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REVIEW ARTICLE

Social Stigma in Diabetes

A Framework to Understand a Growing Problem for an Increasing Epidemic

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Abstract A comprehensive understanding of the social and psychological impact of diabetes mellitus is important for informing policy and practice. One potentially significant, yet under-researched, issue is the social stigma surrounding diabetes. This narrative review draws on literature about health-related stigma in diabetes and other chronic conditions in order to develop a framework for understanding diabetes-related stigma. Our review of the literature found that people who do not have diabetes assume that diabetes is not a stigmatized condition. In contrast, people with diabetes report that stigma is a significant concern to them, experienced across many life domains, e.g., in the workplace, in relationships. The experience of diabetes-related stigma has a significant negative impact on many aspects of psychological well-being and may also result in sub-optimal clinical outcomes for people with diabetes. We propose a framework that highlights the causes (attitudes of blame, feelings of fear and disgust, and the felt need to enforce social norms and avoid disease), experiences (being judged, rejected, and discriminated against), and consequences (e.g., distress, poorer psychological well-being, and sub-optimal self-care) of diabetes-related stigma and also identifies potential mitigating strategies to reduce diabetes-related stigma and/or enhance coping and resilience amongst people with diabetes. The systematic investigation of the experiences, causes, and consequences of diabetes-related stigma is an urgent research priority.

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Key Points for Decision Makers

- People who do not have diabetes mellitus do not perceive it to be a stigmatized condition
- In contrast, people who have diabetes report feeling judged and constantly monitored
- Diabetes-related stigma may have negative consequences for psychological well-being, self-care, and clinical outcomes
- Research on this topic is lacking, and limited by an absence of standard operationalization and measurement of stigma

1 Introduction

Diabetes mellitus affects more than 220 million people worldwide [1] and is increasing at epidemic proportions [2]. Diabetes-related research has focussed largely on management of the physical and medical aspects of the condition but over the past two decades, there has been increased research interest in the psychosocial aspects of diabetes, such as depression [3] and impact upon quality of life [4, 5]. One potentially significant consequence of living with type 1 or type 2 diabetes is the negative social

appraisal, or social stigma, that may be associated with the conditions. While the fact that a person has diabetes is not usually immediately apparent, some of the physical and behavioral features of the condition may be conspicuous, potentially leading to a number of undesirable social, occupational, and emotional consequences.

Stigma is a universal phenomenon and has received substantial research attention in medical conditions such as HIV/AIDS [6–9], epilepsy [10–12] and obesity [13–15], but in diabetes it is relatively under-researched. In the past decade, this issue has begun to receive limited attention, and perhaps research in this area has coincided with publication of landmark studies [16, 17] that have demonstrated that type 2 diabetes can be prevented, which in turn highlights the role of individual behavior in contributing to the development of the condition. This narrative review draws on a wide range of literature regarding health-related stigma in order to develop a framework for understanding the experiences, causes, and consequences of stigma associated with type 1 and type 2 diabetes.

1.1 Theoretical Perspectives on Social Stigma

To assist us to define and conceptualize social stigma, we turn to the theoretical literature. The theoretical perspectives on stigma tend to fall into three categories: namely, social psychological, sociological, or interactionist. Social psychological perspectives on stigma link attributes to undesirable characteristics or stereotypes [18]. Stigmatizing attributes may be visible or invisible, controllable or uncontrollable, and linked to appearance, behavior, or group membership [19]. Sociological perspectives on stigma, on the other hand, tend to describe stigma in terms of characteristics that are socially discrediting and focus on the social conditions that bring about stigma, while interactionist views blend the social psychological and sociological perspectives.

Major and O'Brien [19] have proposed a social psychological model of stigma-induced identity threat. In this model, stigmatized individuals face identity threat when they appraise the demands imposed by a stigma-relevant stressor (e.g., injecting insulin in public) as potentially harmful to their social identity (e.g., being mistaken for an illicit drug user), and as exceeding their resources to cope with those demands. The focus of this model is on how an individual perceives and responds to threats to his or her social identity. As such, this model has a narrow focus (as identity threat is but one component of the self that is affected by stigma) and does not inform us about the causes of stigma. However, the strengths of the model lie in linking social and personal factors to the experience of stigma.

Link and Phelan [20] merge social psychological and sociological explanations in their interactionist conceptualization of stigma, which enables the examination of stigma more holistically than any pure social psychological or sociological conceptualization. The first component in their conceptualization is distinguishing and labeling human differences, which involves categorizing people according to salient characteristics and attributes. In diabetes, the salient characteristics and attributes are usually observable behaviors required to manage the condition (e.g., food choices, injecting insulin, or taking medication) or physical characteristics associated with the condition (e.g., obesity in the case of type 2 diabetes).

The second component of this conceptualization is the linking of categories (with labels) to negative stereotypes (e.g., the stereotype that obese people are lazy). Third, once labels are linked to negative stereotypes, stigma processes lead to a separation of 'us' from 'them' [20], leading to ingroup/outgroup comparisons. This sense that the individuals in the labeled group ('them') are fundamentally different causes stereotyping to take place quickly and, in some cases, become an automated reaction.

Fourth, status loss and discrimination (e.g., being regarded as unreliable employees) are experienced as a result of stereotyping. Members of a stigmatized group may be disadvantaged socially, occupationally, and economically. This corresponds to *enacted stigma*, which refers to episodes of discrimination against people of the stigmatized group. Enacted stigma is contrasted with *felt stigma*, which is the shame of being associated with the stigmatized group and the fear of enacted stigma [21].

Finally, Link and Phelan [20] highlight that stigma is dependent on power—social, cultural, economic, and political power differences between people with the stigmatized condition and people without the stigmatized condition (e.g., the Western cultural values of beauty and youth may be relevant in the case of obesity) [20, 22]. They define stigma as a social process that exists "when elements of labelling, stereotyping, separation, status loss, and discrimination co-occur in a power situation" [20]. Health-related stigma is distinct from general social stigma in that this adverse, social "judgment is based on an enduring feature of identity conferred by a health problem or health-related condition. The judgment is medically unwarranted with respect to the health problem itself" [23]. The strength of Link and Phelan's conceptualization of stigma [20, 22] is that it describes the nature and consequences of stigma. It does not, however, explicate the causes of stigma.

Link and Phelan's ideas provide a useful background to examining the literature about diabetes-related stigma and highlight areas that may require further explication. The theoretical perspectives outlined here provide a foundation to the definition and conceptualization of stigma in general.

We seek to build on this to develop a conceptualization of stigma specifically with regard to diabetes.

2 Aims, Scope, and Literature Review

The purpose of the current narrative review was to develop a conceptualization of social stigma in diabetes that links the causes, experiences, and consequences of stigma, and that identifies potential mitigating strategies to reduce diabetes-related stigma and/or enhance coping and resilience amongst people with diabetes. Our aim was to summarize research about diabetes-related stigma for the purposes of developing a framework for understanding this phenomenon, partially informed by Link and Phelan's conceptualization of stigma [20, 22]. In this review, we summarize and integrate published literature about diabetes-related social stigma, and also literature about health-related stigma in hepatitis C, HIV/AIDS, epilepsy, obesity, and celiac disease. Each of these conditions has chronicity in common with diabetes but also shares another particular feature with diabetes, such as needle use (hepatitis C and HIV/AIDS), behavior perceived as a contributing causal factor (hepatitis C, HIV/AIDS, obesity), seizures and other unusual or conspicuous behavior (epilepsy), and dietary modifications (celiac disease). Furthermore, the stigma associated with obesity and celiac disease may compound diabetes-related stigma, as obesity is a risk factor for type 2 diabetes [24], and celiac disease is more prevalent among people with type 1 diabetes than among the general population [25]. Although it is possible that some people with diabetes experience stigma associated with diabetes-related complications like blindness, having an amputated limb, or being on dialysis, stigma associated with complications was beyond the scope of this review. Our review focusses on stigmatization of the individual with the condition, rather than stigmatization of friends and family by association.

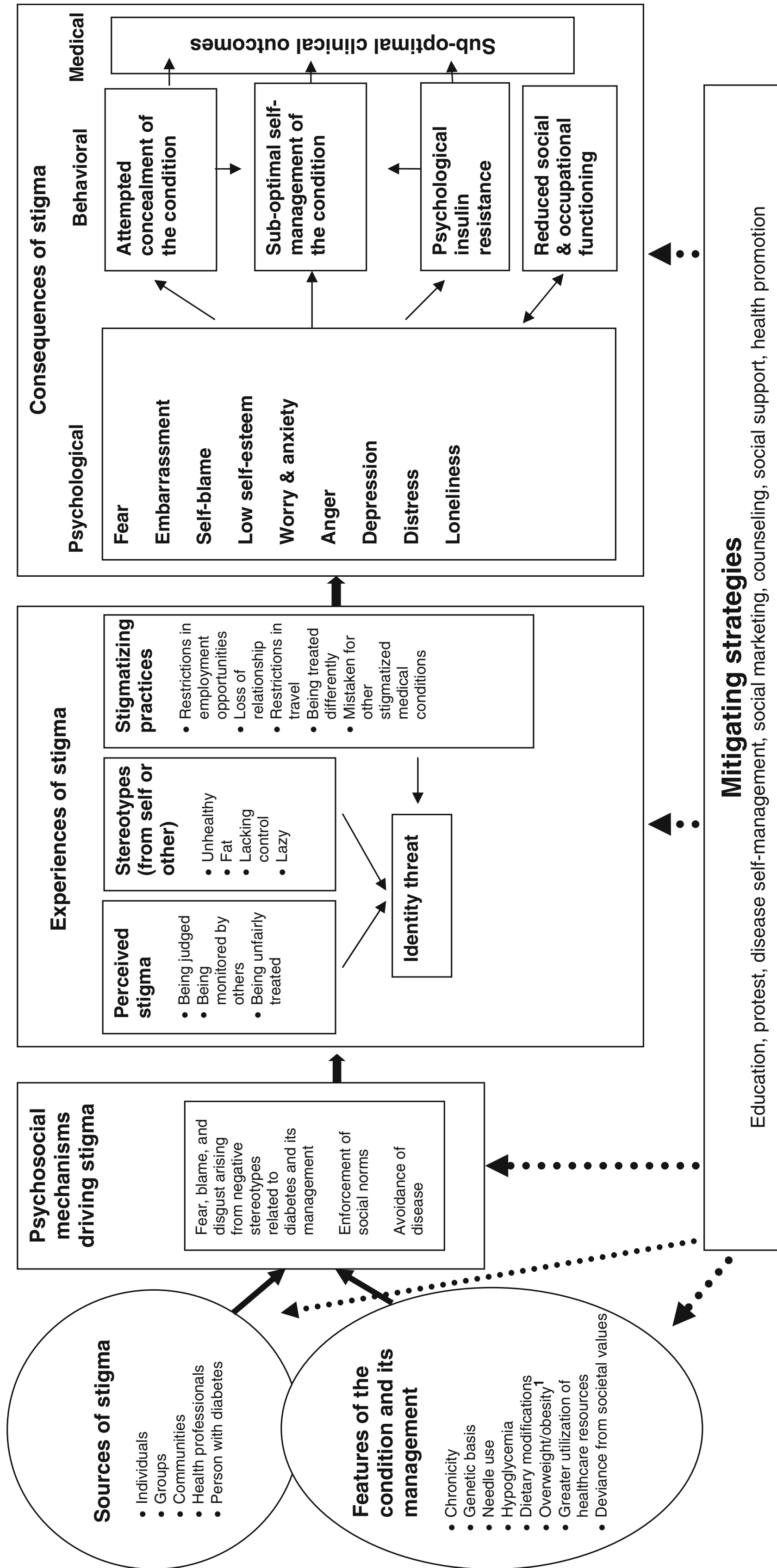
Different elements of society may contribute to or be sources of stigma, from the individual in the community through to the media and to social or health policy. Many of these elements are measurable, including attitudes towards affected people, discriminatory and stigmatizing practices, service availability, legislation, experience of actual discrimination and/or participation restrictions, perceived stigma, and self- or internalized stigma [26]. Stigma that involves the experience or perception of being stigmatized by another is termed 'interpersonal stigma,' whereas self- or internalized stigma is termed 'intrapersonal stigma.' This review focusses on enacted stigma by others, perceived stigma by affected persons, and internalized stigma. Legislation, while important and worthy of further attention, is outside the scope of this review. Furthermore, we focus on the impact on and consequences for people with diabetes only, as the impact on the broader systems and on those who do not have diabetes was also beyond the scope of this review.

We searched the PsycINFO® and Scopus® databases in April 2011 for peer-reviewed articles published in English using each of the keywords 'stigma,' 'discrimination,' and 'social isolation' in combination with each of the following: 'diabetes,' 'hepatitis C,' 'HIV,' 'AIDS,' 'epilepsy,' 'obesity,' 'coeliac disease,' 'celiac disease,' 'health,' 'disease,' 'illness,' 'condition,' 'chronic illness,' and 'chronic condition.' The search combinations that included the keyword 'diabetes' were re-run in May 2012 to ensure no highly relevant literature was missed for the purposes of this review (this search returned only one additional article).

It was evident from our literature review that beliefs about diabetes-related stigma differed substantially between people with and without diabetes. Thus, the evidence is discussed separately below, followed by a discussion of the possible causes, experiences, and consequences of, and mitigating strategies for, diabetes-related stigma. Following this discussion, the ideas and concepts identified in this narrative review are summarized in a diagrammatical representation of a proposed framework for understanding diabetes-related stigma (Fig. 1).

3 Views of People Who Do Not Have Diabetes

In general, people who do not have diabetes tend to perceive diabetes as a non-stigmatized condition. Physical conditions such as diabetes are perceived by many to be less stigmatized than mental illness [27], and the prejudice towards diabetes in the general community is perceived to be minimal [28]. In two studies that asked participants to imagine they had diabetes, one reported little or no expected social stigma [29], and another reported modest levels of expected stigma [30]. In one study, 665 health professionals from six communities of various cultural backgrounds in Australia (Anglo-Australian, Arabic, Chinese, German, Greek, and Italian) answered questions about what they had found to be typical, usual, or average attitudes towards 20 health conditions in their community [31]. Diabetes was consistently rated as one of the four least stigmatized conditions by these health professionals, with HIV/AIDS, mental retardation, psychiatric illness, and cerebral palsy being the four most stigmatized conditions. That healthcare professionals and others who do not have diabetes do not consider diabetes to be a stigmatized condition is not unexpected. Those who do not have diabetes may have limited exposure to stigmatizing behaviors, attributes, or attitudes and may be genuinely unaware of the issue. There may also be an aspect of social desirability bias, which may result in under-reporting of stigmatizing



[1]Type 2 diabetes only

Fig. 1 A framework for understanding diabetes-related stigma

beliefs and practices. The available literature highlights the stark contrast in the perceptions of diabetes-related stigma between those who do not and those who do have diabetes.

4 Experiences and Perceptions of People with Diabetes

People with type 1 and type 2 diabetes need to undertake essential self-care activities to optimize blood glucose levels in order to avoid diabetes-related complications. These activities may include, but are not limited to, monitoring blood glucose levels, injecting insulin, taking medications, eating healthily, and engaging in regular physical activity. However, it is these very activities that are perceived by people with diabetes to be the focus of negative social evaluation. Fear of social embarrassment, rejection, being treated differently, or damaging their relationship with significant others are common concerns associated with injecting insulin [32]. Social embarrassment and stigma, feelings of failure, and guilt are common concerns of people with type 2 diabetes regarding using insulin to manage their diabetes [33]. The perceived social stigma associated with injecting is a contributing factor to psychological insulin resistance (a reluctance to use insulin to manage diabetes) amongst people with type 1 and type 2 diabetes [32, 34]. Adults with type 2 diabetes also report feeling embarrassed when they need to refuse unhealthy food options at social events [35], which may act as a deterrent for making healthy choices in the future. Two qualitative studies provide detailed accounts of the experiences of stigma among people with diabetes [36, 37]. In an interview study, Chinese adults from Hong Kong reported receiving looks of "contempt" from others when injecting insulin in public, being mistaken for an illicit drug user, and feeling that others blame them for causing their own condition [36]. Six of the 13 interviewees reported believing that they would be at risk of losing their job if they disclosed their condition to their colleagues or employer [36]. In a second unstructured interview study, Australian adults with type 2 diabetes told the story of their diabetes from diagnosis to the day of interview [37]. One participant reported negative experiences on a bus tour: he said he was "treated like a leper" ([37], p. 2373) and that all people with diabetes were seated at a separate table and served an extremely limited menu. Some participants also complained about needing a certificate from a doctor to renew their driver's license. Further concerns included being mistaken for a drug user, or as being drunk during an episode of hypoglycemia [37].

Some aspects of diabetes-related stigma may be culturally bound. For example, in addition to restrictions in job opportunities and travel (consistent with above), Japanese adults with type 1 diabetes reported cancelation of marital engagements and divorce following disclosure about their diabetes [38]. It is unclear from the study why this occurred, though we speculate that some possibilities may include not having sufficient information about type 1 diabetes (and therefore being prone to mistaken judgments about management and contagion), not wanting an 'ill' partner, and not wanting to start a family with someone with a hereditary condition. People with diabetes in Ghana indicated that they were often mistaken as having HIV/AIDS due to the weight loss that can result from the onset or sub-optimal management of diabetes [39]. Consequently, other people refused food prepared by them, and attributions of witchcraft or sorcery were reported as common [39]. In one study, British South Asian adults with type 1 or type 2 diabetes reported experiencing difficulty declining offers of sweets in the face of cultural expectations to eat such foods, and that they often experienced pressure from their families to conceal their condition for the purposes of improving their marriage prospects [40]. The findings of these studies highlight the role of cultural beliefs and norms in creating and promoting diabetes-related stigma.

Perceived or experienced stigma can also result in limitations in social and employment opportunities. A qualitative study of adults with diabetes revealed several accounts of workplace discrimination that participants attributed to their health condition [36]. Many further examples of such limitations are evident from the obesity literature, and may be relevant for consideration with regard to diabetes-related stigma given the strong association between obesity and type 2 diabetes. Obese people, particularly women, experience poorer quality romantic relationships [41], and are less likely to be considered as potential sexual partners [42]. Obese people also report higher rates of workplace bias and discrimination than people of healthy weight [43], and are less likely to be invited for a job interview than their healthy weight peers [44]. These limitations and biases may lead to a deterioration of social and/or occupational functioning for people with these stigmatized conditions, which is likely to cause or exacerbate psychological distress and loneliness.

Internalized stigma is portrayed through the feelings, emotions, and self-judgments of people with diabetes, and is particularly relevant for people with type 2 diabetes who express feelings of failure, guilt, and blame [33, 36]. It is unclear from the existing literature whether self-stigma arises from perceived and/or experienced stigma, or, perhaps more likely, whether it may exist independent of perceptions of public views and actual experiences.

Whilst our review of the literature did not identify any studies that examined social stigma in women with gestational diabetes directly, the findings from several qualitative studies indicate that there may be a social stigma

associated with gestational diabetes, which can have adverse effects on well-being [45, 46]. Feelings of personal culpability due to health and lifestyle behavior choices (e.g., being overweight, having poor eating habits and a sedentary lifestyle) are reported by women with gestational diabetes [46], again reflecting the self-stigmatization of the condition. In addition, women report feeling controlled, monitored, and pressured when blood glucose levels fluctuate or are elevated (e.g., others commenting on the weight of the baby or the mother's eating habits) [45], which in turn can result in feelings of inadequacy, shame, and guilt. The controlling behaviors of others (e.g., family, friends, health professionals) may result from concerns about the health of the pregnant woman and her baby, but it is also possible that they may be motivated by feelings of blame towards the pregnant woman for placing herself and her fetus at risk.

5 Consequences of Diabetes-Related Stigma

The psychological impact of living with a stigmatized condition is significant, and may be a barrier to optimal self-care. Consequently, health-related stigma has the potential to impact negatively not only the psychological health but also the physical health of people living with stigmatized chronic conditions. This section focusses on the consequences of stigma for people living with diabetes. There are likely to be other consequences for people who do not have diabetes who hold stigmatizing beliefs and attitudes towards people with diabetes, however here we focus only on the impact of stigma on the lives of people living with diabetes.

Several studies found that people living with a stigmatized health condition reported experiencing depression and other psychological distress [47–49]. As a result of experienced or expected negative appraisal, people with diabetes may attempt to conceal their condition from others, leading to constant anxiety [36]. Concealment attempts include avoiding social activities, injecting insulin only in public toilets or at home (and thus delaying or omitting injections), or not performing regular self-monitoring of blood glucose [36]. Other examples include making unhealthy food choices due to reluctance to decline what is on offer, or not wanting to draw attention to oneself [35, 40]. Concealment attempts due to fear of negative appraisal compromise the self-care that is essential for people with diabetes, leading to sub-optimal blood glucose levels, and possibly short- and long-term diabetes complications (e.g., vascular disease). This indicates that concealment due to fear of negative appraisal can result in sub-optimal self-care and consequently in impaired physical health. Other evidence also suggests feelings of embarrassment when having to undergo diabetes self-management tasks in public, perhaps making it less likely that an optimal self-management routine is maintained [50].

Fear of negative appraisal or judgment can also contribute to a reluctance to share openly with close family, friends, and health professionals about self-management activities, blood glucose levels, or other health outcomes. People with diabetes may fear receiving negative feedback if they do not maintain optimal blood glucose levels, for which they are often held responsible when, in reality, many factors affecting blood glucose levels (e.g., stress, hormones, other medications) are beyond the person's influence. In one study, people with diabetes describe a culture of surveillance, and report using strategies to maintain an image of being "in control" (e.g., manipulating blood glucose diaries) to avoid being judged by significant others and health professionals [37].

Evidence from a systematic review [13] indicates that doctors, nurses, dieticians, and medical students hold stigmatizing attitudes towards people who are overweight and obese. This stigmatization of obesity by health professionals may act as a deterrent to engaging in healthcare, which has potential consequences for physical health and well-being. Up to half of overweight or obese patients reported that they had been humiliated by, or received derogatory comments from, health professionals [51]. This may result in a reluctance to be screened for diabetes in order to avoid the shame associated with failing to prevent the condition. Obese people are less likely than others to participate in breast, cervical, and colorectal cancer screening, and cite weight bias amongst health professionals as one of the reasons for this [13]. Many people with type 2 diabetes are also burdened by the compounding stigma associated with obesity [52].

6 Causes of Diabetes-Related Stigma

A holistic understanding of diabetes-related stigma requires that we attend not only to the perceptions and experiences of stigma but also to the causes of stigma, so that potential mitigating strategies can be identified. Attitudes of *blame* and feelings of *fear* and *disgust* are contributing factors to health-related stigma, and diabetes-related stigma specifically. Literature relevant to each of these concepts is reviewed in turn below. Previously, three functions of stigma have been identified: exploitation and domination, enforcement of social norms, and avoidance of disease [53]. We consider that, of these, enforcement of social norms and disease avoidance are relevant to diabetes-related stigma and may be considered causes of this stigma.

6.1 Blame

There is a culture of blame surrounding overweight and obesity [51], a phenomenon that can reasonably be generalized to type 2 diabetes. Given it is widely known that many cases of type 2 diabetes can be prevented, it logically follows that people with diabetes may perceive the general public to blame them for self-inflicting the condition, and this may lead to self-blame and lower perceived self-worth. Some have reported experiencing discrimination due to the perception that they unfairly utilize and drain societal resources [36], and are somehow less worthy of help than other 'more legitimate' medical conditions. Blame for self-infliction of the condition may also affect those with type 1 diabetes by association (particularly as media reports rarely make any attempt to distinguish the two conditions). Research in hepatitis C suggests that the association with intravenous drug use is so pervasive and persistent that people infected with the virus by other means experience stigma by association [54], and that they try to distance themselves from those who were infected as a result of illicit drug use [48]. Health promotion campaigns and other health-related media have been identified as causes of blame-induced stigma by people with hepatitis C [48] and those who are overweight/obese [55]. Health promotion initiatives with a sole or predominant emphasis on individual behavior as the causal factor in developing a chronic condition (whether it be hepatitis C, obesity, or type 2 diabetes) may facilitate or reinforce attitudes of blame directed at people with the condition [55].

6.2 Fear

Most people with type 1 diabetes and an increasing number of people with type 2 diabetes manage their condition using multiple daily insulin injections, and are therefore susceptible to being associated with the negative social appraisal of needle use. Vials and syringes carry a strong negative connotation and are often linked to illicit drug use or severe illness [32]. People with diabetes report receiving unwanted attention when injecting in public, and worry about being mistaken for illicit drug users [36, 37].

People with diabetes may display other conspicuous behaviors beyond their personal control during episodes of hypoglycemia (or low blood glucose levels). Hypoglycemic symptoms include altered mood and cognition (e.g., irritability, confusion), motor deficits, shakiness, sweating, vomiting, and, in severe cases, seizure. This pattern of symptoms and behavior can resemble being under the influence of alcohol [37], having a mental illness, or having epilepsy. People with epilepsy are commonly characterized as having intellectual impairments, and as being frail, antisocial, hostile and potentially violent, slow, and physically unappealing [56]. Fear of diabetes, then, may arise from feelings of uncertainty and helplessness.

6.3 Disgust

The role of disgust as an emotional reaction has been given increasing attention, particularly in the clinical and social literature, in recent years [57]. A small amount of evidence suggests that disgust may be a cause of health-related stigma [58]. Increased disgust sensitivity (reactivity to stimuli that elicit feelings of disgust) is associated with more negative attitudes towards obese people [59], a bias that is likely to impact many people with type 2 diabetes, and contribute to self-stigmatization. Feelings of disgust may also drive negative attitudes towards people with diabetes injecting or checking their blood glucose levels in public.

6.4 Enforcement of Social Norms

Enforcement of social norms is particularly relevant to observable behaviors or characteristics that are within one's personal control. As such, this is particularly relevant for type 2 diabetes co-morbid with overweight or obesity. While the prevalence of obesity is high in Western societies, the character judgments associated with overweight and obesity (e.g. lazy, no self-control, greedy [60]) may be considered deviations from the social norm. Pressure to meet the social norm may drive the development of self-stigmatization, and serve to justify the perspective of those holding stigmatizing attitudes as it may reinforce ingroup/outgroup comparisons.

6.5 Avoidance of Disease

From an evolutionary perspective, avoidance of disease is important for survival. Illness can be associated with physical changes (e.g., obesity), which may in turn serve to identify the person as being 'unhealthy' [61]. Motivation to avoid such persons may not serve any current function (as most people would understand that diabetes and its related conditions are not contagious), but instead may be rooted in an evolutionary drive to maintain good health, for oneself and on behalf of one's offspring (e.g., the case of not wanting to start a family with someone who may have a genetic predisposition to 'illness').

7 Mitigating Strategies

We were unable to identify any literature regarding strategies to reduce, or assist people to cope with, diabetes-related stigma. However, the literature about health-related stigma in general suggests that stigma-reducing interventions and mitigating strategies can be targeted at [23, 62]:

1. The health problem itself, using strategies such as public health initiatives to promote early detection and management
2. The sources of stigma, or people reinforcing the stigma, using strategies such as education, protest, and social marketing
3. The stigmatized person/group, aiming to reduce the emotional impact of stigma through counseling, peer support groups, and therapeutic communities
4. Social policy, using strategies such as advocacy, lobbying, and legislation, or research support

Some (albeit limited) evidence speaks to the effectiveness of some of these strategies. Persky and Eccleston [63] examined medical students' interactions with and attitudes towards an obese patient after reading about either behavioral or genetic mechanisms of obesity, or a control topic. Compared with both the control condition and the behavioral condition groups, students who read about genetic mechanisms held the patient significantly less responsible for their unhealthy weight. Students in the genetic group recommended weight loss, exercise, and dietary consultations less frequently than those in the control condition group [63], suggesting that the provision of genetic causal information may produce or reinforce fatalistic notions about the development of obesity.

There is some evidence from both HIV/AIDS [64] and epilepsy [56] research that improved knowledge about the condition is associated with less stigmatization. However, results of educational intervention evaluations are mixed [6, 13], possibly because stereotypes are resilient to change [62]. Increasing the level of personal contact between those living with stigmatized conditions and the general public may have educative effects and, because of the potential of this strategy to also demystify the condition, generate empathy, and reduce prejudice and negative stereotyping [65], this approach may be more effective in reducing stigma than information provision alone. Further research about the impact of personal acquaintance on social stigma is necessary. The case has previously been made for more research attention to be directed to health-related stigma intervention research [23].

8 A Framework for Understanding Diabetes-Related Stigma

Stigma is a universal phenomenon, which is associated with a number of medical conditions, including diabetes. With diabetes increasing at epidemic proportions worldwide [2], an increasing number of people are likely to be impacted by the negative social appraisals associated with diabetes (in all its forms). Thus, systematic research into diabetes-related stigma is an urgent priority. We propose a framework for understanding and investigating diabetes-related stigma, which is intended to illuminate the causes, experiences, and consequences of stigma. The framework is summarized in Fig. 1. Based on the evidence outlined in this narrative review, we propose that certain features of diabetes and its management, as well as the attitudes and beliefs of individuals and communities, contribute to the development of negative stereotypes about people with diabetes. The psychosocial mechanisms that cause stigma include blame, fear, and disgust, and the perceived need to enforce social norms and avoid disease. The self-perceptions of stigma, stereotypes (from self or others), and the stigmatizing practices that are common in society result in identity threat, as described by Major and O'Brien [19]. Stigma has a number of consequences for people with diabetes, including impaired psychological well-being and concealment attempts resulting in a compromised self-care regimen, which in turn leads to sub-optimal clinical outcomes. Dual strategies are needed to reduce diabetes-related stigma (e.g., via health promotion and education) and support people with diabetes to enhance coping and resilience (e.g., via peer support).

Future research into each aspect of the proposed framework will serve to build on our understanding of the experience of diabetes-related stigma. A key priority for future research in this area is to develop a standardized self-report tool to assess perceived, experienced, and internalized diabetes-related stigma. While some generalized measures of health-related stigma do exist [66, 67], they are interview based (and therefore resource intensive to administer), and do not encompass all relevant aspects of diabetes-related stigma as outlined in this review. Previous attempts have been made to adapt condition-specific self-report stigma measures (e.g., the HIV Stigma Scale adapted for people at risk of diabetes [29]). However, this too is problematic as the stigma constructs assessed are not completely consistent with what is indicated by the diabetes-related literature and may underestimate diabetes-related stigma. Detailed qualitative studies with people with diabetes are required to explore perceptions, experiences, and domains of stigma specific to diabetes (paying attention to the different types of diabetes), which can then be used to inform scale development. This will then enable quantitative studies to be conducted to explore and assess the perceptions of people with diabetes, and measure change over time or in response to interventions to reduce stigma.

9 Limitations

The synthesization of these research findings is limited by the few studies identified and the lack of a standardized

measure of diabetes-related stigma, meaning that the conceptualization and operationalization of the concept of stigma differs between studies. Consistency in definitions and standardization of measurement in quantitative studies will be crucial for the advancement of research in this area.

10 Conclusion

Current evidence generally reflects the notion that people with diabetes perceive significant social stigma associated with their condition, though this is not consciously corroborated by people without diabetes. Although participants with diabetes in one study indicated that they felt that the stigmatization was diminishing [37], it remains a significant issue faced by people with type 1 and type 2 diabetes, and anecdotal evidence indicates perceived stigma may be increasing. This stigmatization has a significant impact on psychological well-being and results in sub-optimal self-care, which can lead to poorer clinical outcomes. Diabetes-related stigma is driven by attitudes of blame and feelings of fear and disgust, possibly on behalf of both people with and people without diabetes, as well as the felt need to enforce social norms and avoid disease. Well-intentioned health promotion initiatives may have unintended consequences, reinforcing these negative appraisals.

By drawing on the evidence about health-related stigma in diabetes and other chronic conditions, we have developed a framework for understanding diabetes-related stigma that describes the causes and consequences, and also identifies some potential mitigating strategies. This framework is intended to inspire and guide systematic research to improve understanding of diabetes-related stigma and to mitigate this negative phenomenon in diabetes.

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Author Contributions J. Speight and K. Mosely conceived the study. J. Speight, J. Browne, and J. Schabert developed the search strategy, and J. Schabert conducted the literature search and read and summarized relevant articles. J. Schabert, J. Browne, K. Mosely, and J. Speight were all involved in the synthesization of the literature and the development of the framework. J. Schabert developed the first draft of the manuscript, and J. Browne and K. Mosely wrote additional sections of the manuscript. J. Schabert, J. Browne, K. Mosely, and J. Speight reviewed and revised the manuscript in preparation for publication. All authors approved the final version. J. Speight, as senior author, takes overall responsibility for the content of this article.

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