Original Research

# The Multigenerational Legacy of Diabetes and Illness Perception: Influence on Older Adult's Stigma

Melissa Scollan-Koliopoulos [1, *], Donna Naturale [2], Brynn Mahurter [3], Sara Curran [4], Ryan J. Koliopoulos [5]

1. Sacred Heart University, Fairfield, CT, US; E-Mail: scollan-koliopoulosm@sacredheart.edu
2. Caldwell University, Caldwell, NJ, US; E-Mail: dnaturale@caldwell.edu
3. Gettysburg University, Gettysburg, PA, US; E-Mail: mahubr01@gettysburg.edu
4. Montclair State University, Montclair, NJ, US; E-Mail: currans2@montclair.edu
5. Ramapo college of New Jersey, Mahwah, NJ, US; E-Mail: rkoliopo@ramapo.edu

* **Correspondence:** Melissa Scollan-Koliopoulos; E-Mail: scollan-koliopoulosm@sacredheart.edu

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**Abstract**

There is not enough information regarding the impact of stigma associated with a. diagnosis of diabetes in aging older adults. Perceptions of diabetes are passed down generationally and may be influenced by mainstream societal perceptions at the time the perception is shaped. This is known as a multigenerational legacy of diabetes for those with whom the perceptions are shaped within families when a hereditarily predisposed condition occurs. In this study, participants over the age of (n = 88) 60 years old were administered measures of illness perception with social stigma items added to the social consequences domain. Participants were also administered the recollections of diabetes experiences survey developed to measure the multigenerational legacy of diabetes. Hierarchical multiple regression analysis was used to test hypotheses. The results showed that those who anticipate the same complications, especially lower extremity amputations, and who have threatening illness perceptions, are likely to have stigma regarding diabetes ($R^2 = 0.092$, F(2,84), $p = 0.02$). In this

model, a threatening illness perception, (β = -0.20, *p* = 0.05). Findings of this study conclude that if an individual with diabetes has an anticipation of developing similar complications to that of a family member who had diabetes before them, they will be more likely to endorse perceptions of stigma. This is especially true if they have a threatening illness perception of diabetes, and if the complication was lower extremity amputation. Clinical implications include a need to anticipate stigma and provide psychoeducation during healthcare interactions.

**Keywords**

Stigma; older adults; diabetes; illness perception; multigenerational legacy

## 1. Introduction

Diabetes affects approximately 38.4 million people in the United States, 29.2 percent are over the age of 65 [1]. Diabetes is considered a heterogeneous, chronic, and progressive disease that is inherited and expressed because of shared lifestyle factors in many families [2]. For example, lifestyle-associated obesity is an opportunity for phenotype expression into glucose dysregulation for those at risk for type 2 diabetes [2]. Type 2 diabetes has been shown to be a preventable condition in the landmark Diabetes Prevention Program Trial [3]. With the widespread knowledge that diabetes is preventable, comes the inevitable social endorsement that a person with diabetes may be responsible for their own health outcomes. Social endorsements contribute to stigma. Stigma is addressed by the US Center for Disease Control (2022) [4]. According to a consensus statement on diabetes stigma, social endorsements that a person with diabetes contribute to stigma include blame, perceptions of burden or sickness, invisibility, and fear or disgust [5-9]. Healthcare professionals can lead proactive change to end diabetes stigma and discrimination according to international consensus [5-9].

Four out of five individuals with diabetes experience diabetes stigma and one in five report discrimination due to diabetes [5-9]. Yet, there is a dearth of available information regarding perception of diabetes-related stigma in older adults and how it is shaped within families [9]. This is a report on a secondary analysis of the Multigenerational Legacies of Diabetes Study examining illness perceptions, self-care behavior, quality-of-life, and mental health outcomes [10].

The aim of this secondary analysis was to examine the multigenerational legacy of diabetes (MGLDM) [10] on the development of stigma in older adults. Central to the MGLDM Theory is the proposition that individual recollections of a family member's experiences lead to the anticipation that they too may be at risk for similar complications. The MGLDM theoretical propositions include the construct of social consequences of a multigenerational legacy of diabetes. Stigma, a social consequence of diabetes, may be an important predictor of self-care behavior and quality-of-life.

### 1.1 Background

Diabetes-related stigma is defined as negative social judgments, stereotypes, and prejudices [5-9], that lead to feelings such as exclusion, rejection, or blame associated with having diabetes [9]. The most common form of stigma is the perception that the individual is responsible for causing

their own diabetes [9]. Stigma regarding diabetes is a reality and some of it may be reinforced by physicians and healthcare providers [11]. Stigma is affected by upwards of almost 68% of adults with diabetes [12]. Stigma is hypothesized to impact one's self-esteem, resulting in psychological distress, reduced social support due to discrimination and even influence access to healthcare [13]. Stigma has been shown to be associated with self-care behavior [13], glycemic control [14], and quality of life [12]. Individuals who express a higher level of stigma are also more likely to have more physical and mental health complications [14]. Stigma was shown in the Australian MILES-2 study to be a predictor of depression, anxiety, and glycosylated hemoglobin [7].

Stigma researchers have revealed a theme demonstrating that elders are afraid of being helpless and dependent on others, reinforcing a pattern of isolation and helplessness resulting in poor physical health and depression [15]. The older adult may be prone to stigma due to negative attitudes toward age prejudice and stereotypes [15]. Stigma may be more prevalent in those with more visible complications due to diabetes. Some diabetes complications are highly visible. Some examples include, an amputation, limping due to neuropathy, passing out from low blood sugar, blindness, and needing to ask for assistance. Complication-free diabetes may also be an invisible stigma. If an individual recalls a family member with diabetes-related complications and any consequences including dependency on another and/or isolation, expressed blame, shame or guilt, then this may shape their legacy of diabetes. A multigenerational legacy of diabetes includes anticipation of similar physical and social consequences.

Anticipation of complications due to diabetes is a central tenet of the Multigenerational Legacy of Diabetes Practice-based Theory [16, 17]. The Multigenerational Legacy of Diabetes Theory emerged in combination from observed phenomena in clinical practice coupled with Rolland's [18] concept of a Multigenerational Legacy of Illness from the Families, Illness and Disability Model. According to Rolland [18] individuals have a timeline under which they have expectations for a similar trajectory as a family member who experienced the same hereditary illness. Healthcare providers often observe individuals' using their family member's experiences to make sense of their own illness experience. The idea of using a heuristic to make sense of illness narratives is based on Leventhal's [19] Illness Representation and Self-Regulation Model, also known as the *Commonsense Model of Illness.* An Illness Representation includes a schema of illness with the components of causes, timeline, symptoms, controllability, and consequences. According to the Multigenerational Legacy of Illness Theory, which is operationalized using the Illness Representation Theory, stigma would be a social consequence of illness. Stigma results in shame [20] having a negative impact on quality of life [21].

### 1.2 Aim and Objectives

To develop an evidence-base to support the theoretical foundation of the Multigenerational Legacy of Diabetes, hypotheses were tested on a sample of older adults with type 2 diabetes and a family history of diabetes. The specific aim of this secondary analysis was to examine the multigenerational legacy of diabetes (MGLDM) [9] on the development of stigma in older adults with both type 2 diabetes and a family history of diabetes. A multigenerational legacy of diabetes consists of recollections of family member's experiences with diabetes would shape their own illness perceptions of diabetes and stigma of diabetes. The following propositions were tested:

1. If older adults recall visible complications of diabetes in family members, than they will anticipate the development of similar complications.
2. If older adults recall visible complications of diabetes in family members, than their illness perception will be one of threat, such that they will have high scores on the Brief illness Perception Questionnaire, then they will find their own diabetes to be stigmatizing.
3. If one has had self-management education, then they will be likely to alter their diabetes-related self-care practices, resulting in less stigma.
4. If one alters their diabetes-related self-care practices, then they are likely to have a positive quality of life, such that they will be affected by less stigma.

Based on the propositions, the results of the following hypotheses were developed:

**Hypothesis I:** Those with high scores on recollections of diabetes complications in family members will have a high degree of anticipation to develop the same complications as the family member and have a threatening illness perception. Those who anticipate the same complications as a family member and have a threatening illness perception will be more likely to experience stigma than those who do not anticipate the same complications.

**Hypothesis II:** Those who anticipate developing the same complications and perceive diabetes as a threat, will be affected by stigma, controlling for diabetes self-management education received for themselves, such that they will be more likely to care for themselves, with the use of diabetes self-management.

**Hypothesis III:** Those who anticipate developing the same complications and perceive diabetes as a threat, and report sub-optimal diabetes-related quality-of-life, will have low perception of stigma.

## 2. Methods

### 2.1 Theoretical Considerations

To test these hypotheses, the study was implemented using a cross-sectional correlational design using self-reported paper-and-pencil surveys. The Multigenerational Legacy of Diabetes (MGLDM) is a practice-based theory developed by Scollan-Koliopoulos (2004) [10] to specify a disease-specific understanding of Rolland's [18] term Multigenerational Legacy of Illness, posited in his Families, Illness, and Disability Integrative Treatment Model. Scollan-Koliopoulos [10] utilized Leventhal's Illness Representations and Self-Regulation Theory [19] to operationalize the constructs of a Multigenerational Legacy of Diabetes, one of which included the construct of social stigma. The MGLDM theoretical foundation posits that those with recollections of a family member's illness representation, diabetes self-care behavior and complications will have an illness representation themselves that influences their own diabetes self-care behavior [17]. To date, several published studies support that self-care behavior is influenced by recollections of a family member's experiences with diabetes [10, 16, 17].

### 2.2 Participants and Setting

Participants were hospitalized adults with type 2 diabetes and a family history of diabetes recruited from within three Northeast Coast Metropolitan New York/New Jersey Hospitals. All the participants recently transitioned to the use of insulin. As part of a larger study, approximately 250

individuals were recruited from three hospitals, with a yield of 80% participation rate. For this sub-study, 88 adults over the age of 60 years were initially included. Excluded from the study were those affected by critical illness, acute pain, type 1 or gestational diabetes, those who were pregnant, and those unable to provide informed consent. All participants were hospitalized under eight days because the larger study looked at diabetes self-care behavior immediately prior to hospitalization, not reported on in this paper.

### 2.3 Ethical Considerations

The project received approval by the Institutional Review Board (IRB) at Rutgers University (formerly, the University of Medicine and Dentistry of New Jersey) and Hackensack Meridian Health system and Atlantic Health system.

### 2.4 Data Collection and Procedure

Self-reported data was collected using paper and pencil. Participants were provided with a $40.00 gift card to a grocery store as a token of appreciation. Participants were given an hour to complete the surveys and were asked to think about only one family member's experiences with diabetes. Their own experiences were recorded on color-coded paper to make it easier to keep organization when they were answering regarding themselves, or a family member's experiences. The data was de-identified from informed consent forms and no link was maintained. The data was stored and analyzed in the Statistical Software by IBM, SPSS version 29.0. The surveys utilized were valid and reliable measures and used with permission of the original authors unless in the public domain. Participants were administered the following surveys:

1. A Demographic Questionnaire: The demographic items included age, socioeconomic and education, and general recollection items measuring actual recall of complications using dichotomous response.
2. The Summary of Diabetes Activities Self-Care by Toobert et al. (2000) [22] is a valid and reliable survey measuring five constructs of lifestyle factors that influence diabetes control over the past seven days with inter item correlations of 0.20-0.77 depending on the sample consistent with known variability of diabetes self-care behavior [22].
3. Diabetes Quality of Life Brief Clinical Inventory [23] is a 60 item measure that estimates satisfaction with treatment, impact of treatment, worry about diabetes, effects, and worry about social and vocational issues. The measure is a 5-point Likert scale holding excellent internal consistency reliability (r = 0.78-0.92) for type 1 and type 2 diabetes [23].
4. The Brief Illness Perception Questionnaire [24] determines illness threat using a 10-point rating scale ranging from no effect to severe/extreme effects of the construct and can be used as single item to estimate a construct or a full illness perception and are predictive of diabetes self-care behavior and shows construct validity and reliability of each of the eight items of over 0.50 across disease states [24].
5. The Social Consequences of Diabetes Illness Representation Scale [25] is the diabetes version of the Moss-Morris et al., (2002) [26] Revised Illness Perception Questionnaire for which Scollan-Koliopoulos et al. (2007) [22, 25, 27] expanded the survey with eight new items specific to the social consequences of diabetes to tap stigma. Validity and reliability of the subscale held factor loadings over 0.50 and explained 48% variance of illness perception of

diabetes with a Cronbach's alpha of 0.83 [22]. The revised Illness Perception questionnaire is originally 56 items and is valid and reliability and has been utilized in over 57 studies [26].

## *2.5 Data Analysis*

Using GPOWER [28] and a priori sample size was determined to be 100 subjects to provide 80% power to detect a medium difference between responses using regression analysis with three predictors. Bonferroni correction was used to control for a type 1 error rate and list-wise deletion more than two missing items were deleted from the analysis [29]. The data was analyzed using SPSS version 29.0 to calculate Pearson's correlations and linear multiple regression analysis. Descriptive data was estimated using the mean and standard deviation calculations. Multiple hierarchical linear regression analysis was used because it is helpful in explaining the percentage of variance of a predictor variable while controlling for covariation with the dependent variable [29]. Orthogonal factor rotation and internal consistency reliability was estimated with the stigma subscales first reported on in Scollan-Koliopoulos, (2005) [17].

## 3. Results

A total of 88 subjects were included in the final analysis after missing data was accounted for and were aged over 60 in the sample. The survey responses were incomplete for many responses, likely due to hospital interruptions. This limited the sample size to 20 cases because the statistical procedures excluded cases with two or more missing items. The demographic characteristics of the sample included, 73.9% non-Hispanic, 6.8% Hispanic (5.7% did not wish to answer), 19.3% Black race, 68.2% White race, 2.3% Asian race, 1.1% American Indian/Alaska Native, and 3.4% more than one race (1% did not wish to answer).

The average duration of diabetes in the entire sample was 6.6 (Sd 0.75) years. The participants reporting having had diabetes self-management education was 44.7%. Of the entire sample, 38.8% endorsed anticipating the same complications as their family member who had diabetes. The most recalled family members with diabetes were mothers (37.5%) and fathers (37.5%), followed by sisters (18.2%), brothers (22.7), grandmothers (14.8%), grandfathers (5.7%) and aunts, uncles, and cousins each (9.1%). Reporting lived with the family member (56.8%) was approximately 70% of the sample. Type 2 diabetes was recalled by 58%, type 1 diabetes by 20.5%, and 'unknown' type of diabetes by 15.9% of the participants. The most commonly recalled complications were heart disease (44.3%), neuropathy (26.1%) vision loss (18.2%), lower extremity amputations (15.9%), kidney disease (14.8%), stroke (13.6%), gastroparesis (11.4%), erectile dysfunction (3.4%). Insulin use by the family member was recalled by 35.2% and pills by 31.8%. Obesity was reported for the family member by 56.8% of the participants.

Total scores on the social consequences measure included stigma and disclosure items with a range of 9 to 28, (M = 15.89, SD 4.4, N = 67). The Brief Illness Perception Questionnaire had a range of 4.25 to 9.25 (M = 6.96, SD 1.5, N = 20). The Diabetes-Related Quality-of-Life measure had an average of 2.21 to 4.47 (M = 2.94, SD 0.45, N = 21).

First, Pearson's correlations were calculated on the sample to determine if there was any association between the recalled complication and stigma. Inverse non-significant correlations were observed for vision problems (r = -0.17), kidney problems (r = 0.004), heart disease, (r = -0.12) stroke (r = -13), erectile dysfunction (r = -0.05), and gastrointestinal problems (r = -0.07). Not surprisingly

a positive correlation was observed between lower extremity amputations and stigma trending toward significance (r = 0.23, *p* = 0.07). The degree to which one recalled the complication of a lower extremity amputation correlated with the degree of social stigma.

**Hypothesis I:** *Those with high scores on recollections of diabetes complications in family members will have a high degree of anticipation to develop the same complications as the family member and have a threatening illness perception. Those who anticipate the same complications as a family member and have a threatening illness perception will be more likely to experience stigma than those who do not anticipate the same complications*.

To estimate the effects of the degree of anticipation of being affected by the same complications as a family member on one's own development of stigma, a linear multiple regression analysis was conducted. The results showed that those who anticipate the same complications and who have a threatening illness perceptions are likely to have a stigma regarding diabetes ($R^2$ = 0.092, F(2,84), *p* = 0.02). In this model, a threatening illness perception (β = 0.22, *p* = 0.03) contributes unique variance in explaining stigma of diabetes, whereas anticipation of the same complications also contributed to a unique and inverse explanation for stigma (β = -0.20, *p* = 0.05). This indicates that a high degree of anticipation for similar complications results in less stigma when illness perception threat is high. Likewise, a low degree of anticipation of complications results in more stigma when illness perception is high.

**Hypothesis II:** *Those who anticipate developing the same complications and perceive diabetes as a threat will be affected by stigma controlling for diabetes self-management education themselves.*

For this hypothesis, having diabetes self-management education was added into the multiple linear regression model. The results showed that the model continues to significantly explain stigma ($R^2$ = 0.092, F(3,84), *p* = 0.03) with anticipation of the same complications (β = -0.20, *p* = 0.05), illness perception threat (β = 0.22, *p* = 0.04), continuing to contribute a uniquely significant explanation, and having received diabetes self-management education (β = -0.016) not significantly contributing to explaining stigma. The direction of self-management education is interesting in that it is inverse to anticipation and illness perception threat. Those who believed they had self-management education were less likely to be affected by stigma and those who did not have self-management education were more likely to be affected by stigma.

**Hypothesis III:** *Those who anticipate developing the same complications and perceive diabetes as a threat who also report suboptimal diabetes-related quality-of-life will be affected by stigma.*

For this hypothesis, anticipation of the same complications as a family member, a threatening illness, perception of diabetes, and diabetes-specific quality of life were regressed onto stigma. The results revealed that ($R^2$ = 0.097, F(3,84), *p* = 0.04). Diabetes-specific quality of life does not uniquely explain the variance, but the model continues to significantly explain stigma.

## 4. Discussion

The idea that there are visible and invisible stigma within the diabetes condition itself was supported in this study by way of the finding that a lower extremity amputation recall is associated with the degree to which one perceives stigma. The result of Hypothesis I is complicated to explain. Essentially, a patient may be saying, 'If I don't think I will get complications like my family member, my perception of stigma is high'. This could mean that stigma is directed at the family member and not at one's own self and the individual may somehow feel protected against complications (i.e.

perhaps due to diabetes self-care behavior). Similarly, 'if I do think I will get complications my sense of stigma is lowered'. This may be because the individual may feel it's not due to their own behavior but, it's somehow hereditary or out of their control. Complications are something that one can use to identify with the seriousness of a disease. Because diabetes is controllable, people may feel as if they are blamed for falling short on their diabetes self-care endeavors if they develop complications. Although hypothesis two did not yield a finding that would not be due to chance alone, the additional construct may be indicating there is more stigma with less education. Collectively with hypothesis one, the assumption may be that those who are educated may recognize that complications are a reality even when one engages in their best effort to prevent complications.

In understanding hypothesis three, it is unclear if diabetes-specific-quality-of-life interacts or mediates a relationship between anticipation of complications and/or illness threat, is not ascertainable due to the small sample size. If one has a positive quality-of-life specific to their diabetes management and coping, there is a potential protection from stigma. Presumably, those with a positive diabetes-related quality-of-life may be engaging in adequate diabetes self-care shaping the legacy of diabetes in a way that does not include anticipation of similar consequences as a family member.

Observations of how family members are treated potentially contributes to stigma of a hereditary illness because of reinforcing negative social judgements. Avoidant behaviors toward family members, a perception of contamination from a problematic family member, and negative problems from the condition all contribute to family stigma [30]. According, to Schabert, et al.'s (2013) [5], framework for understanding diabetes -related stigma, consequences of stigma may have an actual self-care effect because of psychological stress, resulting in sub-optimal clinical outcomes that require mitigation. Mitigating factors include social support, health promotion, disease self-management and education. This could theoretically explain why those who receive self-management education have a reduction in stigma, whereas diabetes-related quality of life may mitigate the effects of stigma or reduce perceptions of stigma.

When an individual observes a family member being affected by diabetes-related complications, they are aware they may be at risk, and diabetes may be preventable. If diabetes self-care is sub-optimal or ineffective at achieving the end-result of complication prevention, one could see how the multigenerational legacy becomes complicated by stigma. Paradoxically, stigma may result in less diabetes self-care behavior if feelings of embarrassment, failure, and guilt undermine the effort. For example, avoiding insulin injections or not modifying diet in social circumstances. Future studies should look at diabetes self-care practices in response to stigma.

### 4.1 Limitations of the Study

Several limitations warrant caution when interpreting the results of this study. First, the sample size was very small as it was a sub-sample of a larger study. Regression analysis is less stable with small samples than with larger samples. However, the small effect size indicates that a repeated study with a larger sample will be less likely to result in a type 2 research error [29]. All of the subjects in the sample had type 2 diabetes. The findings should not be generalized to those with type 1 diabetes. Since the participants were hospitalized, an awareness of complications due to diabetes could arouse recollections and/or perceptions of stigma. Heightened awareness of

complications and stigma may result in a type 1 research error that may not be replicated in future trials.

### *4.2 Implications for Practice*

This study contributes to a growing body of evidence regarding the stigma of diabetes and chronic disease. Clinicians can use the awareness to address the potential of stigma and potential influence it has on one's diabetes self-care behavior and quality of life in older populations. A threatening illness perception is one that is determined to be inconsistent with what a healthcare provider may view. When one is identified as having a perception of the causes, symptoms, timeline, controllability, and consequences of diabetes that is inconsistent with that of the healthcare provider, or a threat, the clinician has an opportunity to tailor re-education to alter illness perceptions. Altering a patient's illness perception may alter the trajectory by influencing diabetes self-care behavior and/or quality of life. Older adults have recollections from a time-period when there was less diagnostic technology, protocols, and pharmacotherapeutic options to prevent complications, including diabetes-related obesity. Stigma is shaped by multi-faceted perceptions with blame and shame for one's illness at the foundation. Patient's may feel responsible for their complications or feel blamed by others. Stigma will lead to disease burden if the emotional consequences negatively influence quality-of-life. Recommendations include using strength-based and first-person language to reduce stigma [31] and to address image problems [5-9, 32]. Health care providers play an important role in the elimination of stigma [5-9]. Illness perception awareness can provide a point of care intervention to address stigma. Providers can provide reassurance that patients are doing the best they can with the information they have and correct illness perceptions that are threatening or inaccurate during episodic care visits. Threatening illness perceptions that contain content regarding the social consequences of diabetes can be addressed during episodic care sessions by using the few items in the social consequences measure or simply by asking about the consequences of diabetes. Formal diabetes education referrals can help individuals cope with stigma. Consistent with Beverly et al., (2019) [11] reducing perceptions of stigma begins in healthcare provider training programs. Providers can refer patients to the CDC website on how to reduce stigma due to diabetes [4]. In addition, patients should be linked to social support and possibly even psychotherapy since other studies (MILES-2) demonstrated that self-esteem and social support moderated the relationship between stigma and important diabetes outcomes such as depression, anxiety and glycosylated hemoglobin [7].

### 5. Conclusion

There is a dearth of literature on stigma in older adults, with the bulk of stigma information coming from 17 to 70-year-olds. The multigenerational legacy of diabetes theory has been conceptualized as including social consequences and stigma [10]. This study provides some insight into the degree to which adults over the age of 60 perceive diabetes as threatening and the degree to which their perceptions influence a stigma of diabetes. In particular, the findings of this study conclude that if one with diabetes has an anticipation of developing similar complications to that of a family member who had diabetes before them, and if they have a threatening illness perception of diabetes, they will be more likely to endorse perceptions of stigma. Future research should

examine how stigma is formulated within families, especially regarding language use or image problems.

## Author Contributions

Dr. Melissa Scollan-Koliopoulos was the Principal Investigator and study lead, collecting data and survey development, and author designing secondary analysis methods, writing, and statistical analysis and interpretation. Dr. Donna Naturale assisted with methods and was second lead author assisting with writing and interpretation of results. Ms. Sara Curran, Ms. Brynn Mahurter, and Mr. Ryan Koliopoulos contributed with literature review and writing.

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## Competing Interests

The authors have no conflicts of interest to disclose.

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