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Language matters; a UK perspective

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Language matters; a UK perspective.

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3 Novelty statement
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- 6 • This paper reviews existing evidence on the use of language in clinical encounters
 - 7 • Poor language practices can lead to stigma, lack of engagement with self-
8 management, low satisfaction with care and poor clinical outcomes
 - 9 • Research has demonstrated the importance of good communication skills and that
10 **appropriate use of language** can benefit psychosocial wellbeing and support optimal
11 diabetes self-management
 - 12 • Our review has directly informed the publication of a UK Position Statement on
13 Language Matters
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23 Key words: Language, type 2 diabetes, type 1 diabetes, psychosocial aspects
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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

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3 'non-adherent' are often used in diabetes care, can lead to a disconnect between the
4 person with diabetes and the clinician and have a significant impact on health outcomes [7-
5 10]. For example, in one qualitative study in women with diabetes, communication with
6 their health care professional was found to be the most important factor affecting diabetes
7 self-management, with autonomy perceived by the health provider as 'non-compliance'
8 [11]. Ideas about 'non-compliance' and 'adherence' are still prevalent, and indeed on
9 searching the literature we found a substantial number of studies still using this term,
10 perhaps reflecting the lack of clarity about what would be appropriate language.
11 Terms assumed to have a negative connotations however, may not always be identified as
12 such by all. Indeed different stakeholders, be it individuals with diabetes or health care
13 professionals, may have preferences for person-first (*'I am a person with diabetes'*) or
14 disease-first (*'a diabetic'*) language. Some people may simply apply the adjective 'diabetic'
15 to themselves or another person. Although many people with diabetes may accept the label
16 'diabetic' unquestioningly, health care professionals have a responsibility to use language
17 that respects the wishes of the person they are supporting in their diabetes self-
18 management. This, along with the use of third-person language (*'person with diabetes'*)
19 should be recognised as having an important influence on clinical encounters [12]. There are
20 arguments both for and against using person-first language (see Table 2). Stereotypes and
21 generalisations can be addressed by using person-first language and may reduce the stigma
22 experienced by having diabetes, however the opposite has also been posited; as Collier
23 argues, trying to hide a word in a sentence might emphasis stigma [13].

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40 The relationship between providers and people with diabetes (regardless of socio-economic
41 status, ethnicity or culture) is a key component of satisfaction as well as influencing self-
42 management of diabetes [12, 14]. An early study [employing video observations \[16\]](#) has
43 offered useful insights into person-centred diabetes care and patient satisfaction. The
44 authors found that in consultations rated as extremely satisfactory, the doctor was less
45 irritated and more interested, [which are indicators of respectful communication, a key](#)
46 [component of person-centred care \[16\]. Doctors also](#) expressed fewer concerns and
47 patients asked for clarification less frequently. [These features of 'satisfactory' consultations](#)
48 [indicate patients' potential sensitivity to negative communication. It was also noted that](#)
49 doctors tended to be more patient-centred during the diagnostic phase, although investing

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3 less in the relationship after the initial consultation, focussing more on biomedical outcomes
4 and less on psychosocial problems, most often associated with challenges with diabetes
5 self-management. The competing priorities of people with diabetes and health care
6 professionals has also been demonstrated in other studies [15, 16]. However, this scoping
7 review has only included articles published in English; the use of particular terms that may
8 be seen as negative or inappropriate in the UK may not be perceived as such in other
9 countries or indeed reported in the literature.
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15 **Stigma**

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

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

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23 Over a number of years, a person-centred approach to care, which recognises the
24 importance of the relationship between the health care professional and the patient in
25 improving health outcomes, has been strongly advocated [12, 27]. A patient-centred model
26 of care has been described as the “empowered autonomy” of patients as equal and active
27 partners in care, contributing experiential knowledge to the decision-making process of
28 care’ [12]. This approach has implications for communication (the broad focus of most
29 research [in this area](#)) as well as the specific language used to support a positive relationship
30 between the person with diabetes and health care practitioners. Indeed, two recent reviews
31 have highlighted the importance of communication style, giving reassurance and enhancing
32 people’s expectations through the provision of positive information about treatment [27,
33 28]. Overall, one consistent finding has been that the adoption of a warm, friendly and
34 reassuring manner is more effective than consultations that were more formal and did not
35 offer this. Being reassured that diabetes can be managed successfully and provided with a
36 clear plan of action have been found to reduce diabetes-related distress [21]. Other
37 research supports these findings and has reported the positive effects of an open attitude
38 and empathy on wellbeing, including minority ethnic groups [24, 29 - 31]. Structured
39 interventions tailored to the needs of minority ethnic groups which integrate elements of
40 language, culture, religion, and health literacy skills have been found to have a positive
41 impact on outcomes identified as important by the person with diabetes, although less
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3 evidence for an impact on glycaemic control or other health measures has been reported
4 [29].
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7 A small body of literature has considered the potential for addressing stigma, mainly
8 through attempts to increase the information available [online, regarding people's](#)
9 [experiences of diabetes](#) [17]. These included user-generated content and sharing
10 experiences through blogs or tweet chats. However, recently messages about losing weight
11 or healthy eating, obesity and diabetes have shifted the focus to the individual, identifying
12 them as the person responsible for their health and ignoring the socio-economic context
13 within which they live [18, 25]. This has [profound](#)-implications for the provision of care; if
14 communication is suboptimal then [any](#) knowledge or understanding of social circumstances
15 and their impact on self-management [is may not be](#) obtained and care [is](#) likely to be
16 compromised. With the move towards person-centred care and the person with diabetes as
17 the focus, clearly the wishes of the person with diabetes in this regard are paramount.
18 Studies have confirmed this and pointed out that there may be contradictions and
19 idiosyncrasies between the person with diabetes and the health care practitioner such that
20 negatively framed advice could spur people into action whilst for others it would not (33).
21 [The message here is that health care practitioners, through practising practice person-](#)
22 [centred care, need to discover what will motivate each individual patient.](#)
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27 Further evidence supporting the need to tailor interactions for the individual have been
28 reported by Svenningsson et al. (2011). In their qualitative study, participants had type 2
29 diabetes and were either normal weight or obese. An authoritarian approach from health
30 care professionals resulted in the person with diabetes developing strategies to remain in
31 control of the situation, such as being awkward, confrontational, asserting their rights or
32 seeking help from other care providers. In another study, messages which focused on the
33 long-term gains in people who were more future-oriented resulted in improved medication
34 taking [35]. However, in a study which aimed to frame messages in a culturally appropriate
35 manner in order to promote physical activity in British South Asians (although most did not
36 have diabetes) found no effect on physical activity levels [9]. The evidence, therefore,
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3 One important systematic review of studies evaluating the impact of culturally competent
4 diabetes care concluded that diabetes education interventions, including using different
5 media to support the language needs of some minority ethnic groups could produce a
6 positive impact on outcomes [29]. However, there remain challenges in identifying the most
7 relevant impacts of diabetes education; most studies have relied on clinical factors to assess
8 impact, and while quality of life, satisfaction and psychological wellbeing have often been
9 ignored. Indeed, ways for practitioners to easily identify relevant cultural characteristics and
10 link them with culturally sensitive communication still need to be developed further. There
11 are still serious challenges to be addressed with regard to specific terminology and
12 assumptions made about a person's ethnicity or cultural background, based on either
13 appearance or language.
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25 **Training and recommendations**

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27 Research suggests that patient-provider communication is the most important factor
28 affecting diabetes self-management and promotes a person-centred approach to care [11,
29 36]. However, there remains a lack of training opportunities where the language used in
30 clinical encounters which support the person with diabetes in order to optimise their self-
31 management is specifically addressed. Where opportunities do exist, training in
32 communication skills has been found to significantly improve the patient-centred practice of
33 physicians [36], at least in the short term as well as increase knowledge and awareness of
34 the needs of different people with diabetes such as those from minority ethnic groups or
35 people with learning difficulties [30, 37].
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44 Research studies have suggested ways to improve communication or reduce stigma,
45 however evidence which evaluates training of health care professionals in the use of
46 appropriate language is rare. Fisher and colleagues note that there are a range of
47 programmes aimed at improving person-centred diabetes care but that these rely on the
48 ability of the clinician to engage with and motivate the person with diabetes to make
49 changes in how they manage their condition [27]. They recommend a new framework for
50 developing a more empathic, collaborative environment for supportive clinical encounters.
51 This is supported by other specialists in the field who recommend an empowerment
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3 approach to self-management of diabetes which recognises the importance of appropriate
4 questions which influence clinical encounters [38].
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8 **Conclusion**

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

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

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

(doctor-patient relationship*) AND (cultural competence) OR communication
Diabetes AND stigma AND communication
(patient satisfaction) AND (doctor-patient relationship) AND language AND (cultural competence)
nurse-patient communication AND diabetes
diabetes AND language AND empower*
stigma AND diabetes AND patient-centered OR patient-centred AND language OR communication
person first language
diabetes AND (health professional communication)
diabetes AND (patient-provider relationship*)
diabetes AND (patient-provider communication)
Doctor-patient relationship* AND strengths-based language

Table 2: Arguments for and against promoting person-first language

Arguments for	Arguments against
<ul style="list-style-type: none"> • 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). • Person-first language is beneficial not just from a semantic viewpoint, but as a method of changing attitudes (Lynch and Thuli, 1994). • 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) • Identity-first language can depersonalise (e.g. the spinal injury in bed x) (Dunn and Andrews, 2015). • 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). • 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) 	<ul style="list-style-type: none"> • In some research (e.g. Bickford (2004), people with visual impairments preferred disability-first language • '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). • Many people with diabetes are surprised to learn that the word "diabetic" is now considered taboo (Collier, 2012b) • 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). • 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) • 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). • Person-first language breaks the rules of strong writing (Collier, 2012a) • Trying to hide a word in a sentence could emphasise stigma (Collier, 2012a)

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