

# Influences of social issues on type 1 diabetes self-management: are we doing enough?

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## Abstract

Much of the literature on the causes and management of diabetes focuses on biomedical and lifestyle factors, with little attention given to the role of social issues in diabetes management. This study aimed to explore the influence of social issues on type 1 diabetes management from the perspectives of people with diabetes and of health care professionals (HCPs), and to identify strategies to enhance the clinic services.

Semi-structured interviews and focus groups were conducted with eight people with type 1 diabetes and with 15 HCPs. Recruitment was through the patients' HCPs for this service evaluation project.

Findings highlighted the importance of considering the influence of social issues on diabetes management. The dominant themes that emerged from the thematic analysis were: housing situations, divorce, stress, literacy issues, social stigma and financial issues. HCPs suggested ways to improve services by: putting informational boards (e.g. related to benefit services) in the waiting area; providing a peer support platform (to discuss and gain support related to social issues); having a service directory (to refer people to the social services); working at multi-settings (to understand the effect of social issues); and having open clinics at weekends (to support those who are unable to get time off during the week). People with diabetes suggested that bringing in a welfare officer and providing information about benefits could improve the clinic services.

In conclusion, including a systematic assessment of social parameters in health care records might improve the ability of clinicians and the health system to tackle social issues early. This is likely to improve self-management and biophysical outcomes. Copyright © 2016 John Wiley & Sons.

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## Key words

type 1 diabetes; social issues; thematic analysis; interviews and focus groups; service improvement strategies

## Introduction

Type 1 diabetes is a chronic condition requiring an intensive and challenging self-management regimen. This includes daily insulin injections, frequent blood glucose tests, close monitoring of food intake and regular exercise.<sup>1</sup> However, a lack of attention to the importance of social issues that influence health has been suggested as a reason for the lack of population level change in diabetes outcomes.<sup>2–4</sup> Social determinants of health have been associated with increased incidence, prevalence and burden of disease and impact on the health and well-being of individuals and populations.<sup>5–7</sup> Social issues have previously been highlighted as a significant barrier to self-management,<sup>8</sup> with some attempt to systematically identify and address them in primary care where people with diabetes seen predominantly have type 2 diabetes.<sup>9</sup>

Social determinants/issues have been defined as factors in the social

environment. These include: socio-economic status, housing and transportation, accessibility of health care resources, social support,<sup>10</sup> education, unemployment, job security and disability.<sup>11</sup> Intuitively, these factors would appear to be obvious determinants of health.<sup>12</sup> According to Raphael<sup>13</sup> social determinants are the socioeconomic conditions that influence the health of individuals, communities and jurisdictions as a whole. These determinants also establish the extent to which a person possesses the physical, social and personal resources to identify and achieve personal aspirations, satisfy needs and cope with the environment.

However, most of the literature focuses on biomedical, psychological and lifestyle changes,<sup>14</sup> with little if any attention given to the role of social determinants of health in the prevention and management of diabetes.<sup>15</sup> Qualitative studies of people with diabetes living on a low income

suggest that they struggle to survive, let alone manage their diabetes.<sup>16,17</sup> Current research has demonstrated that social issues are associated with the disproportionate development of chronic conditions and challenges encountered when managing them.<sup>16,18–20</sup> The concept of social issues in health seems to link with the health determinants model<sup>21</sup> as it focuses upon individuals, as well as the factors surrounding them. Individuals are at the centre of this layered model, who are influenced by their environment. Dahlgren and Whitehead<sup>22</sup> attempt to map the relationship between the individual, environment and disease.<sup>23</sup>

Understanding the link between social issues in health and diabetes can lead to identifying opportunities for improving/preventing negative health outcomes.<sup>12</sup> It can also enable practitioners to consider the implications of intervening at various points during the ‘process’ of diabetes care.<sup>24</sup>

Thus, a service evaluation project was designed which aimed to explore perspectives of people with type 1 diabetes mellitus (T1DM) and of health care professionals (HCPs) about the influences of social issues on diabetes management, and identify ways of enhancing the clinic services. Our current service includes diabetes consultants, diabetes specialist dietitians, nurses and two case managers meeting people with T1DM on a regular basis to provide clinical care, ongoing support and make referrals as required.

## Methods

Two case managers (CMs) were interviewed, who worked on the diabetes ketoacidosis project.<sup>25</sup> In addition, two semi-structured focus groups were conducted with 13 HCPs: one with diabetes specialist nurses (DSNs, n=7) and the other with diabetes specialist dietitians (DSDs, n=6). Using a convenience sampling approach, eight T1DM people (males n=6, females n=2) were interviewed. They were identified by the HCPs (who knew they would be receptive to participation) from the hospital clinic initially for the purpose of this service evaluation project. The researcher requested the HCPs to inform the potential participants about the study at their last visit in the clinic. Participants were invited via a telephone call made by

Case managers (semi-structured interview)	Health care professionals (focus group)	People with type 1 diabetes (semi-structured interview)
<ul style="list-style-type: none"> <li>• Tell me about your role as a case manager – what does it involve in your regular routine?</li> <li>• What kind of social issues do you come across during your visits to patients?</li> <li>• How do you assess the social issues?</li> <li>• How do those issues affect diabetes management from your point of view?</li> <li>• What kinds of resources are/aren't in place currently to support patients with those issues?</li> <li>• How can current services be improved from your perspectives in terms of providing further support to patients to tackle those issues?</li> <li>• Is there anything else you would like to share with me?</li> </ul>	<ul style="list-style-type: none"> <li>• What kind of social issues do you mostly come across during the consultation?</li> <li>• How do those issues influence diabetes self-management from your perspectives?</li> <li>• Strategies you normally use to help those patients going through such issues?</li> <li>• What are the gaps in our current services from your perspectives?</li> <li>• How can those gaps be overcome?</li> <li>• Is there anything else you would like to share with me?</li> </ul>	<ul style="list-style-type: none"> <li>• Could you tell me about your diabetes management routine?</li> <li>• What kind of issues have you come across during self-managing your diabetes?</li> <li>• How do those issues have an affect on diabetes management?</li> <li>• What coping strategies do you use to overcome those issues or how do you tackle them?</li> <li>• How do you think that the clinic services could help you to manage those issues?</li> <li>• Is there anything else you would like to share with me?</li> </ul>

Table 1. Interview guide

the first researcher two weeks before their next appointment date.

The issue of selecting people with T1DM was resolved by picking those who accepted the invitation (n=13). However, after eight interviews, the researcher had achieved what is often referred to as ‘saturation’,<sup>26</sup> which meant that new interviews did not bring any new information with them. In addition, the residual five participants had no appointments in the clinic for the coming few months.

In terms of the HCPs' sample, there were only two CMs who were interviewed individually. However, focus groups were conducted (by considering a feasible approach to gain rich understanding of their collective views) among all of the dietitians and nurses (involved with T1DM people on a regular basis). All participants' age ranged between 25–60 years and they were from British European descent, comparable to the local population.

All participants were provided with information about the project and reassured about their anonymity, and ability to withdraw, before conducting the interviews. The concept of social issues in T1DM guided the qualitative methodology, interview guide and the analysis of the study. Focus groups (to

generate information on collective views) and semi-structured interviews (to explore the topic area in detail based on individual issues) were conducted by the first author with a background in social sciences. Both types of interview guide (see Table 1) were developed by the first author, by discussion with the co-authors, and aimed to explore participants' perspectives.

The interview guide consisted of three main parts: first, a general question related to diabetes management; second, questions related to social issues and their effect on diabetes management; and, finally, exploring any gaps and some suggestions to improve the services from their perspectives. At the end of the interview, the participants were asked if there was anything else they would like to share with the researcher. This was to assure that aspects they thought important were not left out. Some probing was also used during interviews to clarify whether or not the interpretation was correct. The interviews were conducted in the hospital clinic (urban area) where participants had their appointments. The length of the interviews was up to an hour. All focus groups and interviews were audio-taped and were transcribed verbatim.

This project was approved by the hospital patient safety department as a service evaluation.

Thematic analysis was applied to analyse the data emerging from the materials. The transcripts were read through several times by the first author to obtain a good sense of the entire data. Furthermore, anonymous transcripts were reviewed by the co-authors, who independently noted emerging patterns in themes, on which there was a close agreement. Themes were verified by re-reading the transcripts to ensure that they adequately captured the central ideas in the data. A Word document was created around each main theme with relevant quotations selected from the transcripts that highlighted the sub-themes and related extracts from people with T1DM and from HCPs.

## Findings

The analysis of the data from the two different interview groups highlighted the same themes (due to an emphasis on similar issues). Thus, the findings are presented under three major themes representing the 23 participants' perspectives. These themes are: *Social issues and their effects on diabetes management*; *Psychological issues and their effects on diabetes management*; and *Recommendations (based on individual's comments) to improve current services*. Please note that some of the social issues presented below link with peoples' personal issues due to their connection with the social environment (e.g. relationship breakup).

**Social issues and their effects on diabetes management.** During interviews with the T1DM participants, housing problems were quite common. One young female described it as quite a frustrating experience due to the complexity of her housing situations. Due to financial difficulties, she was unable to afford a new home on a mortgage or live in rented accommodation. The county council was unable to help her, as she already owned a house on paper, which was taken under her name a long time ago. However, in reality, it belonged to her mother, who is paying the mortgage. The county council could help her in this matter only once the house was sold, which does not seem a smooth process in her perspective.

Repeatedly thinking about living in her own accommodation, with her family, and how to manage the complexity of her old home, was a source of constant stress. In this situation, managing diabetes became a lower priority (compared to her housing needs and the needs of her children). She realised that the situation affected her diabetes self-management.

Housing issues seemed to take different forms, e.g. 'wanting to move from a big home to a small flat', as described by a mature female. She has been living alone, disabled, in a three-bedroom house and unable to move to a suitable flat due to facing difficulties with the discretionary housing payment (DHP)<sup>27</sup> process, which is ultimately affecting her diabetes self-management.

Another housing issue was described by a recently divorced young father living with his mother (who had cancer of the pharynx). He wanted to acquire his own residence to live with his son. He seemed quite frustrated living with his mother, which impacted on his ability to enjoy time with his son when visiting, as the mother complained about any noise.

Through his comments it seemed that having his own home could bring a positive change in his life.

Another person had a home but was unable to afford the cost of repairing water leakage in his kitchen. He was also finding it difficult to obtain help from the insurance companies. This issue seemed to be a reason for being stressed, impacting on his ability to manage his diabetes.

On the other hand, losing a relationship or divorcing seemed to have a strong impact on the people and their diabetes self-management. One participant with diabetes became ill after his divorce, impacting on his well-being, diabetes self-management and various other aspects of his life.

A DSD mentioned a similar case concerning a female who was repeatedly admitted to hospital due to episodes of severe hyperglycaemia during her divorce. The DSD seemed to empathise with her personal circumstances. In such situations, looking after children as well as managing diabetes can be quite difficult, stressful and frustrating.

During conversation within the focus group, a CM illustrated that

literacy issues become a barrier for people with diabetes when needing to read information related to diabetes management, as well as, for example, council benefits. Illiteracy and innumeracy impact on the ability to complete benefit-related forms that could help financially.

A further issue, highlighted by a DSD, related to the social stigma of having diabetes as perceived by young people with diabetes. To fit into a school environment of peers, some adolescents tend to deny having diabetes, as they seem to feel embarrassed or have a fear of rejection by others. Having such feelings and behaviour can reduce the likelihood of injecting insulin at key times to manage their diabetes, which ultimately affects their diabetes control.

Furthermore, some people from Eastern European countries were less likely to speak/understand the English language, which made it difficult for the HCPs to assist them in understanding their diabetes management regimen. According to one DSN, non-native-English speakers appeared to have a lack of understanding during consultations (when asking and replying to any questions) related to what had been discussed, thus affecting their diabetes management. According to HCPs, some people involved their family members in clinic visits to interpret the information provided, and, at other times, HCPs utilised the hospital-based interpreter system (to improve communication).

Issues related to money seemed to be quite common among people with diabetes. One DSN described her regular meetings with a couple who seemed to continuously criticise each other in the consulting rooms for being jobless, which had a negative effect on their diabetes management.

Conversely, some people seemed to be working but were currently receiving sick or holiday pay. When the amounts were insufficient to pay their mortgages, they became frustrated and stressed. Such situations do not help people to manage diabetes effectively.

**Psychological issues and their effects on diabetes management.** Contrary to social issues, some of the underlying psychological issues were also highlighted through interviews and focus groups. A CM emphasised one

of the crucial points about considering the underlying psychological issues. In her view, although some people demonstrated difficulties in diabetes management due to social issues, actually they were faced with psychological issues.

A narrative was provided about a homeless person initially given temporary hospital accommodation after hospital admission, and subsequently provided with a one-bedroom flat. Despite his housing needs being met, the accommodation was considered unsuitable as he felt lonely staying there. To address this, he was placed in a sheltered community. Unfortunately, after almost two months, his disruptive behaviour led to further homelessness. Clearly, the underlying issues here were psychological, rather than a housing problem. Such people are provided support if requested by the psychological services through the referral process.

Although stress-related feelings were mentioned quite often during interviews, one male T1DM participant emphasised these feelings as one of the reasons for not being able to manage his diabetes. He reported that stress seemed to make insulin work inappropriately in his body, leading to loss of diabetes control.

A similar issue was noticed with a female. She seemed to have gone through various difficult and stressful life events after her diabetes diagnosis. Facing various challenging situations in her life (from an alcoholic and jobless husband to her own inability to work due to looking after special needs children) seemed to make her believe that stress rather than eating unhealthy food affected her diabetes control.

**Recommendations (based on individual's comments) to improve current services.** Some people with diabetes seemed to talk extensively about their psychosocial issues in detail to get a 'relief' from their day-to-day challenges. Therefore, it was suggested by a female with T1DM that having a 'welfare officer' in the clinic to talk about psychosocial issues informally could lessen this emotional burden.

In addition, the HCPs could gain further insight by listening and understanding the situations affecting diabetes self-management.

One female suggested it would be helpful to provide information about different types of benefits for those who require them. Having such information about these support services could enable them to resolve various issues by contacting them and getting required support, ultimately leading to a positive effect in their diabetes self-management.

A CM highlighted a suggestion to open up the clinic every Saturday, especially for those people who are unable to attend their appointments during the week due to various commitments, including those relating to employment. Having such a service could be quite useful for accessing both advice and support, and induce more attention to self-management.

Another important suggestion was to broaden the continuity of care to those with diabetes by providing services beyond the hospital setting. The current diabetes service had two CMs working in the community as well as in the hospital, and was seen as a useful initiative. Thus, CMs suggested that other diabetes nurses adopt this role. By implementing such a role, they could better assess and understand the needs of people with diabetes from a visit to their homes (i.e. in comparison to the clinic); this could improve referral to appropriate services at an earlier stage. Such a service could be useful for those unable to attend their clinic appointments for other personal reasons, facilitating ongoing support.

A further important area highlighted by one of DSDs was to provide a platform for people in hospital to share information with their local peers to help improve diabetes self-care. She felt that people with diabetes themselves often know the best care to manage their condition, but they just need frequent reminders. Sharing information about diabetes self-care through a platform with their peers could be quite helpful for those who may not have access to the internet at home. In addition, some people with diabetes may find it useful getting information through a social gathering compared with other resources.

The potential need for a social worker in current services was highlighted by a CM. Where current services don't have a social worker available, she proposed the clinic HCPs be

provided with the skills and resources through some training to fulfil that role. As a CM, she seemed to be playing the role of a social worker in any case, partially by considering some social issues faced by people with diabetes.

Furthermore, she added that people with diabetes who have mental health issues also have social issues, and, without a social worker in the diabetes team, it becomes really difficult to find any help for them. One perspective was that, while supporting people with social issues requires substantial time in exploring beneficial resources, this time could be better utilised in addressing diabetes clinical issues. Therefore, she suggested that having a social worker in the team could be quite useful, allowing speedy referral of people needing such support or who could benefit more through an interaction with a social worker rather than HCPs.

One of the gaps in current services was demonstrated by a DSD, in terms of having difficulties finding contact lists of certain services to refer people with diabetes: e.g. alcohol services for those people drinking excess alcohol who also have psychological issues. From her perspective, in this situation it was important to refer diabetic people to alcohol services first, before referring for any additional psychological treatment. Finding the right services for those with diabetes seemed to be a time-consuming process among HCPs. Having a list of different referral services on the hospital web page or as a resource in the clinic could save HCP time and hasten the process of referral.

One of the important suggestions was to provide leaflets, containing contact numbers of different services related to various issues. Diabetic people would be informed to obtain leaflets from the clinic reception and, through those leaflets, might be able to obtain support directly for their issues.

Another useful suggestion was to utilise the waiting area by placing noticeboards in visible sites, containing fact-based, visually appealing information, linking with different types of lifestyle and support facilities. Such a strategy could be effective for people with diabetes who become worried or apprehensive by talking about such issues directly.

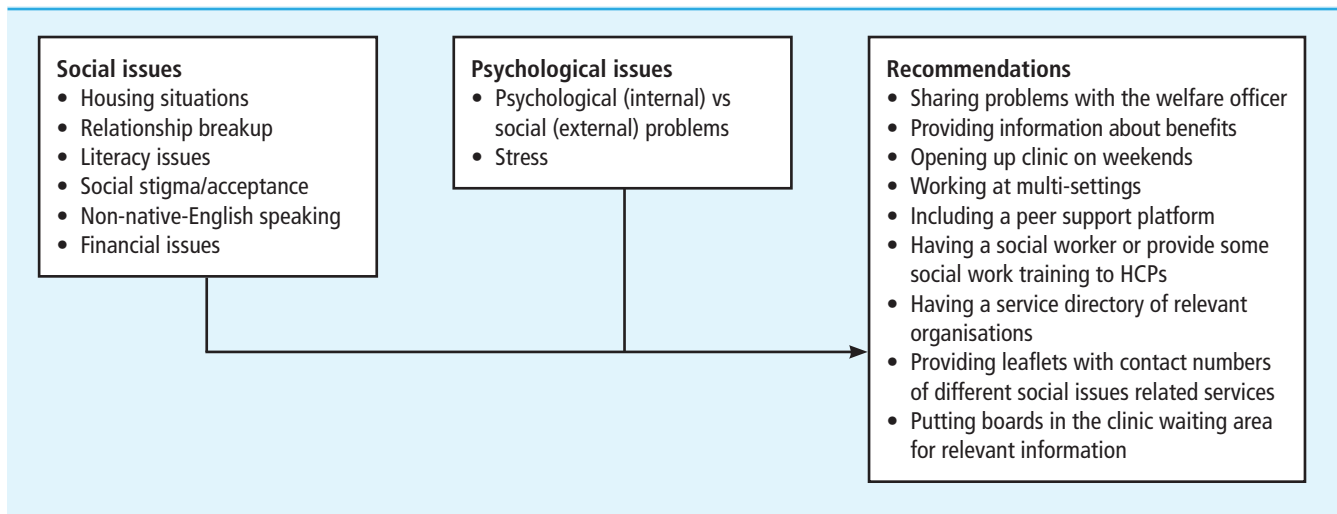


Figure 1. Summary of social issues and recommendations

## Discussion

Participants' perspectives in this study seemed to highlight the need to pay attention to their social issues as well as their diabetes medical requirements. When people feel overwhelmed and frustrated by housing or financial issues, their diabetes self-management may become a lower priority over efforts to solve these more immediate issues. As part of this service evaluation project, people with diabetes suggested bringing in a new service in the form of a social worker or a welfare officer to provide information related to benefits. However, HCPs emphasised that they themselves required more knowledge and there were service changes that could also facilitate addressing the social issues identified (see Figure 1).

Social determinants of health<sup>28</sup> can be viewed as the primary influencers and best predictors of health outcomes at the individual and population levels.<sup>11,29</sup> As evidenced by accumulated international and domestic research, social determinants (e.g. income, education, housing, and access to nutritious food) are central to the development and progression of diabetes.<sup>16,19,20</sup>

The analysis has also demonstrated that social issues affect mental health as well as the management of those with diabetes. A variety of challenging life situations left people in a stressed state, which subsequently affected their diabetes self-care/management. It is commonly believed that stress can precipitate diabetes onset and disrupt

Issues	Suggestions
Financial issues	Providing information about benefits Putting boards in the clinic waiting area for relevant information
Housing situations, literacy Non-native-English issues	Having a social worker or a service directory of relevant organisations Providing leaflets with contact numbers of different services
Relationship breakup Social stigma/acceptance	Having a service directory of relevant organisations Including a peer support platform
Psychological (internal) vs social (external) problems Stress	Sharing problems with the welfare officer

Table 2. A link of suggestions for addressing the reported social issues

diabetes control.<sup>30</sup> Stress seemed to be an inevitable part of life, sometimes due to major, and at other times minor, life events. The UK government's mental health outcomes strategy 'No Health Without Mental Health' places considerable emphasis on the connections between mental and physical health, and gives responsibilities to Improving Access to Psychological Therapy (IAPT) services for supporting the psychological needs of people with long-term conditions.<sup>31</sup> It might be worthwhile for one IAPT worker in each area to see more of those with diabetes, liaise more often with the diabetes specialist services and develop such diabetes-specific expertise. Alternatively, staff who manage people with diabetes could be trained to screen and identify common mental health problems. Lamers *et al.*<sup>32</sup> demonstrated that nurse-led cognitive behaviour therapy interventions were effective, in older adults, in

reducing distress about diabetes, and showed significant differences in glycaemic control after nine months. However, results were significant only for higher-educated people, and interventions were run by nurses with expertise in diabetes.<sup>33</sup>

Nonetheless, this study adds knowledge to the growing body of literature about some of those social issues in diabetes which have not been described previously<sup>2,12,34–36</sup> – e.g. various housing situations, divorce, literacy issues, non-native-English speaking, and social stigma. No qualitative study was found in the literature search exploring social issues from the perspectives of T1DM people and HCPs. In addition, participants' suggestions are also a valuable addition to the literature and to improving the current services to address various social issues (see Table 2).

Reducing social inequalities can benefit society, health systems and

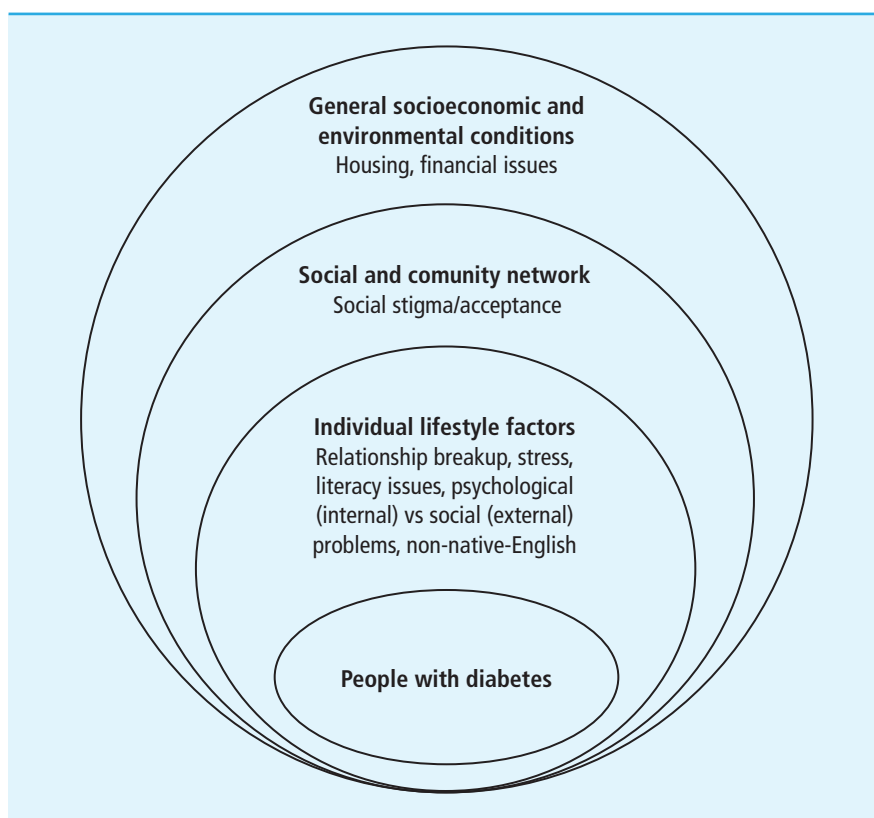


Figure 2. Social issues and their link with the adopted social determinant model

clinicians from public health, ethical and economic standpoints.<sup>37</sup> To guide local and national policies that address health disparities resulting from social issues, it is important to measure the non-medical factors contributing to the development of chronic conditions.<sup>35</sup> Collecting standardised and comprehensive data could allow clinicians, health systems, researchers and policy-makers to better understand the effects of these factors on health outcomes, particularly with regard to diabetes.<sup>35</sup>

On the other hand, reducing such issues requires adopting a systematically multi-layered approach (Figure 2) and working beyond the individual level, with families, communities, work sites and community groups.<sup>23</sup> In addition, utilising multi-agency approaches could be quite beneficial for such issues. Multidisciplinary and multi-agency working involves appropriately utilising knowledge, skills and best practice from multiple disciplines and across service provider boundaries – e.g. health, social care or voluntary and private sector providers – to redefine, re-scope and reframe health and social care delivery issues and reach solutions based on an improved collective understanding of complex patient needs.<sup>38</sup>

**Strengths and limitations.** Overall, it is important to note that all participants were of British descent. Conversely, the strength of this evaluation lies in its qualitative methodology (e.g. interviews and focus groups) to explore an area of limited research in the UK. The use of interviews and focus groups was potentially more beneficial in terms of gaining richer data in comparison to quantitative methodology from such small numbers. These methods were useful to resolve seemingly conflicting information, because the researcher had the direct opportunity to ask about the apparent conflict.<sup>39</sup> The focus group provided an opportunity to gather effective and collective information from a number of HCPs. Semi-structured interviews were conducted with T1DM people to maintain the privacy of individual issues. In addition, it was not feasible to conduct focus groups with them due to their different appointment schedules. Furthermore, this study not only explored perspectives related to social issues from people with T1DM, but also from their HCPs.

This project was conducted for service evaluation purposes rather

### Key points

- Social issues affect mental health as well as diabetes management. In this study, various challenging situations left patients in a stressed state, which ultimately affected their diabetes self-care/management
- People with diabetes highlighted the need to consider their social issues as well as their medical requirements
- This study not only explored the perspectives of people with type 1 diabetes but also those of health care professionals
- Participants' suggestions, in terms of providing clinical staff training related to social issues and providing material resources to support people with type 1 diabetes, could be a valuable contribution to improving the services

than for research reasons and it is recommended that a more comprehensive, deeper qualitative research project be undertaken in the future. In addition, this study included only a small number of people with T1DM.

Overall, the current project adds further knowledge about the influences of various social issues affecting T1DM management (from the perspectives of people with T1DM and their HCPs) which require attention. To improve current services, the suggestions were to provide clinical staff training related to social work, and provide material resources to support such people with T1DM. Introducing systematic approaches to dealing with social barriers to diabetes self-management could add significantly to the psychological and clinical strategies already in place.

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### Declaration of interests

There are no conflicts of interest declared.

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