



# The lived experience of young adults emotionally labouring with type 1 diabetes: Findings of an interpretive phenomenological study

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## ABSTRACT

**Background:** Type 1 diabetes is a life-long metabolic illness. Typically diagnosed in childhood, adolescence, and young adulthood, this diagnosis is often associated with increased psychological vulnerability. Diabetes distress is associated with the daily demands of managing complicated medication and dietary regimes that are emotionally, psychologically, and physically taxing. Emotional labour may be required to manage or negotiate the demands of diabetes distress. Emotional labour is the process of managing feelings and expressions that come with fulfilling the emotional demands of necessary tasks or roles. However, the meaning of emotional labour has not been explored for young people living with Type 1 diabetes.

**Methods:** Using Interpretive Phenomenological Analysis, we conducted this study to explore the lived experience of emotional labour for young adults living with Type 1 diabetes in adulthood.

**Results:** Themes were identified that constituted sources of emotional labour inherent to participants' experiences of diabetes management. The over-expenditure of emotional labour suggests profound implications for mental health outcomes and diabetes distress levels, and participant experiences revealed institutionally imbedded ableism that elicited further expenditure of emotional labour.

**Conclusion:** The findings suggest that reconsideration of educational frameworks and praxis within diabetes healthcare may alleviate emotional labour and diabetes distress.

## 1. Introduction

Type 1 diabetes (T1D) is a life-long metabolic illness that renders the body unable to metabolize glucose. As a result, patients must manage their blood glucose levels with synthetic insulin, diet, and exercise. Also known as juvenile diabetes, T1D is usually diagnosed in childhood and adolescence, the latter considered a phase of increased psychological vulnerability<sup>1</sup> with the added dimension of health care transitions.<sup>2</sup> Because T1D requires round-the-clock rigorous management, many young adults with T1D struggle with non-adherence, increased psychological distress, mental health challenges, social stigmatization, and poorer outcomes for eating disorders. These findings have been consistent for decades, though more recent scholarship has provided a clearer picture of psychosocial challenges for T1D, including higher risk of major depressive disorder, suicidal ideation, generalized anxiety, eating

disorders, social stigma,<sup>3-11</sup> and what researchers now call diabetes distress.<sup>12-15</sup> Diabetes distress is a rational response to the life-changing qualities of diabetes. It is distinct from clinical depression and anxiety in that its causes are rooted in the challenges of diabetes management.<sup>16</sup> There is further evidence linking T1D with increased psychosocial challenges that negatively impact mental health and health regime adherence.<sup>16</sup> This management is complex, demanding, and can elicit emotional labour.

Emotional labour is defined as the process of managing feelings and expressions to fulfill the emotional requirements of a role or task. Emotional labour, which is often invisible, includes negotiating how emotions are processed, expressed, or sometimes all together suppressed.<sup>17</sup> In the context of this research, the 'role' or 'task' was viewed as the ongoing management of T1D as conceptualized by the first author, a social scientist, who was diagnosed at age 15 and has lived with T1D

**Abbreviations:** T1D, Type 1 diabetes; T2D, Type 2 diabetes; IPA, Interpretive Phenomenological Analysis; JDRE, Juvenile Diabetes Research Fund.

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for 20 years. As per her *Personal Reflection on my Emotional Labour and T1D Diabetes* (see [Supporting Information](#)) T1D management consisted of tasks such as generating insulin bolus calculations, bolus corrections, glucose testing, and counting carbohydrates, ratios and adjusting them accordingly. These tasks constitute the physical and cognitive labour of diabetes management. Her reflection indicates that the related affective processes, which go unseen, uncommunicated, and are often entangled in social relations, constitute the emotional labour of diabetes management. Examples of this may include meeting a heightened demand for attention to detail, managing negative feelings that may arise as a product of diabetes management, exercising self-compassion, processing upsetting social interactions, mitigating concern from loved ones, contending with ableism, coping with social stigma, and explaining the illness to laypeople.

While research has focused on the relationships between T1D, mental illness, and/or psychosocial challenges, emerging research suggests that there are new ways of understanding distress particular to T1D.<sup>12–15</sup> However, research has yet to provide evidence about the psychosocial challenges that instigate high occurrence of distress in young adults with T1D. In addition, research on the psychological experiences of people with T1D may benefit from the concept of emotional labour, which has successfully been used in fields such as nursing,<sup>18</sup> education studies,<sup>19</sup> and gender studies<sup>20</sup> to offer insight into why people experience psychological distress in specific contexts. There is little research available on the experiences of young adults emotionally labouring with T1D, especially in relation to diabetes distress. Therefore, the needs of young adults with T1D in regards to their experiences of disease management, diabetes distress, and emotional labour remain unclear. Further, what supports need to be available to them in the context of healthcare provision, education, and practice are also unclear.

Consequently, the purpose of this study was to begin to understand what it is like being a young adult living with T1D and how the phenomenon of emotional labour might contribute to a nuanced and in-depth understanding of living with T1D and its accompanying psychosocial challenges. Specifically, we sought to determine whether young adults with T1D reported experiencing emotional labour and, if so, how and to what extent they experienced it. Accordingly, Interpretive Phenomenological Analysis was used to conduct the study guided by the research questions:

1) How do young adults with T1D experience emotional labour related to their T1D management?

2) How can the concept of emotional labour deepen understandings of why young adults with T1D experience increased risk of psychosocial challenges?

Study findings are meant to inform healthcare stakeholders and people with T1D how to start to better understand the experience of young adults living with T1D in relation to the phenomenon of emotional labour and its accompanying psychosocial issues. This research makes a significant contribution to an evolving framework of understanding the high incidence of psychosocial challenges and diabetes distress experienced by young adults living with T1D. While most studies on T1D and psychosocial challenges are quantitative and aim to establish correlation, there is little qualitative research exploring the *how* and *why* of the phenomena of emotional labour and diabetes distress. The aim of this research therefore was to address the existing knowledge gap in the scholarly literature by articulating the experience of living with T1D in relation to the phenomenon of emotional labour.

## 2. Methods

Interpretive Phenomenological Analysis (IPA) is used in psychology-focused research to explore how people make sense of their personal and social world and how they make meaning of experiences, events, and states.<sup>21–23</sup> This is done by exploring the connections that participants make between their cognitive, linguistic, affective, and physical aspects of being.<sup>21–23</sup> We used IPA because it is an approach to study how

people think about their own experiences, which was well-suited for exploring the experiences of people with T1D. We obtained ethics approval through our university's Ethics Board [File No. 24238].

### 2.1. Population

Nine young adults participated in this study. Participants were eligible if they were between the ages of 18 and 30 or old enough to provide consent, diagnosed with T1D by a licensed physician, and if they had been living with the illness for a minimum of two years. Because the first year following diagnosis can be particularly tumultuous as patients adjust and learn the idiosyncrasies of their illness, participants at two or more years past diagnosis were recruited as they are more likely to have 'settled' into life with T1D and could provide richer experiential accounts of the phenomena under study.

### 2.2. Sampling

Participants were recruited through the social media platform Twitter (now known as X), and through the T1D research database, *ConnecT1D*. Furthermore, the Juvenile Diabetes Research Fund (JDRF) advertised the study. Social media etiquette was used during Twitter recruitment. The researcher placed an open call for participants on Twitter, using appropriate hashtags such as #Type1, #T1, #T1D, and #LiveBeyond, which are frequently used by people with T1D and advocacy groups such as Beyond Type 1 and the JDRF. Our university's recruitment poster template was used in the open call. If the researcher was aware of mutual social media followers who live with T1D, these individuals were also approached through Twitter's private messaging system to gauge interest and subsequently invite participation in the study via email. Participants were consented prior to data collection commencing.

### 2.3. Data collection

The first author conducted semi-structured interviews with open-ended questions in an informal, conversational style consistent with an IPA approach. All interviews were conducted online via Zoom. Given the move towards web-based research interviews even prior to COVID-19, this approach afforded a larger geographical area for recruitment.<sup>24</sup> The interview call was password protected, and only the interviewer and the participant were allowed into the call. All calls were recorded with the participant's consent, and recorded files were stored on a password protected device. Interviews were then transcribed verbatim for analysis and interpretation, and participants were assigned aliases to anonymize their identity and protect their privacy throughout the research (P1 to P9).

### 2.4. Data analysis

While there is no prescriptive way of analyzing data in IPA, rigour was addressed by reading the interview transcripts several times over, utilizing notetaking techniques and then subsequently re-reading the transcript to denote themes and subthemes.<sup>21–23</sup> As such, multiple cycles of condensation were used for the overall analysis. The first cycle consisted of initially reading all the interview transcripts in entirety. Then, the transcripts were re-read to identify words and phrases that meaningfully captured participants' experiences and to better understand participants' state of mind. Concise phrases were generated to encapsulate the essential quality of what was found in these initial notes.<sup>21–23</sup> Transcripts were then re-read to take note of broad and common themes, such as words or phrases that were repeated in and across participants' responses.<sup>22</sup> The transcripts were re-read two more times for clarity, which allowed for theme adjustment and further identification of specific themes and subthemes. In this study, analysis produced six themes and 21 subthemes (see [Table 1](#)).

**Table 1**  
Findings by Themes and Subthemes.

| Themes   | Subthemes  |
|--|--|
| 1. Tough love and interpersonal relationships                            | 1.1 Managing the diabetes police   |
| 2. The need for mental calculus  | 2.1 Educating and empathizing with laypeople<br>2.2 Making diabetes legible<br>2.3 Disclosure  |
| 3. Managing misconceptions from laypeople                                | 3.1 Hurtful and offensive comments<br>3.2 Misinformation<br>3.3 Conflation of T1 and Type 2 diabetes<br>3.4 Visibility of medical devices<br>3.5 Ableism   |
| 4. Systemic barriers   | 4.1 Access to medical devices<br>4.2 Institutional definitions of disability<br>4.3 Medical assumptions  |
| 5. Intrapersonal relationship to diabetes                                | 5.1 Unpredictability of diabetes<br>5.2 Emotional exhaustion<br>5.3 Negative physical experiences<br>5.4 Awareness of mortality<br>5.5 Conceptualizing difference<br>5.6 Social understandings of healthy bodies |
| 6. The “bad diabetic” and an internalized expectation of perfect control | 6.1 Impossible expectations and emphasis on personal responsibility<br>6.2 Glycemic control = Shame, guilt, and worry  |

### 3. Results

Nine young adults participated in this study. All participants were woman-identifying and most specified that they were White (7/9). Most were Canadian (7/9). They ranged in age from 23–29 and had T1D for 5–22 years; the youngest age of diagnosis was two years of age, and one participant was diagnosed in her early twenties.

Two important facets of the interview process included: first, understanding the phenomenon of emotional labour as it resonated with every participant, and second, recognizing that participants had highly individual and valuable lived experience arising from the socio-cultural intersections they occupied. Importantly, none of the participants disputed that T1D requires a high degree of emotional labour, and they unanimously treated it as a given reality. In short, emotional labour was already assumed to be an inherent part of living with diabetes.

In keeping with the participants’ reports of what living with emotional labour was like for them, the findings are reported here by theme and subthemes alongside excerpts from participants’ narratives. Consistent with analysis in accord with IPA, reporting findings thematically is meant to amplify the participants’ voices and to deconstruct how and why particular experiences might come to constitute emotional labour for the participants. Thus, the analysis is not a presentation of unequivocal fact but one of interpreted perspectives.

#### 3.1. Tough love and interpersonal relationships

The interpersonal dynamics of people living with T1D were central in the data. Five out of nine participants reported experiencing “tough love” from family, friends, and healthcare professionals, which caused them to expend emotional labour. They recounted that others’ rigid demands for ideal glycemic control created friction, eroded trust, and rendered interpersonal and medical spheres combative rather than supportive. These dynamics created a demand for the participants’ emotional labour, as they often took responsibility for managing others’ feelings, diffusing conflicts, and setting boundaries. Participants did not experience tough love as motivating and responded with deception, such as faking results in their logbooks, which compounded feelings of loneliness, isolation, guilt, and shame. The related phenomenon of the

“diabetes police” arose as a facet of tough love, which participants had to manage with emotional labour.

##### 3.1.1. Managing the diabetes police

Participants experienced tough love related to T1D through policing behaviour by family, friends, and healthcare professionals. Parents were described as strict and lacking the tools to be emotionally supportive and available (P2, P5). For instance, P5 referred to her mother as “the diabetes police,” and P6 reported being chaperoned by her mother at the doctor’s office, which frightened her out of asking about alcohol and diabetes. P1 recounted that her doctor asked her parents why they were not “controlling” her. This put strain on P1’s support systems, namely, her family, who felt pressured to appease the physician. Participants indicated that the policing and intrusive behaviour they experienced from family, friends, and healthcare professionals made them feel responsible for managing others’ emotions, diffusing conflict, establishing boundaries, and over-empathizing with those who policed them: “I’m being yelled at because mom is tired [or] had a really bad day. As long as I could identify why [my parents] were doing something that was unfair to me, I could be okay with [it]” (P2).

##### 3.2. The need for mental calculus

“Mental calculus” emerged as a common theme across participants’ accounts. Mental calculus refers to a decision matrix participants felt forced to engage in when interacting with laypeople about T1D. Mental calculus was described in three situations: when the participant felt pressure to educate or empathize with an uninformed layperson; when attempting to make their diabetes legible to the point of proving trauma; and when the participant felt pressure to disclose to laypeople that they had diabetes.

##### 3.2.1. Educating and empathizing with laypeople

Six of the nine participants (P1, P2, P4, P6, P7, P9) identified with performing “mental calculus” when engaging with laypeople whose comments warranted correction, education, or an expression of empathy. P4 indicated that she did not always have the energy to do so and said, “I don’t feel that I should be the one that has to take on the emotional burden of being the fact police and dealing with being on an educational crusade.” P7 described mental calculus as a substantive process that occurred internally without the other person’s knowledge whereby, she considered the appropriate level of disclosure, the potential reaction, and whether the outcome was worth the labour.

##### 3.2.2. Making diabetes legible

Three participants expressed struggling to make diabetes legible to others. Legibility refers to how participants worked to make a complex condition understandable to people who did not have to engage with that condition. These demands, coupled with the impulse to oversimplify diabetes, contributed to participants’ feelings of alienation and their over-expenditure of emotional labour. P6 reported that it was “really frustrating...to communicate [diabetes] in a way...they’ll understand.” She emphasized that the task of making diabetes and her diabetes-related suffering legible to others was her greatest source of emotional labour.

##### 3.2.3. Disclosure

Pressure to disclose one’s illness when speaking to laypeople also prompted a “decision matrix” and required emotional labour for participants P1, P3, P4, and P7, who reported overexerting emotional labour to maintain the comfort of a hegemonic group. P3 shared that on dating apps, she often only provided “bare bones” answers because it took effort to fully explain diabetes, and she did not want to disclose layered details about herself. To protect her time investment, P3 exerted additional layers of labour to determine the appropriate level of disclosure in social relationships.

### 3.3. Managing misconceptions from laypeople

All nine participants reported that managing misconceptions from laypeople required emotional labour. Often the misconceptions were hurtful or offensive, and participants expended emotional labour to manage their feelings and responses. Misconceptions involved misinformation, the conflation of T1D and Type 2 diabetes (T2D), and reactions to visible medical devices, all reflecting ableism.

#### 3.3.1. Hurtful and offensive comments

Three participants emphasized the role of inappropriate, hurtful, or offensive comments, jokes, and scrutiny from others (P1, P4, P7). Such comments created an incongruence between participants' self-concept and how they others appeared to perceive them. Comments overstating or joking about limb amputation and diabetes revealed a reductive and stereotyped understanding of diabetes that was likewise incongruent with participants' self-concepts. Emotional labour was required to manage participants' reactions to misconceptions and calculate how best to respond.

#### 3.3.2. Misinformation

Seven participants (P2, P3, P4, P5, P7, P8, P9) expressed that encountering misinformation was a common occurrence that demanded their emotional labour. For instance, participants expressed expending emotional labour managing misinformation about diet and diabetes, specifically, the culturally ingrained belief that people with diabetes cannot eat sugar or carbohydrates (P2, P3, P8, P9). As an example, P8 reported being asked multiple times if she had diabetes because she ate too much sugar as a child—a common misconception that perpetuates the idea that diabetes is a “lifestyle” illness resulting from poor choices. Managing the negative emotions that arose from these encounters required emotional labour that, for some participants, resulted in a loss of emotional bandwidth when explaining diabetes to others (P9).

#### 3.3.3. Conflation of T1 and T2 Diabetes

Broadly disseminated stereotypes about T2D in cultural imaginary have led to the common conflation of T2D and T1D, and this conflation is a source of social stigma for people with T1D.<sup>11</sup> Because laypeople tend to view T2D as a “lifestyle” illness based on poor choices and a financial burden to society, participants felt they had no choice but to correct misconceptions when they arose. P7 received comments such as, “*But you're so thin,*” suggesting that P7 did not fit negative stereotypes of T2D. Because fatness was perceived as emblematic of an unhealthy lifestyle, this type of comment further demonstrated how people with T2D are often blamed for their diagnosis, prompting defensive responses from those with T1D.

#### 3.3.4. Visibility of medical devices

Four participants (P1, P2, P5, P9) expressed past and/or present discomfort with the visibility of their medical devices. P5 described feeling shame because of her visible diabetes devices. She recounted an incident when two other women loudly asked one another, “*What do you think is wrong with her? She must be super sick. That [the device] isn't normal.*” P5 decided to approach them and explain what the device was for and highlighted this as a pivotal moment in helping her be more open about her illness.

#### 3.3.5. Ableism

Ableism is defined by its ‘othering’ of those who do not conform to the standard of an autonomous, independent, fully able-bodied, and productive individual.<sup>25</sup> Participants reported interpersonal instances in healthcare settings where providers showed discomfort with sick youth (P2, P3, P4). When disclosing that she had T1D, P3 received responses from healthcare providers such as, “*Oh, but you're so young.*” She relayed that nurses had said to her, “*you shouldn't be this sick.*” These comments from healthcare providers made participants feel othered for their illness

and revealed ableist assumptions about what constitutes a life of thriving.

### 3.4. Systemic barriers

Eight of nine participants (all but P1) expressed that people with T1D experience added stress from the layers of bureaucracy they must navigate to access care. Frequently, they had to demonstrate compliance and prove that they were “valuable” enough to be entitled to financial aid and access to life-saving medical devices. Poor social and institutional understandings of T1D also resulted in inadequate models of disability and risk assessment, which further impacted participants emotionally and psychologically. Navigating systemic barriers included working within these limitations and was identified as a source of emotional labour for participants.

#### 3.4.1. Access to medical devices

Three participants (P3, P5, P9) identified institutional and bureaucratic requirements such as rigid timelines, age limitations, and proving compliance to access medical as a source of emotional labour and a stressor for their T1D management. P5 described institutional pressure to acquire an insulin pump before she turned 18 as part of a provincial requirement to receive insulin pump funding as an adult. In reference to government funding programs for T1D patients with strong medical compliance, P3 said of herself, “*I've never been able to prove I'm a good enough diabetic to get [the pump].*” Institutions and bureaucracies reinforce problematic categories like “good diabetic” and “bad diabetic” by imposing stringent requirements on people with diabetes to prove that they are managing their illness well enough to receive additional care. Navigating these value judgments—whether positive and negative—required participants' emotional labour.

#### 3.4.2. Institutional definitions of disability

P6 and P8 both characterized institutional and bureaucratic definitions of disability as frustrating, reductive, and limiting. For instance, the Government of Canada requires people to engage in or manage their condition for a minimum of fourteen hours a week to qualify for certain disability benefits. Both P6 and P8 noted that quantifying hours spent on T1D management is ineffectual because people with T1D are “constantly on,” as their entire lives revolve around management. P6 noted that the term “invisible disability” revealed assumptions about how disabled people ought to present and perform. She pointed this out, saying: “*I'm able-bodied, but if you have to have things attached to your body in order to stay alive, are you really able-bodied?*”

#### 3.4.3. Medical assumptions

Participants noted that medical assumptions rooted in inadequate knowledge about T1D created systemic barriers to receiving proper care, which compounded expenditure of emotional labour. While combating an ear infection, P4 dealt with a general practitioner who advised taking an ambulance to the hospital for high blood sugar despite that hyperglycemia is common with infection. Not seeing the need for hospital care, P4 reported being made to sign a waiver acknowledging her risk of death for not following the doctor's advice to go to the hospital. This incident demonstrated that some non-specialists are disconnected from the lived experience of people with T1D, which in turn informs inappropriate medical opinions or advice.

### 3.5. Intrapersonal relationship to diabetes

All nine participants indicated that diabetes informed their relationship to themselves. This intrapersonal relationship encompassed one's inner life as it pertained to diabetes and emotional labouring. This included how participants related to their illness, the kind of relationship they built with diabetes, how their experience with diabetes informed their identity, and the core beliefs they internalized about

themselves and their diabetes management.

### 3.5.1. Unpredictability of diabetes

Four participants (P2, P5, P8, P9) expressed that the unpredictability of T1D management warranted emotional labour. This was due to the innumerable variables they needed to account for coupled with their inherent distrust in their own body's functionality (P2, P5, P8). P5 explained, "I don't have trust in my body to be able to do basic human things." For participants, T1D was not only a great deal of physical and mental labour (e.g., preparing for a worst-case scenario), but it took emotional labour to process and cope with the anxiety and distress that arose from this physical and mental labour.

### 3.5.2. Emotional exhaustion

Participants (P1, P5, P6, P7) described contending with anxiety, depression, burnout and disengagement related to T1D, which was a function of exhaustion. Exhaustion in turn hindered their ability to manage their blood glucose (P6, P7). P1 noted:

*I think the emotional labour feels [like] more than it ever [did], with educating others, interacting with my partner [and] various different people, and also within myself. I feel the emotional weight and the emotional labour of having Type 1 diabetes now more than ever, even though things are better now than they've ever been.*

Importantly, P1's comments reveal that ideal glycemic control does not minimize emotional labour but may compound it because maintaining a stringent glycemic range increases the demands of management.

### 3.5.3. Negative physical experiences

Seven participants (P1, P2, P3, P6, P7, P9, P8) noted that managing the relationship between physical and emotional wellbeing was a source of emotional labour. For instance, participants expressed frustration with fluctuating blood glucose (P1, P2, P7, P9). P9 touched on how negative physical experiences such as hypoglycemia spurred fear and anxiety about future events. P9 described hypoglycemia as such: "You feel like you're dying. Your body is literally like, 'Sh\*t, guys, everything is going down. The ship is sinking. This is it; we're done.'" The physiological response to hypoglycemia was so uncomfortable that it fueled fears and anxieties around experiencing it and being unable to correct it.

### 3.5.4. Awareness of mortality

Five of the nine participants (P3, P5, P6, P7, P8) expressed experiencing an increased awareness of mortality, which they named as a source of emotional labour. This awareness was linked with diabetes distress, and to cope with this distress and protect their mental health, participants had to expend emotional labour. P8 noted that a single major disruption to supply chains and access to medical supplies could incapacitate insulin-dependent diabetics. P8 stressed: "I'm not suicidal. I'm not depressed. But it would be so much easier if I just didn't have to deal with it. Can I just not for two days? [But] I know that two days would literally kill me."

### 3.5.5. Conceptualizing difference

Four of the nine participants (P5, P6, P7, P8) expressed feeling at odds with common, frequently positive rhetoric about T1D and chronic illness more broadly (P5, P8). P5 expressed feeling that she was not like others but was surrounded by messaging that she was. Resultantly, P5 felt that she *should* be able to do anything and that she was supposed to pursue her goals the same way any able-bodied person would. The discrepancy between this messaging and her lived reality and identity created a deep sense of alienation and loneliness.

### 3.5.6. Social understandings of healthy bodies

Participants expressed grappling with social understandings of healthy bodies when trying to understand how T1D informed their

identity (P4, P7, P8). Because diabetes is an illness that carries social implications, participants expressed navigating and negotiating complex identities that were entangled in social and institutional structures responsible for producing ideas about non-normative bodies. P8 self-identified as fat and disclosed feeling a great deal of distress whenever speaking to dietitians, who are typically part of diabetes care teams. P8 emphasized that her emotional labour was more wrapped up in her relationship to her weight than diabetes, though the intersection of the two created unique challenges. The medical demands of T1D forced her into more situations where she was confronted with distress about her weight.

### 3.6. The "bad diabetic" and an internalized expectation of perfect control

The term "bad diabetic" was used as a self-descriptor across participants' narratives. Six of nine participants (P1, P2, P5, P6, P7, P9) independently used this term; seven of nine participants (P1, P2, P5, P6, P7, P8, P9) reported strong attachment to the concept of "control" and linked their perceived level of glycemic control to their moods and sense of self-worth. Periods of perceived poor control were associated with guilt, shame, and worry, however, these feelings persisted even when control was perceived to be strong. The feeling that one is a "bad diabetic" appeared to have its origins in an internalized expectation of perfect glycemic control. As a result, poor glycemic control impacted self-worth and created feelings of worry, shame, and guilt.

#### 3.6.1. Impossible expectations and emphasis on personal responsibility

Four participants (P1, P2, P5, P6) expressed that unrealistic expectations were imposed on them since being diagnosed with T1D in their adolescence. P1 recalled that being told by her pediatric endocrinologist that she was a "bad patient" instilled in her a negative belief about herself that persisted into her early adulthood:

*I still feel like that little girl; that's how she felt, and that's how I've felt most of my life, so I don't know. Those formative years might always be there, but I'm hopeful that...it will go away with time (P1).*

Five of the nine participants (P2, P5, P7, P8, P9) revealed that feeling personal responsibility for their glycemic management represented substantial emotional labour. As a result, some participants disclosed feeling an enormous amount of responsibility for themselves, and this affected their mental health and well-being.

#### 3.6.2. Glycemic control = shame, guilt, and worry

Participants (P1, P2, P5) indicated that their best and worst days revolved around diabetes. They described their best days as those in which their blood sugars were "in range" or "under control." Five participants (P1, P2, P5, P7, P9) expressed feeling shame, guilt, and worry about their glycemic management irrespective of how strong their glycemic control was. P1 articulated understanding that energy is finite but nonetheless felt guilt for prioritizing anything except her glycemic management. Subsequently managing that guilt and deconstructing why it arose constituted emotional labour for her.

## 4. Discussion

Current research on T1D and mental health has demonstrated incidence of psychological distress, mental health challenges, and stigmatization.<sup>5</sup> While diabetes distress is named, defined, and regular assessment is recommended,<sup>12-15</sup> most of the literature focuses on clinical depression, anxiety, and eating disorders. Canada's Clinical Practice Guidelines (2018), for example, focus heavily on conventional mental health diagnoses dominated by the DSM-V.<sup>16</sup> These guidelines indicated a 30% prevalence of depressive symptoms and twice as much major depressive disorder (10%) compared to other chronic illnesses,<sup>26</sup> which is consistent with this study's findings. There is little research, however, that addresses mitigating diabetes distress with the exception

of a recent pilot study, which demonstrated that a group-based program run by diabetes specialist nurses was associated with significant reduction in diabetes distress.<sup>27</sup> Likewise, the concept of emotional labour is not seen in research about diabetes management but is used in gender studies, education research, nursing, and popular discourse.<sup>17–20</sup> Participants in our research showed familiarity with the term and expressed that it resonated with their experience of living with T1D. Participants revealed that their emotional labour with T1D consisted of struggling with feelings of social alienation, shame, guilt, and challenges to self-worth. However, much of the literature treats mental health complications as being incidental or comorbid to T1D. While diabetes distress asserts an important relationship between diabetes and mental health challenges, it does not account for *how* and *why* diabetes spurs such intense distress. As such, this research starts to address this gap in the literature by offering further insight into diabetes distress via emotional labour.

Recalling that diabetes distress arises as a response to a life-changing illness, findings from this study reveal that diabetes distress may arise more specifically in response to the demand for emotional labour related to the illness. Importantly, emotional labour does not arise solely from the material and mechanical demands of T1D management. Rather, our findings identified specific aspects of living with T1D more broadly as sources of emotional labour, and the over-expenditure of emotional labour was heavily associated with managing external stressors that challenged participants' mental health. In research by Kelly et al. (2019), emotional labour functioned as a dissociative coping mechanism,<sup>19</sup> meaning that when over-expended, individuals tended to distance themselves from the stressor. This disengagement emerged as a serious challenge for participants in our study, who often disengaged from diabetes-related stressors such as glycemic management, as well as complicated dynamics with family, friends, romantic partners, and healthcare providers. At the same time, given the need for relational realities, our findings also showed young adults' tendency to structure their approach to relationships around diabetes; they implicitly understood diabetes to be a potential wedge in their relationships, suggesting that people with T1D experience a kind of doubling of responsibility because they frequently assume responsibility for managing others as well.

The failure to recognize people with T1D as entangled parties in a web of social relations is evident in how medical non-adherence or poor glycemic control is understood. The idea that knowledge of consequences should modify behaviour appears to be a key assumption that many family, friends, laypeople, and healthcare providers hold, as demonstrated in our study as well. This compounds emotional labour for people with diabetes, as they feel they must justify themselves to navigate the perspective that people will act rationally once they have knowledge of consequences. These interactions then become a source of shame, as the perception of being a "bad diabetic" can stem from feeling judged for knowing the consequences of high blood glucose but failing to control it, nonetheless. It is possible, then, that the notion of feeling like a "bad diabetic" occurs simultaneous to diabetes distress. More research into whether and how diabetes distress can be mitigated in the context of interpersonal relationships is therefore needed. Such research will further understandings of how re-framing others' expectations of the diabetic person can enhance rather than detract from one's ability to manage their illness and their emotional labour expenditure.

Social understandings of chronic illness, which are unfortunately steeped in ableist logic, impact the interpersonal, professional, medical, and casual relationships of people with T1D. Our study findings indicated that participants often felt trapped in a liminal space between reductive notions of 'disability' and 'able-bodiedness.' The first author identified this position as 'conditional able-bodiedness,' which she related to as a person with T1D herself. However, the ways in which those with diabetes do experience disability profoundly impacts all facets of their lives. The findings of this study provide new insights into how people with diabetes navigate ableism by over-expending

emotional labour.

Participants' interactions with the healthcare system and government bureaucracies further revealed the extent to which ableist frameworks pervade systems-level institutions. Here, historian and philosopher Michel Foucault's notion of biopower is useful. Biopower describes how state apparatuses seek to optimize the health of the population by producing what Foucault called "docile bodies" that can be "subjected, used, transformed, and improved."<sup>28</sup> Biopower separates people into the categories of "normal bodies" and "abnormal bodies" and is exerted by training the population to be self-regulating in order to maximize able-bodiedness (i.e., preventative medicine is a form of biopower, and the self-regulating subject is educated to seek out preventative medicine). However, for those with chronic illness, biopower is particularly restrictive as it demands greater effort to perform able-bodied functionality even as a prerequisite for attaining needed medical devices. This creates a tenuous relationship between chronically ill populations and the healthcare system, which is an extension of the state. Furthermore, this tension trickles down to the interpersonal interactions between healthcare providers and patients. Participants in our study reported encountering presumption, hurtful or inappropriate comments, and lack of empathy from healthcare providers. These attitudes stemmed from ableist assumptions about what constitutes a life of thriving and the belief that the patient is solely responsible for their health outcomes. Such attitudes are the interpersonal microcosm of Foucaultian biopower, which emphasizes the individual's obligation to self-regulate. Importantly, lack of empathy is hardly a trivial matter in healthcare and can profoundly impact health outcomes.<sup>29</sup>

To start to address these misconceptions, a philosophical reconsideration of the roles of optimism and futility in relation to chronic disease management are helpful not only to individuals with chronic illness but to healthcare providers responsible for educating and supporting these individuals. The rhetoric around how things ought to be, or that they can be "fine" and "normal" does not permit people with diabetes to process their own feelings in relationship to their diabetes, and it does not allow them space to consider what management and care look like to them, especially as they transition from pediatric to adult health care providers and settings. Participants reported internalizing optimistic messages from healthcare providers who encouraged them to strive for able-bodied normalcy and overemphasized personal responsibility in their health outcomes. However, participants reported feeling misled by this optimistic philosophy and discovered that despite their best efforts, they could not attain able-bodied normalcy. This, in turn, incited feelings of failure and inadequacy, which are tied to diabetes distress. Here, one might consider the work of philosopher Lauren Berlant, who argues that optimism is cruel when "the object/scene that ignites a sense of possibility actually makes it impossible to attain the expansive transformation for which a person risks striving."<sup>30</sup> In the context of T1D, striving for the possibility of able-bodied normalcy is inevitably corrupted by its material and emotional impossibility. Good glycemic control is tenuous; once attained, it is always under threat, and when absent, it confirms the impossibility of able-bodied normalcy.

Therefore, a re-evaluation of the philosophical underpinnings of chronic illness care and education is warranted. Rather than presuming that the goal of T1D care and education is able-bodied normalcy and longevity at any cost, healthcare providers ought to consider what underlying biases inform their care approach. As patients transition into adult life and adult health care with chronic illness, their new care teams would benefit from a greater breadth of training in critical theory that unpacks normative assumptions of health. Specifically, literature that addresses the sweeping impacts of ableist thinking—systemically, socially, and interpersonally—will better equip healthcare providers to extend compassion and empathy to young people who are transitioning to adult care. Research has shown that diabetes complications for patients with doctors who score high in empathy were 40 % lower than for those with doctors who scored low in empathy.<sup>31</sup> Therefore, training that provides healthcare professionals with the critical toolset to

examine their biases and nurture empathy may be useful.

In *The Already Dead* (2012), Eric Cazdyn upends the assumption that longevity is the worthiest goal of chronic illness management.<sup>32</sup> His analysis helps highlight how a healthcare environment fixated on longevity may deprioritize empathy and frame incommensurable experiences of illness as bearable to convince patients that gruelling self-management at any cost is in their best interest. This is not to say that concern for longevity and positive reinforcement have no place, but they need greater tempering, and there ought to be more allowance for patients to experience a full range of emotional responses to their illness, including futility.

For the participants in our study, moments of futility created an important contrast between *what is* and *what is expected*, and this reveals the degree to which the pretense or veneer of management and control elicits a performance of self-care even when one feels unworthy of care. Emotional labour involves managing a pretense for the comfort of others, and futility, which arises from an emotional “rock-bottom,” creates a space in which one no longer feels compelled to mitigate and manage for the sake of others. The bid to decree those with chronic illnesses normal and their condition bearable is not a kindness, but an added expectation of emotional, physical, and psychological labour. Perhaps, then, it would be more charitable, more compassionate, to acknowledge that there is something unbearable in the demand for constant (unachievable) control, and that the resolve to live with the unbearable makes those that live with chronic illness truly remarkable.

Moving forward, this study should be replicated with a more diverse population and other sample sets. Attention to demographic factors such as race/ethnicity, socio-economic status, education level, and local institutions is paramount, as these factors may inform participant perspectives and offer insight into the unique challenges of different populations. Furthermore, a re-evaluation of current praxis in both educational and healthcare settings is warranted. Specifically, the role of deeply ingrained ableism in how healthcare providers and educators imagine their patients *should* be living ought to be reckoned with, and holistic models that appreciate the entire person for who they are and beyond what they can do, ought to be considered in approaches to patient and provider population health.

#### 4.1. Limitations and positionality statement

The researcher’s positionality as a T1 diabetic with training in critical theory and discourse analysis informed the research. Therefore, the intrinsic connection between the researcher’s experience and the research demanded transparency around bias rather than its total elimination. As such, attention was paid to positionality and reflexive journaling was employed to minimize the researcher’s unconscious ‘insertion’ of personal opinions and judgments.

The COVID19 pandemic may also have had an impact on participants’ lived experiences given the specific challenges the pandemic presented to those required to self-manage their chronic conditions. At the same time, the pandemic provided a fruitful opportunity to study emotional labour in chronically ill populations.

Discussing sensitive topics such as one’s experiences living with T1D could cause participants emotional or psychological distress. To mitigate this, all participants could refrain from discussing anything upsetting, discontinue the interview or withdraw their participation as needed and in relation to the informed consent process.

## 5. Conclusions

While existing literature has established that living with T1D is difficult, this research has demonstrated a need to explore in more detail and with greater nuance why it is difficult. While diabetes distress offers a novel way to think about *what* people with T1D experience in response to their illness, little attention has been given to the mechanisms behind diabetes distress. The concept of emotional labour, which has been used

in other fields to demonstrate why people experience distress in specific contexts, may prove useful in explaining why young adults with T1D experience diabetes distress. Study participants resonated with the concept of emotional labour and consistently identified specific situations/dynamics pertaining to T1D management that demanded their emotional labour. Likewise, health care providers need to apply a nuanced understanding of emotional labour to their clinical care and education of young people transitioning to adult care settings. Critical examination of ableist attitudes in patient/provider interactions with young adults with T1D and other conditions demanding task intensive chronic care management, has the potential to increase provider compassion and empathy; perhaps even expressed admiration for who these young people *are becoming* rather than focusing on their glycemic control and disease-related self-management.

## Ethics statement

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## CRediT authorship contribution statement

**Alexandra Jovic:** Conceptualization, Data curation, Formal analysis, Writing – original draft, Writing – review & editing. **Karen Cook:** Supervision, Validation, Writing – original draft, Writing – review & editing. **Gwen Rempel:** Supervision, Validation, Writing – original draft, Writing – review & editing.

## Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

## Data availability

The data that has been used is confidential.

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## Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at [doi:10.1016/j.hctj.2024.100061](https://doi.org/10.1016/j.hctj.2024.100061).

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