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EDITORIAL

Changing the Narrative: Confronting Diabetes-Related Stigma in Healthcare

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Abstract

Stigma refers to negative attitudes and beliefs that are directed at individuals based on perceived differences, such as living with diabetes. Stigma is commonly experienced by those with diabetes. Stigmatization often originates from healthcare professionals (HCPs) who may be unaware of the consequence of their judgemental attitudes on patients and on how personally challenging living with diabetes can be. A lack of empathy from HCPs can risk individuals choosing not to manage their diabetes as advised or even seek support. Harmful comments may also evoke feelings of guilt or shame in individuals, which can further affect their mental wellbeing and ability to self-care appropriately. Wider HCP understanding and appreciation of the impact of stigma in diabetes care could do much to help individuals with diabetes feel supported and understood and not judged. More constructive, person-centred dialogue offered by HCPs, such as avoiding using the threat of developing diabetes complications to drive individual behaviour change has the potential to contribute to better outcomes in diabetes and improve the confidence of individuals living with diabetes in their healthcare teams.

Key words: stigma; diabetes; complications of diabetes

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Introduction

When someone announces they have lung cancer, it is unusual for others to remark "is that because you smoked?" And yet, when someone announces they have diabetes, another serious disease, it is more common for that person to be asked 'is that the good one?', or something food related, such as 'is that because you ate too many cakes as a child?', or when making a sugary food choice (which could be to treat hypoglycaemia), be asked 'should you be eating that?' These are examples of diabetes-associated stigma, where negative attitudes, beliefs and behaviours are directed towards individuals with diabetes. As someone working in the clinical field of adult diabetes, this is something that I have both seen firsthand and heard about from people living with diabetes.

What is Stigma?

Stigma was classically defined by Erving Goffman (1963) as 'an attribute that is deeply discrediting'. This can then result in individuals being unfairly labelled, discriminated against or defined by their disease. Diabetes-associated stigma can

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arise from misconceptions about the disease. There is a widely held view that diabetes is a self-inflicted consequence of gluttony, laziness, and irresponsibility (Abdoli et al, 2018), often without consideration of the impact of associated environmental, genetic, socioeconomic, or psychosocial factors (Hill-Briggs et al, 2020). Those without diabetes are not always aware of the harm that these negative views can cause. Several studies suggest that an estimated 80% percent of people living with type 1 or type 2 diabetes have experienced diabetes stigma in some form (Liu et al, 2017; Puhl et al, 2020; Puhl et al, 2022). What may have been meant as an innocent comment or joke, without fully understanding the impact, could and has caused hurt and harm. Some people feel the need to comment on others who they see as different to themselves. We should embrace our differences and learn from each other.

Stigma Perpetuated by Healthcare Professionals

People with diabetes may also encounter judgmental attitudes from healthcare professionals (HCPs) working in a non-diabetes-associated discipline (Browne et al, 2013; Browne et al, 2014). Hence, instead of not appreciating the challenging and relentless nature of living with diabetes; from the need for daily glucose monitoring or time critical administration of certain medications, through to juggling multiple medical appointments (all perhaps whilst caring for others and working), some HCPs are comfortable labelling individuals as 'non-compliant' or 'poorly controlled', based on blood result data being out of recommended range, or the presence of diabetes complications for example. Such labels are also often given within earshot of patients, such as during ward rounds, or even used directly during consultations. Stigmatising language is also included in medical records (e.g., 'poorly controlled diabetic'), which then when read by other HCPs, can add to collective stigma perpetuation in healthcare. In addition, other medical interventions, such as having an operation or receiving steroid-based therapy can also destabilise diabetes, through no fault of the individual, but can add more daily challenges. The use of more engaging and empathic language, less blaming in its tone, is actively encouraged.

Medical Consequences of Stigma

Diabetes stigma has also been shown to have medical consequences. From the healthcare perspective, being subjected to stigmatizing behaviours, with a lack of empathy from HCPs can discourage individuals from disclosing their diabetes, attend medical appointments, manage it as advised (e.g., not monitoring glucose levels or administering insulin) or discuss it openly with others, all of which can negatively affect their health outcomes and increase risk of developing diabetes complications (Browne et al, 2013; Jeong et al, 2018; Kato et al, 2016; Liu et al, 2017; Ortiz-Domenech and Cumba-Avilés, 2021; Puhl et al, 2020). There are also the systemic consequences of not taking treatment, such as wider costs to healthcare to consider.

Personal Consequences of Stigma for the Individual with Diabetes

On a personal level, experiencing stigma through harmful comments can be exhausting. Such language can evoke feelings of guilt, shame, or embarrassment about diabetes, as well as worrying about developing complications of the disease. This can impact people personally, and their families (Fisher et al, 2015; Tanaka et al, 2022). This in turn can affect emotional wellbeing, resulting in increased rates of anxiety, reduced emotional wellbeing and depression (Speight et al, 2024).

How Healthcare Professionals can Help Reduce Stigma

Where necessary, how can HCPs help reduce stigma in diabetes care? They are encouraged to be better informed and educated, either through formal training or their own research. They should challenge their personal misconceptions and beliefs where required, such as understanding that diabetes does not develop solely because of lifestyle choices made by individuals and that a person is not defined by their diabetes, or test results. Like many of us, their patients with diabetes may also be living complex lives, under challenging personal circumstances. HCPs are also encouraged to use their position to be supportive, culturally sensitive and deliver stigma-free consultations and documentation, sometimes listening more and talking less, to really understand their patients' situation. This is not about being complicit in accepting diabetes as not being well managed, but being understanding and constructive in approach, avoiding 'scaremongering' messaging (e.g., using veiled threats about the risk of blindness, heart attacks or amputations to drive behaviour change) and offering sincere empathy. Language Matters (NHS England, 2018) serves as an invaluable concise resource for HCPs on how to offer and have more effective diabetes communications and consultations, through being respectful with a person-centred approach.

Being vocal, resisting the urge to blame and shame, being supportive when called for, not being complicit in the passing of inappropriate comments, as well as speaking up when education and understanding are needed, can all do much to help support tackling stigma.

Challenging stigma around diabetes is just as important within the medical workforce. If a member of your team must leave the ward round or clinic to self-administer insulin or treat hypoglycaemia, understanding and appreciating that you getting upset about it is not the response being sought when asked for permission. Taking a moment to walk a mile in the shoes of someone else's life can be powerful and inciteful.

The stigma associated with diabetes is pervasive. It is imperative that HCPs seek to tackle this, given that it can adversely affect patient outcomes, treatment adherence and quality of life. People living with diabetes should feel listened to and supported by HCPs, to empower them to seek to manage it with dignity, helping to reduce their risk of developing physical complications and deteriorating mental

health. In time, as we collectively move to dispel the myths associated with stigma in diabetes, there can be a larger shift of the narrative from blame to understanding, resulting in better support, empathy, and empowerment for those living with diabetes.

Conclusion

A deeper and wider understanding by HCPs of the impact of stigma on diabetes healthcare delivery and the approaches to reduce it, is an ongoing educational journey that will take time. Through challenging their biases, by prioritizing compassionate communication skills, HCPs are well placed to offer and support a more constructive, collaborative wider narrative around diabetes. People feeling supported and understood are more likely to engage with their diabetes care, leading to better outcomes for them and the wider healthcare system.

Key Points

- Approximately 80% of people living with diabetes have experienced stigma associated with this.
- Diabetes-associated stigma continues to be facilitated by media, the wider public and healthcare professionals (HCPs).
- Experiencing diabetes-associated stigma by HCPs can risk individuals neglecting their self-care and disengaging with HCPs and health organisations, putting their future health at risk.
- Increased neglect of self-care in diabetes increases the risk of developing diabetes complications and the associated wider healthcare implications of this.
- Where necessary, HCPs can do much to review their personal communication skills, always seeking to offer stigma-free support.

Availability of Data and Materials

Not applicable.

Author Contributions

MP was the sole author and was responsible for the design of the work, drafting and revision of content, and approval of the version to be published. MP has participated sufficiently in the work and agreed to be accountable for all aspects of the work.

Ethics Approval and Consent to Participate

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Conflict of Interest

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