
<tr>
<td></td>
<td>• Person-first language breaks the rules of strong writing (Collier, 2012a)</td>
</tr>
<tr>
<td></td>
<td>• Trying to hide a word in a sentence could emphasise stigma (Collier, 2012a)</td>
</tr>
</tbody>
</table>
References


5. Dickinson, JK., Guzman, SJ, Maryniuk, MD et al. The Use of Language in Diabetes Care and Education. Diabetes Care 2017; 43: 551-564


   Understanding diabetes management among adult females. Patient Education and

12. Brundisini F., Vanstone M., Hulan D et al. Type 2 diabetes patients’ and providers’
    differing perspectives on medication nonadherence: a qualitative meta-synthesis.

13. Collier, R. (2012a) 'Person-first language: Laudable cause, horrible prose', CMAJ :


    understanding and day-to-day practice of patient empowerment in diabetes; time to

16. Van Dulmen, AM, Verhaak, PFM and Bilo, HJG. Shifts in doctor-patient
    communication during a series of outpatient consultations in non-insulin-dependent

17. Thomas N, McLeod B, Jones N et al. Developing Internet interventions to target the
    individual impact of stigma in health conditions. Internet Interventions 2015;2:351-
    358.

18. Browne JL, Ventura A, Mosely K, Speight J. ‘I call it the blame and shame disease’: a
    qualitative study about perceptions of social stigma surrounding type 2 diabetes.

19. Thesen J. From oppression towards empowerment in clinical practice -- offering

20. Schabert J, Browne, J. L., Mosely, K., et al. Social Stigma in Diabetes. The Patient -

    Diagnosis of Type 2 Diabetes Associated With Attitudes and Self-management Over
    Time? The Diabetes Educator 2010;36.;828-834.

22. Fisher L, Polonsky WH, Hessler DM et al. Understanding the sources of diabetes
    distress in adults with type 1 diabetes. Journal of Diabetes and its Complications


37. Brown