

# Diabetes Distress Sources among Filipinos with Type 2 Diabetes Mellitus in the Outpatient Department of a Tertiary Government Hospital

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## ABSTRACT

**Objective.** The sources of diabetes distress, defined as hidden negative emotions from the demands of daily self-management, are unknown to Filipinos with type 2 diabetes mellitus in the outpatient department. Therefore, we aimed to 1) explore the sources of distress in the perspective of Filipinos with type 2 diabetes mellitus and 2) create a conceptual framework of diabetes distress for Filipinos with T2DM.

**Methods.** Focus group discussions were done and audiotaped among Filipinos with type 2 diabetes (n=17). The transcript underwent content analysis to generate themes and subthemes. Relationships were determined between codes, categories, and themes elicited in the study to create a conceptual framework unique to Filipinos.

**Results.** The content analysis revealed five themes of diabetes distress: caregiver factor, socio-economic factor, psycho-emotional factor, medication-related factor, and health care service delivery factor. The socio-economic factor was a distinct theme missing in the prevailing validated questionnaires. Therefore, an adapted conceptual framework was created, as approved by the expert panel.

**Conclusion.** In conclusion, Filipinos with type 2 diabetes mellitus in the outpatient department have multiple sources of diabetes distress, namely, caregiver factor, socio-economic factor, psycho-emotional factor, medication-related factor, and health care service delivery factor. The socio-economic factor is a unique theme identified among Filipinos. Recognizing the sources of diabetes distress is vital to accurately screen Filipinos with type 2 diabetes mellitus and optimize management outcomes. The study findings will help develop and validate the questionnaire to screen diabetes distress unique to Filipinos.

*Key Words: diabetes distress, outpatient, type 2 diabetes mellitus*

## INTRODUCTION

Type 2 diabetes mellitus (T2DM) is a chronic disorder characterized by elevated blood glucose. Long-term effects of chronic uncontrolled blood sugar may involve small and large vessels that may lead to complications such as blindness, renal failure, neuropathy, amputation, stroke, and myocardial infarction. About 6.7% of Filipinos are affected, and the numbers are growing.<sup>1</sup>

The daily lives of persons with diabetes have been occupied with multiple self-care behaviors such as balancing diet, physical activity, self-monitoring of blood sugar (SMBG), and adhering to medications like oral hypoglycemic agents (OHA) and insulin to target optimum glycemic control. However, hidden negative emotions may burden the everyday demands in self-managing a lifelong disorder like diabetes. This is known as diabetes distress.

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Diabetes distress leads to adverse health outcomes. It has been negatively correlated with poor self-care behaviors, including less medication adherence, physical activity, proper insulin use, and SMBG.<sup>2-4</sup> Diabetes distress was associated with more psychological issues like anxiety, worry, and depression.<sup>3,5</sup> Lastly, it has been linked to worsening glycemic control.<sup>2,3,6,7</sup> Because of the said consequences, the American Diabetes Association advocates routine screening of diabetes distress.<sup>8</sup> Most of these are easily addressed by self-management interventions, even computer-assisted, to improve self-care behavior, thus, improve glycemic control.<sup>9,10</sup>

To screen for diabetes distress in patients with T2DM, two questionnaires are available online and suggested by the American Diabetes Association: The Problem Areas in Diabetes (PAID) questionnaire and the Diabetes Distress Scale (DDS). Dr. William Polonsky led the formulation of both questionnaires in 1995 and 2005, respectively.

The 20-item PAID questionnaire is widely recognized as the first patient-reported outcome measure to investigate diabetes-related emotional responses.<sup>2,11</sup> However, the drawbacks of the PAID questionnaire included unclear items, incomplete items on areas of concern, and only one item on health care providers.

The 17-item DDS builds on the shortcomings of the PAID questionnaire. For example, DDS has four subscales: emotional burden, physician-related, regimen-related, and interpersonal (involves family and friends), in which clinicians can target interventions for diabetes distress.<sup>12</sup> DDS, on the other hand, lacks hypoglycemia-related items.

The prevalence of diabetes distress differs per country. In a meta-analysis of the prevalence of diabetes distress, the all-inclusive prevalence was 36%.<sup>13</sup> In a lone study on the prevalence of diabetes distress in the Philippines using the PAID questionnaire, the prevalence was slightly higher at 42.6%.<sup>14</sup> However, the questionnaires were not validated in the Philippines with a distinct culture and may not screen any culturally specific distress perceived by Filipinos.

Furthermore, cultural factors may influence how people with T2DM react to their illness. Filipinos have known cultural values, including family-centered living, the importance of interpersonal ties, and resiliency. Malabed et al. found that the most common reasons for preventable hospitalization of Filipinos with diabetes included social vulnerabilities, including life instability, financial problems, and health care system problems.<sup>15</sup> These cultural factors are needed to be incorporated to optimize management outcomes in diabetes.<sup>16</sup>

Diabetes distress is a novel concept in diabetes management. It affects more than one-third of type 2 diabetes patients but is not yet commonly screened. Therefore, addressing diabetes distress can be viewed as the missing piece in managing diabetes and avoiding unnecessary drug prescriptions effectively. A screening via a questionnaire would refine diabetes treatment to include the physiological, medical, and behavioral aspects of diabetes care.

Therefore, we aimed 1) to explore the sources of distress in the perspective of Filipinos with T2DM and 2) to create a conceptual framework of diabetes distress unique to Filipinos with T2DM in the outpatient department.

## MATERIALS AND METHODS

The Consolidated criteria for reporting qualitative research (COREQ) 2007 was used as this study's framework.

### Research Team and Reflexivity

The research team consisted of three male endocrinologists (MDF, FMM, and MAS) and one male medical statistician with training in clinical epidemiology (AJM). All were affiliated in the study setting. The two investigators (MDF and FMM) were fellows-in-training in the Division of Endocrinology, Diabetes and Metabolism. They were involved in patient care with diabetes mellitus in the outpatient department.

No relationship between participants and investigators was established before the study. However, the participants were made aware of the investigator's reasons for doing this research. Rapport was established while discussing the content of the informed consent and answering questions with the intended participants. MDF was particularly interested in the behavioral aspect of diabetes management.

### Study design

Content analysis was the methodological guiding principle behind the research.

### Participant Selection

We used purposive sampling to select adult Filipinos with T2DM with uncontrolled glycemia. Participants were approached face-to-face by either of the two investigators (i.e., MDF or FMM) based on predetermined criteria. The criteria used were any of these laboratory results: HbA1c  $\geq 7.0\%$ , FBS  $\geq 130$  mg/dL, or 2h PPBS  $\geq 180$  mg/dL.

We stratified two groups: non-insulin requiring and insulin-requiring. Based on several studies, insulin-requiring is more consistently distressed compared to non-insulin requiring.<sup>17-20</sup>

Those who were acutely ill or needed emergency care, on bereavement, pregnant, with cancer of any stage, and those on medication (e.g., steroid, antipsychotics, growth hormone, oral contraceptive pills, diuretics – thiazide and loop diuretics, anti-infectives – fluoroquinolones, and antiretrovirals) and conditions (e.g., pancreatic disorders, active endocrinopathies – acromegaly, Cushing's syndrome, pheochromocytoma, hyperthyroidism, glucagonoma, and somatostatinoma) who were predisposed to hyperglycemia, were not recruited.

The eligible participants were identified through the consultation list of the individual clinics. Inclusion and exclusion of the patients were assessed through a review of the personal patient chart. Eligible participants were

approached individually. The study was introduced, and informed consent was secured. A minimum of eight participants was targeted for each FGD session, as previously recommended.<sup>21</sup>

We recruited ten participants with an allowable 20% attrition rate while waiting for their consultation time. The reasons for the refusal and dropouts were: participants had to work, family matters to attend to, and time constraints.

**Setting**

Participants were recruited from the three clinics in the outpatient department of the Philippine General Hospital. The clinical units provided services to patients with T2DM: Department of Family Medicine, Department of Medicine (Division of Endocrinology).

The hospital where the study took place is a state-owned tertiary teaching hospital. As a referral center, the hospital caters to more than 200 patients with diabetes per week. Two elderly participants had a non-participant companion during focus group discussions. The majority of the intended participants belonged to the lower socio-economic status.

**Data Collection**

We created guide questions of the possible sources of diabetes distress based on the dimensions of diabetes distress from previous studies.<sup>5,12</sup> (Table 1) We did two single focus group discussions where the moderator was MDF and FMM as note-taker.

Focus group discussions (FGD) were adopted in the study, which was ideal for investigating the experiences of the intended participants.<sup>21</sup> The FGDs were conducted in Filipino. There was no recruitment of patients whose primary physicians were the investigators in this study. Written informed consents were secured.

At the start of the FGDs, we explained the definition of diabetes distress. Since “distress” was confusing to the participants, we opted to ask to elicit distress or hidden negative emotions, *“Ano ang inyong mga kahirapan kung bakit hindi pa kontrolado ang diabetes?”* (What are the challenges that make it hard for you to control diabetes?).

Question #2 of Table 1 served as an additional set of questions if they had not been addressed in the first guide question.

Each participant was given a chance to speak. The moderator engaged the discussion by asking questions, facilitated an orderly flow of dialogue, and acknowledged the persons who wanted to speak. However, the moderator inhibited himself from giving opinions on the questions. Instead, probing questions were asked to further elicit related ideas on the category being discussed.

The FGDs were recorded, which lasted 70-95 minutes, excluding the introduction and rapport building. After the two FGDs, the investigators felt that data saturation had been achieved since no new information on diabetes distress can be elucidated.

**Table 1.** Open-ended Questions used during Focus Group Discussion

<b>Question 1</b>	What are the difficulties in controlling your diabetes?
<b>Question 2</b>	How do the following affect your way of life living with diabetes? a. Physician b. Treatment Regimen c. Food and Lifestyle d. Family and Social Support

**Data Analysis**

FGDs were transcribed verbatim and read at least twice before conducting thematic and content analysis as previously described.<sup>22,23</sup> The participants were anonymized during transcription. The two authors (MDF, FMM) independently searched the transcripts for negative statements related to diabetes distress. The steps included condensing the meaning of units, forming codes, and developing categories and themes with possible subthemes (in consecutive order).<sup>22,23</sup> Themes were derived from the data. The participants were anonymized.

Disagreements were presented to the senior consultant (MAS) and an expert panel for content validation as part of a more extensive study. The expert panel consisted of three endocrinologists, a family medicine physician, an internal medicine physician, a psychiatrist, a nutritionist-dietitian, and a nurse educator.

Microsoft Excel was used to manage data. No participant checking was done.

**Creation of Conceptual Framework**

Relationships were determined between codes, categories, and themes elicited in the study to create a conceptual framework. Finally, the proposed conceptual framework was presented to the expert panel, underwent revisions from received feedback, and approved by a majority of the expert panel.

**Ethical Consideration**

Before starting focus group discussions, written informed consents were secured. The study protocol was approved by the University of the Philippines Manila Research Ethics Board (UPMREB).

**RESULTS**

The two FGDs consisted of 17 participants. The first group consisted of eight T2DM patients who were on OHAs only. The second group consisted of nine T2DM patients who used insulin with or without OHAs. The median age (SD, range) of the participants was 64 years (± 8, 45-73) with a mean diabetes duration (SD, range) of 12.1 years (± 10.2, 0.75 – 34.0). The mean HbA1c (SD, range) was 9.6% (± 2.2, 7.1 – 14.3). Forty-seven percent (47%) have microvascular complications, while 53% have a family

**Table 2.** Clinical Profile of Participants

	FGDs (n = 17)
<b>Age (Median ± SD)</b>	64 ± 8 (45 - 73)
<b>Gender (%)</b>	
Male	6 (35)
Female	11 (64)
<b>Diabetes Profile (Mean)</b>	
Duration (years)	12.1 ± 10.2 (0.8 - 34.0)
<b>Diabetes Medications (%)</b>	
OHA only	8 (47)
Insulin only	2 (12)
OHA+Insulin	7 (41)
<b>Complications</b>	
Microvascular (%)	8 (47)
Neuropathy	3 (24)
Nephropathy	2 (12)
Retinopathy	3 (24)
Macrovascular (%)	3 (18)
<b>BMI (kg/m<sup>2</sup>)</b>	22.0 ± 3.7 (19.53-30.43)
<b>Family History of DM (%)</b>	9 (53)
<b>Laboratories Results (Mean)</b>	
HbA1c (%)	9.6 ± 2.2 (7.1 - 14.3)
FBS (mg/dL) (n=4)	182 ± 33.0 (133.9 - 204.0)
<b>Source (%)</b>	
Endocrinology	7 (41)
Internal Medicine	5 (29)
Family Medicine	5 (29)
<b>With Regular Source of Funds (%)</b>	
Yes (Employment, Pension)	4 (24)
No	13 (76)
<b>Smoker (%)</b>	
No	16 (94)
Yes	1 (5.8)

history of DM. The majority were female (64%), overweight (40%), and unemployed (76%). Most participants came from the endocrinology clinic (41%). (Table 2)

Both FGDs were interactive and free-flowing. The FGDs lasted for 70-95 minutes, excluding the introduction and rapport building. Male participants volunteered more responses. Generally, the participants expressed sadness. Sometimes, their comments were laced with humor.

Five themes (factors) emerged from the data and were labeled: psycho-emotional, caregiver, socio-economic, health care, and medication-related.

### Psycho-emotional Factor

**Living with T2DM.** Most participants felt T2DM diagnosis meant restrictions to one's personality and activities like restrictions to food, suggestive of the stigma of the illness.

#### Male #1, Non-insulin requiring:

*"Nakakalungkot nga na may diabetes kapag sinabi na may diabetes (kasama) na agad sa personality (at) pagkatao mo... May gusto kang kainin (pero) hindi mo makain kasi iniisip mo na barwal.*

(It's really sad to have diabetes because it's as if it's an affront to your personality. If there's something you want to eat, you can't because, in your mind, it's not allowed.)

T2DM, a lifelong disease, provided sentiments of hopelessness and helplessness to the participants. Some participants stated how they wanted their life to revert to when diabetes was absent.

#### Female #5, Non-insulin Requiring:

*"Nadisourage ako kasi parang wala ng pag-asa. For life na iyong sakit na iyan."*

(I felt discouraged because there seems to be no more hope. It is a lifelong disease.)

#### Male #2, Insulin-Requiring:

*"Kasama na rin siguro sa nararamdaman ko na problema kapag may kinasasaktan ako na wala naman akong magarwa"*

(What adds up to the problem I bear is the pain I am feeling that I cannot do anything about.)

Most of the participants expressed fear of T2DM complications, notably liver and kidney problems.

#### Female #1, Non-insulin requiring:

*"Nakakatakot talaga kasi kapag sinabi mong may diabetes ka... iyong kidney (at) liver mo (ay) maapektuhan."*

(It's frightening because if you have diabetes, your kidney and liver (may be affected).)

Moreover, some participants were bothered that they were unaware of their glycemic control due to infrequent blood sugar monitoring.

#### Male #3, Insulin Requiring:

*"(Ang) monitoring ng blood sugar ko (ay) hindi naman araw araw... So, hindi ko alam kung araw araw nga (ay) nakontrol ko iyong blood sugar ko. Malalaman ko lang kapag nagmonitor ako ng blood sugar ko."*

(My blood sugar is not monitored daily. So, I don't know if I have controlled blood sugar. I will just know if I will monitor my blood sugar.)

**Perception of Burden.** Most participants expressed perceptions of burden to self and family. Due to perceived burden to self, they overthink their sources of difficulty; overthinking was linked to further elevation of blood sugar, a common notion for participants. In addition, they wanted their family members to be exempted from the additional burden of caring for them in the household.



**Female #1, Non-insulin requiring:**

*"Minsan hindi maiwasan na tumaas yung asukal ko (dabil) sa sobrang pagiisip sa kabuhayan at sa karamdaman."*

(Sometimes, the reason my blood sugar can't be controlled is because of worrying too much about my livelihood and my sickness.)

When asked about the feeling of having diabetes. *"Pasakit."* (Torture.)

**Female #2, Non-insulin requiring:**

*"Ayokong maging feeling nila na pabigat ako sa kanila or maramdaman ko na nakakaawa ako dahil meron akong (sakit)."*

(I don't want them to feel that I am a burden to them or for me to feel that I am pitiful because I have an illness.)

**Diet-related.** Food-related problems dominated the FGD discussion as the source of distress. Of the seventeen participants, nine of them gave food-related issues as the initial response. Of the nine participants in the insulin-requiring group, seven of them gave the same answer. All participants shared varied stories of the challenges of internal food craving against externally imposed restrictions. Limitation of food choices was evident when living with family members and attending friends' gatherings. However, the majority ate what was served during mealtimes, even if prohibited.

**Male #1, Non-insulin requiring**

*"Mahirap talaga (dabil) marami kami sa bahay ng mga anak ko. Syempre iyong pagkain nila (ay) hindi pwede sa akin. Kaya nahihirapan ako (kaysa) hindi na ako kumain (kaya) nakakain ko na rin yung barwal sa akin. Ito yung nakahanda eh (dabil) hindi naman pwede tatlo o apat na pagkain pa."*

(It is really hard because I live with my kids and there are many people at home. Of course, I am not allowed to eat the food that they are eating. That is why it is hard for me. Instead of not eating at all, I just resort to eating those that I am not allowed to. Because that is what's being served. We can't afford to have three or four kinds of meal.)

Adding to the distress, they perceived guilt and blamed themselves whenever they consumed prohibited food.

**Female #4, Insulin requiring**

*"(Kapag) natikman mo, kakainin mo na lahat hanggang sa maubos... Walang self-control, walang disiplina at katakarwan (dabil) nadadala ng stress."*

Once you've tasted it (prohibited food), you're going to continue eating until you've finished all

of it... No self-control, no discipline and overeating due to stress.)

**Literacy.** Literacy is the ability of an individual with T2DM to gain and interpret health information and make their own health decisions. For example, some participants wanted to know more about improving blood sugar control, despite their exhaustive efforts. In addition, perceptions heard from their acquaintances added distress to them. For example, the non-insulin requiring group expressed objection to insulin initiation, as "insulin" meant terrible prognosis.

**Female #3, Non-insulin requiring:**

*"Iniisip ko kung ano ba ang dapat kong garwin para makontrol."*

(I keep thinking about what I need to do to control it (diabetes).)

**Male #1, Non-insulin Requiring**

*"Iba na kasi yung dating pag nag-insulin. Mamamatay ka na... Parang malapit ka na."*

(It's different when you're on insulin. It's like you are near (death).)

**Socio-Economic Factor**

**Availability of Financial Resources.** When the FGD participants were asked initially about the source of distress, the second most common reason revealed was financial challenges (4/17). Employment and pension, for non-elderly and elderly, respectively, are the sources of funds to sustain medication and T2DM needs. From where and from whom they will seek funds cause them distress. They are reluctant to ask for financial help from their family, either because of the perceived embarrassment of begging and because family members have their own respective families.

**Male #2, Non-insulin requiring**

*"Yung mga anak ko (ang) inaasahan ko. Nahibiya ako sa mga anak ko. Ayaw ko talaga umasa sa mga anak ko. Nagkaroon ako ng distress na hindi na ako nakakatulog."*

(I only depend on my children. I already feel sorry for them. I really don't want to depend on them. I feel distressed that I can no longer sleep.)

**Female, Non-insulin Requiring**

*"Pinoproblema (ko ang pambili) dahil wala akong trabaho. Ayaw ko naman na hingi nang hingi lalo kung may bagong gamot. Marami na rin akong nararamdaman."*

(It is a problem because I don't have a job. I don't want to keep asking them for help whenever a new medicine is needed. I also have a lot of symptoms.)

**Cost of Medications and Monitoring needs.** The expense of medications and monitoring needs for capillary blood sugar (CBG) added to the weight of financial trouble. As a result, some participants cannot comply with the treatment regimen and resort to search for cheaper alternatives like herbal supplements, a common topic asked for both groups. For others, more expense for T2DM treatment meant lesser fund allocation for food and further overthinking of problems, adding to the distress.

### Female # 3, Non-Insulin Requiring

*"Hindi tuloy-tuloy ang inom (ng gamot). Wala nang pambili."*

(I cannot maintain taking medication. I am out of funds.)

### Male #1, Insulin requiring

*"Mahal talaga kasi yung (blood sugar)strip kung bibili ka sa sarili mo.. Napupunta ako sa generic (pharmacy at) magbabayad ka ng 30 (pesos) para malaman ko kung tumaas o bumaba (ang blood sugar)"*

(The blood sugar strips are quite expensive if you will buy them yourself. I have to go to generic (pharmacy) and pay ₱30 to find out if it (blood sugar) went up or down.)

### Male #2, Non-insulin requiring

*"Baka naman po sa herbal (ay) mag normal (ang blood sugar) so hindi na ako iinom ng gamot."*

(Maybe my blood sugar will normalize if I take herbal medications so that I won't take my (prescribed) medicine anymore.)

### Caregiver Factor

**Caregiver Burden.** Family members attending to the participants' T2DM care, or caregivers, had produced distress directly by blaming the added expense and acquiring diabetes. For some, that situation created relationship strain and feelings of not being understood. Participants felt compelled to follow what the caregivers advised for those who are financially reliant on their families. Caregivers' constant monitoring of their loved ones reflects a fear of possible complications of blood sugar elevation if left unchecked.

### Female #2, Insulin requiring

*"Kapag asawa ko (ay) puro sumbat aabutin ko. Sasabihin sa akin puro raw ako gastos."*

(If it's my husband, I'll be sure to get a mouthful. He'd tell me that I have too many expenses.)

### Female #1, Insulin-requiring

*"Ginusto mo yan kaya ka nagkasakit."*

(It's your choice; that's why you have the illness.)

### Female #2, Insulin requiring

*"Ang feeling kasi naming komo kayo ang bumibili ng gamot para kaming "robot" (na kailangan sumunod) Kapag sinabing huwag kumain (pero) kapag kumain, ang sakit sa amin."*

(Sometimes we feel that because you are buying our medicines, we are treated like robots that are required to follow. When you direct us what not to eat, it is painful for us.)

**Diet-Related.** Most considered being guarded regularly by caregivers primarily on their food choices prompting them to restrict intake. Most participants felt that caregivers identified them as hard-headed for opposing the doctor's guidance on food but were still serving meals prohibited in diabetes.

### Female #1, Non-insulin Requiring

*"Binabantayan ako ng mga anak ko. Sometimes if may pagkain na bawal sa akin, sasabihin sa akin, "Oh, si lola titikim"... Hindi na ako kikibo."*

(My children are always watching over me. Sometimes if there's food that I'm not allowed to eat, they will tell me, "Oh, grandma is going to taste it"... Then, I won't speak anymore.)

### Medication-Related Factor

**Perceptions on Side Effects.** All participants had various concerns about their medications: efficacy, side-effects, regimen complexity, and perceptions. Of the medication classes, metformin use provided them worries, and even fear, as revealed by both groups. Metformin was the most commonly used oral T2DM medication for both groups. Most of the participants linked metformin to kidney problems and symptoms like chest pain and edema. Thus, some reduced their medication dosage and frequency and sought safe and "natural" alternative preparation like herbal plants. During the discussions, some participants were puzzled why doctors were not recommending herbal preparations, which they also believed to be cheaper.

### Male #1, Non-insulin requiring

*"Kabit na alam na iyong metformin (ay nakakasira) sa kidney, iyun pa rin ang binibigay na gamot."*

(Even though metformin is known to cause kidney problems, it is still the medicine that's being prescribed.)

Being "overdosed" or taking multiple medications worries participants. A participant even linked multiple medication adherence with the premature death of an acquaintance who also had T2DM.

### Female #3, Insulin requiring)

*“Baka maoverdose ako sa dami. (May) Fluimucil (at) injection pa ko, sitagliptin at losartan pa”*

(I could get overdosed with the large amount (of medicine) I am taking – Fluimucil, then I still have injections, sitagliptin, and losartan too.)

After the experience of its manifestations, hypoglycemia occurrence worries all insulin-requiring and some non-insulin-requiring participants. The manifestations ranged from feeling weak to losing consciousness needing hospital admission. In addition, the unpleasant experiences forced them to self-adjust insulin and oral hypoglycemia agent doses and increased the intake of sugar-rich food to avoid recurrence.

### Female #3, Non-insulin requiring

*“Kung paano malaman na mababa iyong sugar? Parang nanghibina ka tapos parwis na parwis.”*

(How to tell when sugar is low? It's like you feel weak and you sweat a lot.)

### Female #2, Non-insulin requiring

*“Ang bigay sa akin na Lantus 26 units (ay) binabaan ko. Kasi lagi ako nagba-“hypo” pagdating ng alas-dos ng madaling araw”*

(I've reduced the 26 units of Lantus prescribed to me. Because I always get hypo (hypoglycemia) at 2:00 AM.)

### Complex Drug Regimen Factor

Most of the participants were taking medications like antihypertensives and lipid-lowering medications, in addition to T2DM medications. As a result, some have trouble following each medication schedule. This led to errors in the intake and caused hypoglycemia and non-adherence.

### Male #1, Non-insulin Requiring

*“Medyo mahirap nga iyon lalo na sa edad gamut. Hindi gamut matandaan kung nakainom na kami. One time, nakainom ako nadoble. Nagkahypoglycemia pala ako. Sumama pakiramdam ko. Iyon pala nadoble pala inom ng gamut.”*

(It is kind of difficult, especially at our age. We tend to forget that we have already taken our medicine. One time I took the medicine twice. I got hypoglycemia. I felt ill. And the reason is because I took the medicine twice.)

For participants on insulin therapy sometimes cannot inject their insulin outside their home.

### Male #3, Insulin requiring

*“Hindi nakaka-inject ng insulin lalo kapag nasa labas ka.”*

(I could not inject insulin, especially when I am outside (home).)

### Health Care Delivery Service Factor

**Physician Factor.** Most of the participants declared satisfaction with their relationship with their physicians. But, few expressed wariness over new attending physicians' change of treatment regimen.

### Male #2, Insulin requiring)

*“Baka nga mali ang distribution ng (insulin). Hindi katulad noong ginagawa sa akin sa Medical City na nagpapa-endo rin ako.”*

(What I worry about is there might be a mistake in the distribution (of insulin). What was done to me is different in the Medical City by an Endo (Endocrinologist).

During the consultations, other participants observed their doctors as disinterested – focusing more on the chart; arrogant – wanted only their treatment decision; and inability to explain their proposed treatment regimen thoroughly. These perceived attitudes caused strained relationships with their respective doctors.

### Female #5, Non-insulin requiring

*“Ang ibang doctor (ay) sulat na lang ng sulat. (Ang) concern niya parang kulang. Hindi ako na-satisfied.”*

(Some doctors were always writing (during consultation). I felt little concern. I am not satisfied.)

### Female #2, Non-insulin requiring)

*“Mayroon lang ibang doktor na hindi maayos magpaliwanag o arogante. Antipatiko.”*

(There are just some doctors who do not explain things well or are arrogant. Displeasing.)

### Male #2, Non-insulin requiring

*“Sinabi (ng doctor) tigilan mo na iyan kung gusto mo pang mabuhay... Pwede namang sabihin na kung maari barwasan o alisin mo na iyan”*

(The doctor said: “stop that if you still want to live.” Those kinds of words. He could have just said: perhaps you can reduce or get rid of that.)

**Clinic Factor.** Another source of distress during the consultation was the long waiting time and not having primary doctors in the outpatient department.

### Male #1, Non-insulin requiring

*“Pumunta kami nang before seven (AM) pagkatapos matatarawag kami (nang) ala-una.”*

(We get here before 7:00 AM then we get called at 1:00 PM.)

**Male #2, Non-insulin requiring**

*“Ako (ay) walang personal doktor na naka-assign. Paiba-iba iyong tumitingin.”*

(In my case, no personal doctor was assigned to me. It changes every time.)

**Conceptual Framework**

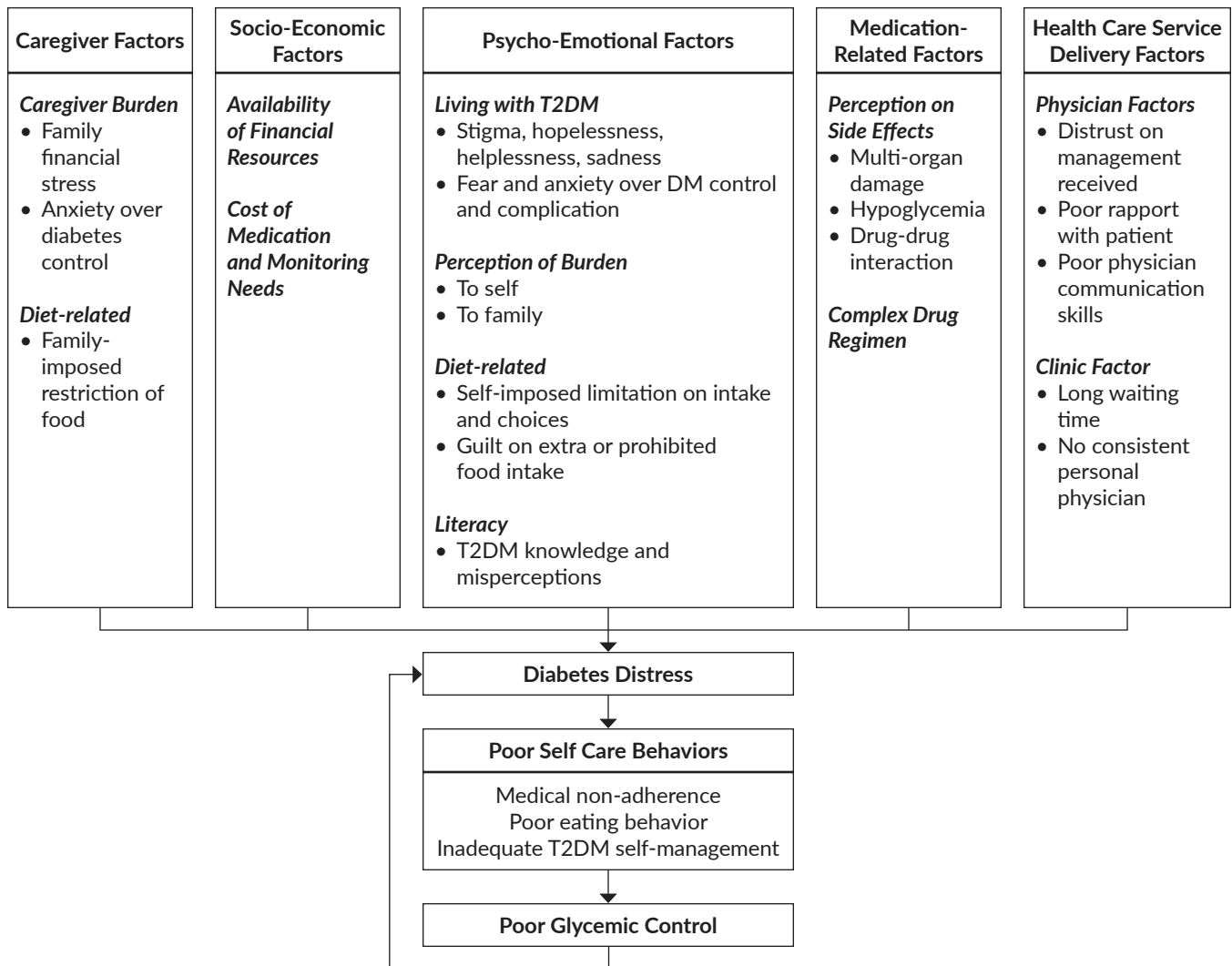
The result of the FGDs is a conceptual framework on the sources of diabetes distress, how it affects self-care behavior and the consequent decrease in glycemic control. The sources of diabetes distress were caregiver factors, socio-economic factors, psycho-emotional factors, medication-related factors, and health care service delivery factors (Figure 1). All of these were the sources of diabetes distress that may negatively influence self-care behavior. Poor self-care behavior may eventually lead to decreased glycemic control. Reduced glycemic control may lead to worries and fear, leading to diabetes distress, hence the feedback loop.

**DISCUSSION**

In this study, we explored the sources of diabetes distress among Filipinos with T2DM in the outpatient department. Five factors were elicited from the discussions: psycho-emotional, socio-economic, caregiver, medication, and health care service delivery factors. To our knowledge, this is the first study that explored diabetes distress among Filipinos with T2DM in the outpatient setting.

We utilized focus group discussions, the ideal method<sup>21</sup>, to capture valuable experiences from the participants and to obtain data not elicited with direct questioning of participants. With the guidance of an expert panel, we devised the adapted diabetes distress conceptual framework (Figure 1) among Filipinos with T2DM in an outpatient department setting in a government tertiary hospital.

The first source of distress was the psycho-emotional factor or those identified within an individual with T2DM.



**Figure 1.** Adapted Conceptual Framework of Diabetes Distress as Perceived by Filipinos with Type 2 Diabetes Mellitus in the Outpatient Department.



This reflected how participants responded to the daily care of diabetes. The subthemes under this theme were feelings and worries of living with T2DM, a perception of burden, diet-related concerns, and T2DM literacy. As expected, the anxieties, fears, and other negative feelings were evident as they endured the demands of living with T2DM. Interestingly, most participants linked elevated blood sugar to unrestricted eating. Aguilar et al. described this typical Filipino eating behavior as "uncontrolled," defined as the propensity to eat more than usual due to lack of control and subjective hunger thoughts.<sup>24</sup> This eating pattern may be due to an undiagnosed binge eating disorder, which is prevalent in up to 25% of patients with T2DM.<sup>25</sup> Furthermore, the association of uncontrolled eating to having diabetes may indirectly cause participants to feel the stigma of diagnosis and perhaps diabetes distress.<sup>26</sup>

Culture plays an essential role in Filipino dietary practices because "fiesta," or any festival linked to a religious celebration, is commonly practiced by families in the community.<sup>27</sup> Filipinos may binge eat for celebration or ridicule by the host family for less than average quantity of food, which can be a concern for those with diabetes who limit their diet. On the other hand, Wardian et al. found that adherence to a healthy diet for greater days in a week confer decreased distress scores.<sup>28</sup>

Furthermore, the stigma attached to diabetes diagnosis can make patients experience shame and guilt of letting their family down, eat more, and feel they were being punished for doing something bad in the past. Externally evident complications of diabetes (e.g., limb amputation and possibly non-healing wound) were regarded as "ugly and painful."<sup>29</sup> The result is the patients' unwillingness to disclose the diagnosis, hence their lack of social and economic support and low self-esteem, and reluctance to change their diet in public that can expose their illness to others.

The last subtheme in the psycho-emotional factor is health literacy. This is defined as the extent to which a patient can acquire and learn essential information to make effective decisions about health. The extent to which patients can receive, process, and understand basic health information and resources necessary to make effective health decisions is known as health literacy. As of the time of writing, no study directly correlates health literacy and diabetes distress. No research specifically interrelated health education and diabetes distress when it is published. Increased health literacy rates were, however, significantly related to decreased blood sugar in a meta-analysis, using glycosylated hemoglobin (HbA1c) ( $r = -0.048$ ,  $p = 0.027$ ), but with high heterogeneity ( $i^2 = 71\%$ ).<sup>30</sup>

The second theme described the social standing of the participants or socio-economic factors. Socio-economic factors involved the availability of financial resources and increased cost of medication and monitoring needs. The socio-economic factor is a distinct theme missing in prevailing validated questionnaires.<sup>2,12</sup> From the data, it was

clear that financial struggle was a source of distress as it was the second most common response upon initial inquiry in the focus group discussions. This distinct factor may be explained by the difference in the economic status of our country, a lower-middle-income country, and the United States of America where the questionnaires were developed.<sup>31</sup>

Health care has been primarily an out-of-pocket expense. Most of the participants were jobless or, due to complications of diabetes, have limited earning capacity, a typical patient profile in the study setting.<sup>32-34</sup> In addition, the Philippine Health Insurance Corporation (PhilHealth), the Philippine public health insurance, does not cover consultations in the outpatient department.<sup>34</sup>

The third theme involved those who directly provide care for persons with diabetes or caregiver factor. The caregivers usually are family members, including parents, offsprings, and spouses. It is well known that Filipino families are extended. Domingo and Asis's (1995) study on the Filipino elderly's living arrangements revealed that most of them live with family members (including married children) who continue to extend support. Additionally, 83% of the elderly live with someone aged 15-59.

In comparison, after having launched their children, Western families move from their focus from children to couple-centered.<sup>35</sup>

The participants in our study perceived their caregivers as a source of distress when family members continuously monitor their self-care, particularly their diet regimen. Thus, caregivers may act as the "diabetes police," as described in the excluded item of the diabetes distress scale.<sup>12</sup> This may suggest the demonstrated concern and family-centeredness shared by caregivers to the participants, a typical Filipino family.<sup>36</sup> Participants showed distress when they expect something in return emotionally and financially. Likewise, caregivers expect family members to follow them and blame family members if their concerns are ignored. This reflects the close-knit relationships of Filipino family members characterized by a mutual dependence on each other.<sup>36</sup> This also suggests the significant part of caregiver support to either increase or decrease diabetes distress depending on family dynamics.

The fourth theme involved is medication-related issues. Of the T2DM medication, metformin was the medication the participants were most concerned about. The medication instilled fear of kidney and liver damage, which was counterproductive as metformin was the initial medication recommended for T2DM, if not contraindicated.<sup>37</sup> In addition, there were worries of being "overdosed," coined by participants on multiple medications, which may be required when monotherapy failed, and glycemic control worsened.<sup>38</sup> One observation was that participants mostly heard the perception from relatives and neighbors and not from physicians. This may also reflect the need to improve health literacy for Filipinos with T2DM and those around them as they may contribute to the distress.

Another subtheme was the fear of hypoglycemia. Fear of hypoglycemia may happen for both insulin and non-insulin requiring group. However, hypoglycemia items were absent in the diabetes distress scale. The implication was that hypoglycemia avoidance contributed to unrestricted eating to eliminate hypoglycemia symptoms and the self-adjustment of medication made by the participants and, therefore, the uncontrolled blood sugar. Multiple studies showed that increased frequency of hypoglycemia episodes was associated with higher diabetes distress scores.<sup>39-41</sup>

The fifth theme involved was health care service delivery that consisted of the physician and the consultation setting. Although most participants were satisfied with their attending physicians, some view them as arrogant and thus developed a weak rapport with their physician. This may reflect the participants' susceptibility to being criticized by health care providers, which may lead to diabetes distress.<sup>42</sup> A poor patient-physician relationship may lead to less confidence in the treatment regimen and result in non-adherence. In addition, less trust among physicians meant higher diabetes distress.<sup>43</sup> Another subtheme that also came into view was the extended waiting time for outpatient consults. An interesting finding, which may also cause distress, is not having a primary physician during the consult. This may be distinct in a government hospital where doctors may have different responsibilities. As a result, another doctor may have to see the patient, even if they are not their regular doctor.

The results of the study contribute to the knowledge by offering a different viewpoint on diabetes distress. New and uncaptured by the available scales are the socio-economic factor and the inclusion of hypoglycemia questions to non-insulin requiring patients. The clinical framework also provided the clinicians involved in diabetes care an overview of how diabetes distress can lead to decreased glycemic control. The framework may also serve as a guide in developing a culturally specific questionnaire to assess diabetes distress.

### Limitations

The findings of the study have to be seen in the light of some limitations. First, the research was done in a single-center setting. Second, most participants are of low socio-economic status, which can affect the generalization of the findings to patients in the private hospitals, who have the means to procure medications and have more available financial resources. Third, transcripts were not returned to the participants for comment and corrections. Fourth, the presence of the investigators may have affected others from opening up about physician-related concerns. The investigators made sure that their patients were not recruited from the start. Finally, we could not include younger participants (<40 years old) due to unavailability during recruitment in the outpatient setting.

Further studies can explore different Filipino eating behavior and health literacy improvement on diabetes distress scores. It would also be interesting to explore the distress levels experienced by spouses or family members taking care

of patients with type 2 diabetes mellitus, considering how tight-knit the relationship of most Filipino families.

### CONCLUSION

Filipinos with type 2 diabetes mellitus in the outpatient department have multiple sources of diabetes distress, namely: caregiver factor, socio-economic factor, psycho-emotional factor, medication-related factors, and health care service delivery factor. The socio-economic factor is a unique theme.

Recognizing the distinct sources of diabetes distress was needed to accurately screen Filipinos with Type 2 diabetes mellitus and optimize management outcomes. The study findings may help in developing and validating questionnaires to screen diabetes distress unique to Filipinos.

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All authors participated in the data collection and analysis and approved the final version submitted.

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