

ARE YOU AN ADULT WITH TYPE 1 DIABETES?

Help us learn more about the relationship
between type 1 diabetes and mental health.



	<p>Are you eligible for this study?</p> <ul style="list-style-type: none">• 18 years or older• Fluency in English• Diagnosed with type 1 diabetes <p>Participants will be asked to participate in one 20-minute online survey</p>
<p>PARTICIPANTS WILL BE PROVIDED WITH MENTAL HEALTH AND MEDICATION AFFORDABILITY RESOURCES.</p>	

Appendix B

Implied consent form

Saint Elizabeth University Institutional Review Board (IRB) implied consent for anonymous, minimal risk surveys

Dear Prospective Participant,

I am conducting a study of adults with type 1 diabetes to learn more the factors that play a role in increasing and decreasing mental health symptoms. The study is in partial fulfillment of the Doctoral Program in Counseling Psychology at Saint Elizabeth University. The Psychology Program faculty, as well as the Institutional Review Board at the Saint Elizabeth University, have approved this study and results should provide information needed to improve counseling services.

I am asking you to complete an **anonymous** online survey about your various experiences, feelings, and opinions regarding type 1 diabetes. The survey will take you no longer than 20 minutes to complete. Your participation is **voluntary**, and you may skip any question that you do not want to answer. You may stop answering at any point. Since it is impossible to identify respondents, there is no way to penalize or reward anyone for participating or declining to participate.

Please feel free to contact me at **trego@steu.edu** if you have any questions about this survey. For answers to any questions you may have regarding your rights as a research subject, contact the Chair of the Institutional Review Board, Dr. Michele Yurecko, at **irb@steu.edu** or **973-290- 4073**.

Outcomes of the study could better assist the medical community, the mental health community, and families of individuals with type 1 diabetes to receive support. Although we anticipate no risks to taking this survey, it could be possible that you may experience troublesome personal thoughts, feelings, or behaviors associated with some of the questions asked.

If you would wish to speak to someone, please contact your **local psychiatric hotline**. (For example, if you live in Morris County, NJ, you can contact the Morris County Crisis Hotline: 973-540-0100). You may also contact your **state's psychological association** (If you live in New Jersey, you would contact NJPA, 414 Eagle Rock Avenue, Suite 211, West Orange, NJ 07052, 973-243-9800, NJPA@psychologynj.org).

Additionally, you may also contact a **national psychiatric hotline** at Mental Health America: 1-800-273-TALK (8255). ***By continuing with this survey, you are agreeing to participate.***

Thank you,

Triana Rego, MA

Student in the Counseling Psychology (Psy.D.) Doctoral Program Saint Elizabeth University

Appendix C

Sociodemographic and descriptive data

Please respond to the following questions as truthfully as possible.

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- | | | | |
|-----|---|-----------------------|---|
| 1. | Have you been diagnosed with type 1 diabetes? (If you personally have <i>never</i> been diagnosed with type 1 diabetes, please, do not resume this survey.) | <input type="radio"/> | Yes |
| | | <input type="radio"/> | No |
| 2. | Is English your primary language? | <input type="radio"/> | Yes |
| | | <input type="radio"/> | No |
| 3. | How old are you? (If you are 17 years of age or younger, please, do <i>not</i> resume this survey.) | | |
| 4. | What is your gender? | <input type="radio"/> | Male |
| | | <input type="radio"/> | Female |
| | | <input type="radio"/> | Other |
| 5. | If you entered "other" for gender, what do you identify as? If you do not feel comfortable responding, please skip this question. | | |
| 6. | What race do you primarily identify with? | <input type="radio"/> | White |
| | | <input type="radio"/> | Black or African American |
| | | <input type="radio"/> | American Indian or Alaskan Native |
| | | <input type="radio"/> | Asian Native Hawaiian or other Pacific Islander |
| | | <input type="radio"/> | Biracial or Multiracial |
| 7. | Are you Hispanic (descended from Spanish-speaking populations) or Latino (from or descended from people from Latin America)? | <input type="radio"/> | Yes |
| | | <input type="radio"/> | No |
| 8. | What is your sexual orientation? | <input type="radio"/> | Heterosexual |
| | | <input type="radio"/> | Homosexual |
| | | <input type="radio"/> | Bisexual |
| | | <input type="radio"/> | Other |
| 9. | If you entered "other" for sexual orientation, what do you identify as? If you do not feel comfortable responding, please skip this question. | | |
| 10. | What is your relationship status? | <input type="radio"/> | Married |
| | | <input type="radio"/> | Single |
| | | <input type="radio"/> | Divorced |
| | | <input type="radio"/> | In a relationship |
| | | <input type="radio"/> | Living with partner |
| 11. | What state and country do you reside in? (If you live in the USA, you can just name your | | |
-

state. If you live outside of the USA, please name your country of residence as well.)

12. What is your annual household income?
- Less than \$35,000
 - \$35,000 to \$49,999
 - \$50,000 to \$74,999
 - \$75,000 to \$99,999
 - \$100,000 to \$149,999
 - \$150,000 or more
13. What is your highest level of education?
- Some high school
 - High school/GED
 - Some college
 - Associate degree
 - Bachelor's degree
 - Master's degree
 - Doctoral degree
 - Professional degree
14. Please state the age in which you were diagnosed with type 1 diabetes.
15. Does anyone else in your family have type 1 diabetes? If so, who?
16. Have you ever been diagnosed with another autoimmune disease or chronic medical condition?
- Yes
 - No
- a. If so, please, list the medical diagnoses have you been diagnosed with.
17. How long have you been involved in the T1D community (e.g., participating on social media or at in-person events with other individuals with type 1 diabetes)?
- 1 to 3 months
 - 3 to 6 months
 - 6 to 12 months
 - 1 to 2 years
 - 2 to 3 years
 - 4 to 5 years
 - Over 5 years
18. Approximately, how many days a week do you participate in the diabetes online community (e.g., posting photos/stories, reading/watching posts/stories, communicating with other individuals with type 1 diabetes, etc.)
19. Have you ever attended an in-person T1D meet-up or event?
- Yes
 - No
- a. If so, in what year did you first attend an in-person meet-up or event with other individuals with type 1 diabetes?
- b. Please state approximately how many in-person T1D meet-ups or events you have attended.
-

20. Have you ever had to make economic sacrifices in order to purchase your diabetic supplies? ● Yes
● No
- a. What types of economic sacrifices have you had to make in order to afford diabetic supplies?
21. Have you ever had to ration insulin due to unaffordability? ● Yes
● No
22. Approximately how much must you pay for a month's supply of insulin?
23. Approximately how much must you pay for other diabetic supplies per month?
24. Did you experience any trauma (a deeply distressing or disturbing experience) prior to your diagnosis of type 1 diabetes?
-

Appendix D

PTSD Checklist for *DSM-5* (PCL-5)

Below is a list of problems and complaints that individuals sometimes have in response to stressful life experiences. Please read each question carefully and, *thinking specifically about your experiences with type 1 diabetes (e.g., highs, lows, DKA, acquiring insulin or supplies, etc.)*, indicate how much you have been bothered by each problem *in the past month*. Please answer according to the scale below:

- | Not at all
(0) | A little bit
(1) | Moderately
(2) | Quite a bit
(3) | Extremely
(4) |
|-------------------|---------------------|-------------------|--------------------|------------------|
|-------------------|---------------------|-------------------|--------------------|------------------|
1. _____ Repeated, disturbing, and unwanted *memories of the* stressful experience?
 2. _____ Repeated, disturbing dreams of the stressful experience?
 3. _____ Suddenly feeling of acting as if the stressful experience were actually happening again (as if you were actually back there reliving it)?
 4. _____ Feeling very upset when something reminded you of the stressful experience?
 5. _____ Having strong physical reactions when something reminded you of the stressful experience (e.g., heart pounding, trouble breathing, or sweating)?
 6. _____ Avoiding memories, thoughts, or feelings related to the stressful experience?
 7. _____ Avoiding external reminders of the stressful experience (e.g., people, places, conversations, activities, objects, or situations)?
 8. _____ Trouble remembering important parts of the stressful experience?
 9. _____ Having strong negative beliefs about yourself, other people, or the world (e.g., having thoughts such as: I am bad, there is something seriously wrong with me, no one can be trusted, the world is completely dangerous)?
 10. _____ Blaming yourself or someone else for that stressful experience or what happened

after it?

11. _____ Having strong negative feelings such as fear, horror, anger, guilt, or shame?
12. _____ Loss of interest in activities that you used to enjoy?
13. _____ Feeling distant or cut off from other people?
14. _____ Trouble experiencing positive feelings (e.g., being unable to feel happiness or have loving feelings for people close to you)?
15. _____ Irritable behavior, angry outbursts, or acting aggressively?
16. _____ Taking too many risks or doing things that could cause you harm?
17. _____ Being “super alert” or watchful or on guard?
18. _____ Feeling jumpy or easily startled?
19. _____ Having difficulty concentrating?
20. _____ Trouble falling or staying asleep?

Appendix E

Posttraumatic growth inventory (PTGI)

Indicate for each of the statements below the degree to which this change occurred in your life as a result of your experiences with type 1 diabetes, using the following scale:

-
- 0 = I did not experience this change.
1 = I experienced this change to a very small degree.
2 = I experienced this change to a small degree.
3 = I experienced this change to a moderate degree.
4 = I experienced this change to a great degree.
5 = I experienced this change to a very great degree.
-

Possible Areas of Growth and Change:

1. _____ I changed my priorities about what is important in life.
2. _____ I have a greater appreciation for the value of my own life.
3. _____ I developed new interests.
4. _____ I have a greater feeling of self-reliance.
5. _____ I have a better understanding of spiritual matters.
6. _____ I more clearly see that I can count on people in times of trouble.
7. _____ I established a new path for my life.
8. _____ I have a greater sense of closeness with others.
9. _____ I am more than willing to express my emotions.
10. _____ I know better that I can handle difficulties.
11. _____ I am able to do better things with my life.
12. _____ I am better able to accept the way things work out.
13. _____ I can better appreciate each day.
14. _____ New opportunities are available which wouldn't have been otherwise.
15. _____ I have more compassion for others.

16. I put more effort into my relationships.
17. I am more likely to try to change things which need changing.
18. I have a stronger religious faith.
19. I discovered that I'm stronger than I thought I was.
20. I learned a great deal about how wonderful people are.
21. I better accept needing others.

Appendix F

Meaning in life questionnaire (MLQ)

Please take a moment to think about what makes your life and existence feel important and significant to you.

Please answer as honestly as possible according to the scale below:

Absolutely Untrue	Mostly Untrue	Somewhat Untrue	Can't Say True or False	Somewhat True	Mostly True	Absolutely True
1	2	3	4	5	6	7

1. I understand my life's meaning.
2. I am looking for something that makes my life feel meaningful.
3. I am always looking to find my life's purpose.
4. My life has a clear sense of purpose.
5. I have a good sense of what makes my life meaningful.
6. I have discovered a satisfying life purpose.
7. I am always searching for something that makes my life feel significant.
8. I am seeking a purpose or mission for my life.
9. My life has no clear purpose.
10. I am searching for meaning in my life.

Appendix G

Debriefing form

Please print this sheet in case you have any questions about this research project.

Dear Participant,

Thank you for participating in this study! During the course of this study, you were asked demographic information, as well as specific information regarding personal feelings and experiences related to your type 1 diabetes. This study was designed to help assess the impact of type 1 diabetes, connecting with other individuals with type 1 diabetes, and medical equipment affordability on trauma symptoms and positive mental health symptoms (e.g., post-traumatic growth and meaning in life) in adults with type 1 diabetes. On the survey, you answered questions from the PTSD Checklist for *DSM-5* (PCL-5), the Posttraumatic Growth Inventory (PTGI), and the Meaning in Life Questionnaire (MLQ).

This study will allow physicians, psychologists, and other support professionals to more effectively treat adults with type 1 diabetes and provide them with more efficient support. It will create awareness about the mental health impact of type 1 diabetes. Although there is some risk of possible troubling thoughts and emotions by participating in the study, outcomes of the study could benefit the medical community, the psychological community, and families of individuals with type 1 diabetes. Your participation contributes to the research. Therefore, your voice will be heard, and you will provide valuable experiences to guide further intervention strategies.

If you do experience troublesome thoughts or feelings associated with some of the questions asked, please do not hesitate to reach out for professional support. If you experience an emergency or feel that you or someone else may be in danger, please dial **911** right away or go to your local emergency room. If you do not feel you or someone else is in danger, but experience an urgent need to speak with someone right away, please contact your local psychiatric hotline (e.g., Morris County Crisis Hotline: 973-540-0100). If you live outside of New Jersey, you can contact the **National Suicide Prevention Lifeline** at 1-800-273-TALK (8255). For individuals who are deaf or hard of hearing, call 1-800-799-4889.

If you feel that you would like to speak to a mental health professional about these thoughts and feelings, and would not consider it an emergency, you may contact **SAMHSA Treatment Referral Helpline** at 1-877-SAMHSA7 (726-4727), which can provide you with general information on mental health and locate treatment services in your area.

For assistance with prescription affordability, please contact the following:

- I. GoodRx at www.goodrx.com
 - II. Needy Meds Helpline at 1-800-503-6897 or www.needymeds.org
 - III. Rx Outreach (for uninsured patients) at 1-888-796-1234 or www.rxoutreach.org
 - IV. The PAN Foundation (for uninsured patients) at 1-866-316-7263 or www.panfoundation.org
 - V. Diabetes Will's Way (helps U.S. patients obtain grants for medical supplies) at www.diabeteswillsway.com
For Novo Nordisk Users (e.g., Novolog, Fiasp, Tresiba, Levemir):
 - VI. Novocare (for patients who are uninsured or have Medicare Part D) at www.novocare.com
 - VII. Novo Nordisk Savings Cards (for patients with commercial insurance) at www.novonordisk-us.com/products/diabetes.html
- For Eli Lilly Users (e.g., Humalog, Basaglar)
- VIII. Lilly Cares (for patients who are uninsured or have Medicare Part D) at 1-800-545-6962 or www.lillycares.com
 - IX. Lilly Diabetes Solution Center (for patients who recently lost their job or insurance) at 883-808-1234
 - X. Lilly Savings Cards (for patients with commercial insurance) at www.insulinaffordability.com/savings-cards.html
 - XI. Eli Lilly Short-term \$35 Copay Card at 1-833-808-1234
For Sanofi Users (e.g., Lantus, Apidra)
 - XII. Sanofi Patient Assistance Connection (for patients who are uninsured or have Medicare Part D) at 1-888-847-1797 or www.sanofipatientconnection.com
 - XIII. Lantus Copay Card (for patients with commercial insurance) at www.lantus.com/sign-up/savings-and-support
 - XIV. Apidra Copay Card (for patients with commercial insurance) at www.apidra.com/savings
- For Dexcom Users
- XV. www.dexcom.com/assistance

While the above affordability options are not answers to the insulin crisis in the United States, they are options that you should take advantage of, if needed. **For information about type 1 diabetes advocacy and community events, please visit T1 International at www.t1international.com or Beyond Type 1 at www.beyondtype1.org**

For answers to any questions you may have about your rights as a research subject, contact the Chair of the Institutional Review Board, Dr. Michele Yurecko, Ph.D. at irb@steu.edu or 973- 290-4036. Please feel free to contact me at trego@steu.edu if you have questions about this research.

Thank you, Triana Rego, MA

Student in the Counseling Psychology (Psy.D.) Doctoral Program
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