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The Lived Experience of Longevity of Type 1 Diabetes in a Self Care Framework

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**Lived Experience of T1D**

Learning objectives:

- Increase the knowledge of the lived experience of those with Type 1 Diabetes related to long-term self-care practices to assist them in adapting Diabetes Self-Management Education programs to improve the self-care behaviors and health outcomes of those with Type 1 Diabetes.
- Utilize the findings from lived experiences of those with Type 1 Diabetes for 65 years or longer as they apply to self-care practices to provide additional skills to improve the health outcomes of those with Type 1 Diabetes through Diabetes Self-Management Education.

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**Lived Experience of T1D**

Type 1 Diabetes: Impact on

- Longevity
- Health-Seeking Behaviors
- Self Care

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**Lived Experience of T1D**

Statement of Purpose

The purpose of this study was to explore the lived experience of those who have been diagnosed with Type 1 Diabetes for 65 years or longer and their self-care activities utilized in living with this disease

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### Lived Experience of T1D

**Study Design**

A phenomenological method was utilized to conduct a qualitative study to explore the lived experience of those who have lived with Type 1 Diabetes for 65 years or longer. Qualitative methods uncover the meaning of an experience through analyzing individuals' descriptions as they relate to the structure and essence of the experience.

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### Lived Experience of T1D

Dorothea Orem Theory of Self-Care Deficit Theory of Nursing (SCDTN)

Self-Care Requisites:

- Universal
- Developmental
- Health-Deviation

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### Lived Experience of T1D

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### Lived Experience of T1D

**Statistical Methods**

- Self-administered questionnaire
- Audiotaped interviews
- Van Kaam's Psychophenomenological Method

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### Lived Experience of T1D

Van Kaam's Psychophenomenological Method

Study emergence of patterns in phenomenon of living with T1D in order to uncover meaning of these "experiences humanly lived"

13 steps

1. Descriptions	8. Integral structure
2. First impressions	9. Psychophenomenological
3. Differentiation	10. Metalanguage of science
4. Repetitious statements	11. Fidelity
5. Tentative relation	12. Paradigm of experience
6. Statements	13. Statement of limitations
7. Methodological reflection	

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### Lived Experience of T1D

Age	75-83
Race	Caucasian
Marital Status	3 married, 1 separated, 2 widowed
Education	3 high school, 2 college, 1 graduate school
Age of Diagnosis	8-14
Rate Health	2 good, 4 fair
Hospitalized for T1D past year	0
Insulin	2 multiple injections, 4 pumps
SMBG	1 daily, 5 6-8 x day
Complications	
Exercise	
Meals/Snacks per Day	22 meals/3 snacks, 43 meals/0 snacks
Last Hba1c	6-9.4
Smoker/Nonsmoker	0 smokers
Last Dental Exam	6 2017
Last Foot Exam	6 2017
Sleep	6-8 hours per night

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## Lived Experience of T1D

### Interview Guide to Elicit Qualitative Data

1. What has living with Type 1 Diabetes for more than 65 years been like for you?
2. What things do you do and have you done over the past 65 years to help take care of yourself?
3. How has having Type 1 Diabetes for more than 65 years affected your ability to care for yourself?

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## Lived Experience of T1D

### Common Threads

1. Ownership and personal responsibility
2. Perseverance and discipline
3. Camaraderie
4. Sense of mortality
5. Faith
6. Resilience

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## Lived Experience of T1D

### Ownership and personal responsibility

"I understood that this was the way it was going to be"  
 "From the beginning you knew that's what you had to do"  
 "my dad took me aside and said this is your disease and you have to live with it all the time and I want to encourage you to give yourself your shots"  
 "if I wanted to be independent I had to plan my own life. My parents were smart enough to let me do that"  
 "I'm an only child; there is no one else to take care of me"  
 "you have to find your own dance and make it your own"  
 "it was part of my life; I was fortunate enough not to have polio"  
 "when it's your own you accept it, you've gotta want what you've got or what you have. It can destroy your life"

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## Lived Experience of T1D

### Perseverance and discipline

"when you develop diabetes, it's a blessing in disguise for you and your family if you don't go around as a victim. If you confront the fact that you have it and live with it 24/7 and learn about it and take care of it and keep your blood sugar close to normal and not be obsessive about it, all those people that are obsessive I have danced on their grave. Test your blood when you don't know, don't think you know when you don't know. You're a juggler and you juggle exercise, meds, nutrition, and you can better juggle when you're testing and when you get educated and keep yourself up to date"  
 "My mom cared a lot and I think she babied me but she disciplined me too and helped me make the decision to take care of myself"  
 "I did exactly what they told me, I tried. I always tried"  
 "part of being a diabetic is being selfish that you care about keeping yourself healthy and doing the right things if you're forced to do it and I was forced. I couldn't let a doctor be there at my side at the end of the phone"  
 "I guess I decided to do what I needed to do. It was scary at first to take the shot, I didn't care if someone else gave it, but it took me a while to deal with it, but I just made the choice"  
 "I wasn't very good at it and sometimes the first month being a diabetic on my own it would take me an hour sitting in front myself trying to fire a shot into my stomach"

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## Lived Experience of T1D

### Comeraderie

"when I went to grade school the teachers were more aware of my condition and they kept a snack for me"  
 "it's a team effort"  
 "The backup of family is important and makes a difference"  
 "It takes a whole village to help with diabetes"  
 "my dad's wonderful attitude: he went to many classes with me then he let me take care of myself"  
 "I was really getting low...I stopped at a drug store, the pharmacist knew my dad and knew I had diabetes and I walked up there stuttering and he handed me a candy bar that melted easily and I thought that was neat he could do that"  
 "one gal at last place: she took care of me, would bring me candy when I was low"  
 "yes, everyone knew, no secret"  
 "everyone at school knew"

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## Lived Experience of T1D

### Sense of mortality

"Mom had a cousin that lived in southern Ohio and at that time they did not know much about insulin and he could not afford it so he passed away"  
 "most of them thought I wouldn't live past age 21-25 at that time when I first got it and I proved that wrong"  
 "later I found out you were gonna die early and have complications"  
 "in class he said that according to the statistics I would be blind by 30 and dead by 40"  
 "it did impact me; I expected to be dead by the time I was 50"

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### Lived Experience of T1D

**Faith**

"we accepted Christ into our lives and that seems to have helped all this time"  
 "I thought I'm really lucky and it took me till I was 75 that it was by the grace of God and not by luck"  
 "knowing that God is seeing me through everything is enormous in my life. I chat with God all day long out loud. Anyone walking by the house would think I had company. I'm a very strong believer"  
 "My faith has grown strong especially with my relationship with diabetes: God is in control, I've got to do this and look to Him for strength and faith and that's why I'm a very positive individual in attitude"

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### Lived Experience of T1D

**Resilience**

"Well, I think life is full of choices. And every day is a choice. It makes a big difference what you choose. Sometimes you feel like what's the use? And then other times everything goes great you almost forget you have it"  
 "when I made it to 60 I was proud that I had lived that long and now that I'm 75 it's kind of like, shit, I really beat the fucking odds. I did impact me in terms of being somebody who tried to get the most out of each day"  
 "Nothing bad is going to happen to me. Even though we lost our house, and my husband's bankrupt, there's nothing. Look at me, look where I'm living, look at what I've got. New Englanders make do" "everyone has to find their spot at any age"  
 "it's a job you did not apply for, you cannot quit, and you get no vacation, no pay, for all you put into it. Nothing you know unless you live with it a long time. It's not always smooth"  
 "I never thought of it that way or compared myself to anyone else. Never crossed my mind, still doesn't. Everybody has challenges, you face your challenges and take care of yourself"

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### Lived Experience of T1D

**Definition**

Longevity with Type 1 Diabetes involves ownership and taking personal responsibility for your disease which leads to discipline in self-care. Despite a sense of mortality, they persevere with faith and camaraderie to remain resilient as they live with this disease.

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### Lived Experience of T1D

**Implications for education**

The findings from this research study provide diabetes educators with a better understanding of the experience of living many years with Type 1 Diabetes as it related to self-care behaviors. This data provides a basis for developing additional interventions aimed at enhancing self-care behaviors in the daily lives of people with diabetes from which health promotion and wellness strategies can be developed.

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### Lived Experience of T1D

- Responsibility
- Commitment
- Discipline
- Strength
- Prevention of complications

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### Lived Experience of T1D

- **Limitations**  
small study
- **Future Research**  
replicate

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## Lived Experience of T1D

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## Reflections from a Diabetic Soul

Insulin, lancets, syringes, and meters...  
 All new subjects for the diagnosis "Diabetic"  
 Leaving the Dr's office, my thoughts in a fog,  
 A whole new lifestyle to track in a log

There is no cure, no plan the genetic test,  
 While the medical community works on to share  
 Of progress in research to find a cure...  
 25.8 million Americans would benefit for sure.

36.6 million diabetics worldwide, every hour another child,  
 One American dies every 3 minutes from the beguiled.  
 Courage to go on, is the paramount key,  
 Along with the struggle, remains a future "to be".

Partnership with this dreaded disease  
 Is one I must accept, to appease  
 The haunting' fear of complications.  
 Diabetes won't allow for taking vacations.

Doctors, denied insurance, hospitals, and care  
 Are pushing into my life with an urgent stare  
 I'm very angry and sad, yet thankful and glad  
 That I live in America, where care is good, not bad.

Choose life again, I pray, emerge back in a whole different way.  
 Corrie Ker

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## Lived Experience of T1D

Thank you  
 for your  
 attention

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