# IMPACT OF MOBILE HEALTH (MHEALTH) IN DIABETIC RETINOPATHY (DR) AWARENESS AND EYE CARE BEHAVIOR AMONG INDIGENOUS WOMEN

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By

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#### **ABSTRACT**

Diabetes is increasingly prevalent among Indigenous people and diabetic retinopathy (DR) is an eye complication of diabetes, and a common cause of blindness among adults in Canada. Indigenous women have a high risk of diabetes likewise increasing their risk for DR. The study examined factors that motivate and constrain Indigenous women from adopting healthy eye care behaviors and identified the changes in DR awareness and eye care behavior as a result of a mHealth education intervention among adult Indigenous women with diabetes or at-risk of diabetes (n=78). This was a pre-post-study which adopted an embedded concurrent mixed methods approach guided by self-determination theory and the medicine wheel. Pre-intervention DR awareness and eye care behavior information were collected from participants. Thereafter, participants received daily diabetes-eye related text messages for 12 weeks. Post-intervention, the impact of mHealth promotion on DR awareness and eye care behavior was assessed. Data was collected via sharing circles and surveys and underwent thematic and statistical analysis.

Pre-intervention, participants indicated limited understanding of eye care costs/payment, guidelines, and eye complications and resolve to manage diabetes-eye conditions influenced eyecare. Also, fear originating from family history of diabetes, interaction with health care practitioners, and dependence on eye glasses affected their eye care. Participants requested information-resources on complications, prevention, and management of diabetes and DR which were included in the mHealth intervention. Age, diabetes status, and education level were significantly associated with DR knowledge, attitude, and practice scores.

Post-intervention, the DR knowledge, attitude, and practice scores significantly improved. The DR attitude and practice post-score for individuals with diabetes increased compared to those at risk of diabetes. Women with higher education levels had higher pre-post-change in knowledge and practice score compared to women with low education levels. Older women had lower pre-post-change in practice score compared to younger women. Participants noted that voice or text messages via various mobile platforms, the telephone number used to send messages, the tone of messages, group activities, and message content were all important when using mHealth for health information. The mHealth intervention created awareness of DR and encouraged change in diabetes-eye care behavior. mHealth has the potential to be used for health education in different populations, and motivate, provide support, and empower individuals to prevent and manage chronic conditions and reduce the risk of complications.

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# **DEDICATION**

To Osinachi Emmanuel Umaefulam. You always said, "learn something new everyday". My unquenchable thirst for knowledge and research focus is because of you.

#### **PREFACE**

Researchers are influenced by the society in which they exist, and their experiences affect their approach to research. As such, I have described my background and its possible influence on this study.

I grew up in a liberal Nigerian family, in a patriarchal society, where everyone was treated equally and could freely express their opinions irrespective of age or gender. The larger society I lived in often designated women as childcare providers and home builders with little to no participation in healthcare decision making. The seeming discordance of my upbringing within this broader societal context has shaped the principles and values I hold.

Eye care has always been a major part of my life particularly with a history of various eye conditions ranging from glaucoma to age-related macular degeneration and DR, among the women in my family, which has resulted in low vision and vision loss in several family members. This often occurred due to limited awareness of the importance of eye care, limited access to eye care services, and inadequate eye care management. Obtaining an optometry degree enabled me to gain a better understanding of the ocular manifestations of systemic diseases and the need for well-rounded management of health conditions. My formal health education enabled me to look at health care as a systematic process with clearly defined conclusions, where an action or cause results in an effect.

These assumptions have evolved, especially as my career focus moved away from clinical practice to community practice which eventually led me to obtain a master's degree in public health. I was astonished by the numerous traditional health care practices and beliefs in some communities which complimented and, in some cases, were more effective than modern medicine but tended to be disregarded by orthodox health professionals. For instance, while working with an eastern tribe in Nigeria, the Elders introduced me to the use of herbs in the management of dry eyes which was referred to as "gritty/sandy eyes." Thus, I developed an appreciation of how different experiences and perspectives shape ones' health, with one view not necessarily being superior to the other. Working in a diabetic eye clinic equally enlightened me on the diabetes-eye practices of persons living with diabetes. I realized that people mainly seek medical assistance or use health services if they are aware of the need to use the available services and if these services are rendered in a culturally competent manner. To bring about

health behavioral change, people must engage in the processes, bearing in mind that the community in which they live, shapes their lives.

As an optometrist, I worked with a Western perspective in addressing health conditions and issues. In many cases, I leveraged on the "fear factor" in motivating patients to make eye health and behavioral changes which on reflection, I have come to realize often does more harm than good. This is due to individual needs, cultural norms and beliefs, and the need for autonomy in making health decisions without fear of "finger-pointing and blame" from health care professionals. I know that for sustainable change to occur in any individual or group of people, communication in both directions must exist, where all involved listen and reflectively act upon lessons learned. This will evolve into respectful and trusting relationships between health care providers and the diverse communities they serve.

I had the opportunity to volunteer with the Canadian National Institute for the Blind (CNIB) Saskatoon where I was part of the telehealth team that provided services and support to Indigenous communities in the North of Saskatchewan. The CNIB clients I met frequently indicated that they would like to acquire more information about how to take care of their eyes, manage their vision and live independent productive lives despite vision loss, which they could share with their families. As a result of this experience, I became aware of the vision loss and vision health challenges experienced by Indigenous peoples particularly related to diabetes eye diseases. These experiences are the reasons behind my focus on DR among Indigenous women.

I understand the relevance of research in society and its potential impact on the community. However, to carry out research and understand the underlying reasons why people behave in a certain way and what they consider important in respect to their health, it is essential to develop and maintain relationships. For instance, to carry out research with peoples in my home country, I must know the customs and traditions of the people I intend to work with, in many instances learn a bit of the local language (particularly greetings); and design protocols in consultation with the local agencies as well as involve community chiefs/representatives. This process should equally apply when working with peoples of other cultures including Indigenous peoples so as to carry out the research in the appropriate way and for the right reasons.

I know that my culture, values, assumptions, and beliefs influenced my approach to this study. Nevertheless, I recognize that different ways of knowing and practices exist, and I am open to learning and integrating the differences in eye care promotion. The focus of this study

emerged from my background and reflects facets of who I am: a Nigerian female, Optometrist with a community health background, and a migrant in Canada. These personas shape who I am, and influenced the approach and decisions made in the study.

# TABLE OF CONTENTS

Contents	Page
Permission to use	i
Disclaimer	i
Abstract	ii
Acknowledgements	iii
Dedication	iv
Preface	v
Table of Contents	viii
List of Tables	xvi
List of Figures	xvii
List of Abbreviations	xviii
Glossary of Terms	xix
CHAPTER 1	1
1 INTRODUCTION	1
1.1 Defining the Problem	1
1.2 Purpose of the study	4
1.3 Research Questions	4
1.4 Background	4
1.4.1 Diabetes in Canada	4
1.4.2 Diabetes in Saskatchewan	5
1.4.3 Canadian Indigenous Peoples	5
1.4.4 Diabetes in Indigenous Peoples	6
1.4.5 Diabetes in Indigenous women	7
1.4.6 Diabetic Retinopathy (DR)	8
1.4.7 DR in Indigenous communities wo	rldwide9

1.4.8	DR in Canada	10
1.4.9	DR Prevention and Management	10
1.4.10	Mobile Learning; Mobile Health	12
1.4.11	Health in Rural versus Urban Indigenous Communities	13
1.4.12	Research in Indigenous Communities	14
1.4.13	Research Challenges and Approach	14
1.5 De	limitations	15
1.6 Su	mmary of Chapter One	15
CHAPTER	2	16
2 LITERA	ATURE REVIEW	16
2.1 Ge	neral Scope of Literature Review	16
2.2 Va	riables and Factors Influencing DR	16
2.2.1	Age and DR	16
2.2.2	Gender and DR	17
2.2.3	Ethnicity and DR	18
2.3 Soc	cial Determinants of Health and Diabetes	18
2.3.1	Colonization	18
2.3.2	Stress and Diabetes/DR	19
2.3.3	Food Insecurity and Diabetes/DR	20
2.3.4	Work Status, Education, and Diabetes/ DR	21
2.4 Fac	ctors influencing eye care service utilization for DR	22
2.4.1	Knowledge/Awareness	22
2.4.2	Income/ Health Insurance	24
2.4.3	Health care access in Urban Indigenous populations	25
2.4.4	Cultural Competency	25

	2	2.4.4.1 Interaction with health care practitioners	. 26
	2	2.4.4.2 Indigenous women and health education	. 27
	2.5	Mobile Phones and mHealth Platforms	. 27
	2.5	Health Education and Behavior change via mHealth	. 28
	2.5	mHealth for DR management in Indigenous Peoples	. 29
	2.5	Developing/Designing mHealth education for Indigenous Peoples	. 29
	2.5	Challenges in designing and implementing mHealth intervention in Indigenous	
	cor	mmunities	. 30
	2.6	Summary of Chapter Two	. 31
C	НАРТ	TER 3	. 32
3	ME	ETHODS	. 32
	3.1	Overview	. 32
	3.2	Justification of using Mixed Methods	. 32
	3.3	Philosophical underpinnings	. 33
	3.4	Study Design	. 33
	3.5	Theoretical perspective	. 35
	3.6	Framework	. 37
	3.7	Research Location	. 39
	3.8	Research Ethics	. 40
	3.9	Methods and Outcome measures	. 40
	3.9	.1 Methods	. 40
	3	3.9.1.1 Sharing circles	. 40
	3	3.9.1.2 Survey	. 42
	3.9	Data Generated	. 43
	3 10	Research Team and Roles	45

3.11	Par	ticipants & Sample Size	46
3.	11.1	Participants	46
3.	11.2	Sample Size	46
3.12	Inte	ervention	48
3.13	Dat	a Collection Procedure	48
3.	13.1	Preliminary Phase	49
3.	13.2	Pre-Intervention Phase	49
3.	13.3	Content Development Phase	50
	3.13.3	3.1 Content Selection	52
	3.13.3	3.2 User Input	52
	3.13.3	3.3 Review and Refining of Messages	53
	3.13.3	3.4 Pre-Testing of Messages	56
3.	13.4	Intervention Implementation Phase	57
3.	13.5	Post-Intervention Phase	58
	3.13.5	5.1 Follow up and Study retention	58
	3.13.5	5.2 Post-Intervention Data Collection Process	59
3.14	Ana	alysis Overview	60
3.	14.1	Qualitative Analysis Procedure	60
	3.14.1	.1 Phase 1: Data Familiarization	61
	3.14.1	.2 Phase 2: Generating Initial Codes	61
	3.14.1	.3 Phase 3: Searching for Themes	61
	3.14.1	.4 Phase 4: Reviewing Themes	62
	3.14.1	.5 Phase 5: Refining Themes and Producing the Report	62
3.	14.2	Quantitative Analysis Procedure	62
	2 1/1 1	) 1 Variables	62

3.14.2.2 Quantitative Analysis Process	63
3.15 Quality Assurance	64
3.16 Summary of Chapter Three	64
CHAPTER 4	65
4 RESULTS	65
4.1 Overview	65
4.2 Pre- Intervention Results	65
4.2.1 Findings from Research Question One	66
4.2.1.1 Awareness and Understanding	67
4.2.1.2 Resolve/Intention	68
4.2.1.3 Fear	69
4.2.1.4 Summary of Findings from Research Question One	71
4.2.2 Findings from Research Question Two	71
4.2.2.1 Information on Diabetes-Eye Care	72
4.2.2.2 Strategy for Information Dissemination	73
4.2.2.3 Summary of Findings from Research Question Two	73
4.2.3 Findings from Research Question Three	73
4.2.3.1 Population Characteristics	73
4.2.3.2 DR knowledge and eye care behavior of Indigenous women with diabetes	s or at-
risk of diabetes in Saskatoon	75
4.2.3.3 Summary of Findings from Research Question Three	83
4.3 Post- Intervention Results	83
4.3.1 Findings from Research Question Four	83
4.3.1.1 Characteristics of women that completed the study	83
4.3.1.2 Comparison of the baseline evaluation between women that completed ar	nd did
not complete the study	85

4.3.1.3	DR KAP post-test descriptive analysis as a score	87
4.3.1.4	Effect of the mHealth education intervention on DR awareness and	self-reported
eye care	e behavior among Indigenous women	88
4.3.1.5	Qualitative evaluation from survey	92
4.3.1.6	Summary of Findings from Research Question Four	97
4.3.2 I	Findings from Research Question Five	97
4.3.2.1	Nature of Message Delivery	99
4.3.2.2	Impact of messages	100
4.3.2.3	Interaction	102
4.3.2.4	Content	102
4.3.2.5	Delivery Style	103
4.3.2.6	Summary of Findings from Research Question Five	104
4.4 Integr	ration of Qualitative and Quantitative Results	105
CHAPTER 5.		106
5 DISCUSS	ION AND CONCLUSION	106
5.1 Outli	ne	106
5.2 Discu	ssion of Results	106
5.2.1 F	Factors influencing DR eye care	106
5.2.1.1	Awareness and Understanding	106
5.2.1.2	Resolve/Intention	109
5.2.1.3	Fear	112
5.2.2 I	mpact of DR mHealth Intervention	116
5.2.2.1	Physical Health	116
5.2.2.2	Emotional Health	119
5.2.2.3	Mental Health	121

5.	.2.2.4	Spiritual Health	123
5.	.2.2.5	Summary points regarding impact of the mHealth Intervention	123
5.2.	3 P	erception of mHealth as a Tool for Health Information	124
5.	.2.3.1	Delivery Style	124
5.	.2.3.2	Nature of Message Delivery	127
5.	.2.3.3	Message Content and Format	128
5.	.2.3.4	Summary points regarding mHealth use for health information	129
5.3	Sumn	nary of Discussion of Results	130
5.4	Qualit	ty and Rigor	130
5.4.	1 R	tigor and Trustworthiness in Qualitative Study Phase	130
5.	.4.1.1	Credibility	131
5.	.4.1.2	Transferability	132
5.	.4.1.3	Confirmability	132
5.	.4.1.4	Dependability	132
5.4.2	Qua	ality in the Quantitative Phase of the study	133
5.	.4.2.1	Threats to Validity due to Study Design	133
5.	.4.2.2	Threats to Validity due to Mixed Methods Approach	134
5.5	Other	Strengths and Limitations of the study	135
5.5.	1 S	trengths	135
5.5.	2 L	imitations	136
5.6	Implic	cations on Population health, Practice, and Policy	137
5.7	Resea	rch Contributions Summary	138
5.8 study		rcher reflections on the use of SDT and the Medicine Wheel framework in the	
5.9	Resea	rcher reflections on the research journey	139

5.10 Recommendations	141
5.11 Future Research Directions	142
5.12 Summary and Conclusion	143
6 REFERENCES	145
Appendix A: Research Poster	189
Appendix B: Consent Form	190
Appendix C: Sharing Circle 1 Discussion Guide	192
Appendix D: DR Knowledge, Attitude, and Practice Survey (Pre-intervention)	194
Appendix E: Initial Messages before Selection and Refining (n=115)	196
Appendix F: Sample of Messages	201
Appendix G: Bulk Messaging Platform	202
Appendix H: Sharing circle 2 Discussion Guide (Post-intervention)	203
Appendix I: DR Knowledge, Attitude, and Practice Survey (Post-intervention)	205
Appendix J: Diabetes-Eye Key Message Brochure	208
Appendix K: DR Attitude Post-Score adjusted by variables and pre-score (Multivariate GLM regression) in a population of Indigenous Women with or at risk of Diabetes, Saskatoon	210
Appendix L: DR Practice Post-Score adjusted by variables and pre-score (Multivariate GLM regression) in a population of Indigenous Women with or at risk of Diabetes, Saskatoon	211
Appendix M: Word Cloud of Recurrent Words in Post-Intervention Survey	212
Appendix N: Comments on the impact of the text messages on physical, emotional, mental, ar	nd
spiritual health	214
Appendix O: Published Article	219

# LIST OF TABLES

Table 3.1: Summary of Research Questions, Methods, and Data Produced
Table 3.2: Roles of Research Team
Table 3.3: Multidisciplinary Team involved in Content Development
Table 3.4: Changes made to text messages
Table 3.5: Types of Text Messages
Table 4.1: Population Characteristics (pre-intervention)
Table 4.2: Distribution of DR KAP Score at baseline in a population of Indigenous Women with
or at risk of Diabetes, Saskatoon, 2017 (n=78)
Table 4.3: DR KAP score by Age, Indigenous Ancestry, Diabetes Status, Work Status, and
Education Level in a sample of Indigenous Women with or at risk of Diabetes, Saskatoon, 2017
(n=78)
Table 4.4: Variables associated to DR Knowledge baseline score (Simple/multiple regression) in
a sample of Indigenous Women with or at risk of Diabetes, Saskatoon, 2017 80
Table 4.5: Variables associated to DR Attitude baseline score (Simple/multiple regression) in a
sample of Indigenous Women with or at risk of Diabetes, Saskatoon, 2017
Table 4.6: Variables associated to DR Practice baseline score (Simple/multiple regression) in a
sample of Indigenous Women with or at risk of Diabetes, Saskatoon, 2017
Table 4.7: Population Characteristics (Post-Intervention)
Table 4.8: Comparison between Completed and non-completed groups
Table 4.9: Comparison of the KAP for completed and non-completed groups (in the baseline). 87
Table 4.10: Distribution of DR KAP Score post-intervention in a population of Indigenous
Women with or at risk of Diabetes, Saskatoon, 2018 (n=50)
Table 4.11: Effect of diabetes-eye mHealth education on Knowledge, Attitude and Practice in a
population of Indigenous Women with or at risk of Diabetes, Saskatoon (n=50)
Table 4.12: Variables associated to pre-post-change in DR Knowledge score (Simple/multiple
regression) in a population of Indigenous Women with or at risk of Diabetes, Saskatoon 90
Table 4.13: Variables associated to pre-post-change in DR Practice score (Simple/multiple
regression) in a population of Indigenous Women with or at risk of Diabetes, Saskatoon 91

# LIST OF FIGURES

Figure 3.1: Visual representation of the Concurrent Embedded study design	35
Figure 3.2: A Medicine Wheel	38
Figure 3. 3: Number of Participants during data collection	47
Figure 3.4: Flow Chart of Data Collection Process	48
Figure 3. 5: Content Search and Selection Process	53
Figure 3.6: Process of developing and refining text message content.	57
Figure 4.1: Sequence of results presentation	65
Figure 4.2: Map of Themes and Sub-themes.	66
Figure 4.3: Medicine Wheel Evaluation Image 1	94
Figure 4.4: Medicine Wheel Evaluation Image 2	95
Figure 4.5: Medicine Wheel Evaluation Image 3	96
Figure 4.6: Medicine Wheel Evaluation Image 4	96
Figure 4.7: Medicine Wheel Evaluation Image 5	96
Figure 4.8: Outline of themes and sub-themes on the perception of mHealth as a tool for	
receiving health information	98

## LIST OF ABBREVIATIONS

ASC: Aboriginal Students Centre

CDA: Canadian Diabetes Association

CI: Confidence Interval

DR: Diabetic Retinopathy

eHealth: Electronic Health

GDM: Gestational Diabetes Mellitus

IQR: Interquartile Range

KAP: Knowledge Attitude and Practice

LiveWell Fitness, Food, and Fun

mHealth: Mobile Health

mLearning: Mobile Learning

NIHB: Non-Insured Health Benefits

PDR: Proliferative Diabetic Retinopathy

QUAL: Qualitative

quan: Quantitative

SAO: Saskatchewan Optometric Association

SD: Standard Deviation

SDT: Self Determination Theory

SES: Socioeconomic Status

SIMFC: Saskatoon Indian and Métis Friendship Centre

SMS: Short Message Service

SSRL: Social Sciences Research Laboratories

WHO: World Health Organization

# **GLOSSARY OF TERMS**

**Aboriginal people:** The term Aboriginal people refers to Inuit, First Nations, and Métis people as defined in the Canadian Constitution Act of 1982 (1).

**Indigenous People:** The term Indigenous people is the term accepted by the United Nations Declaration on the Rights of Indigenous Peoples and refers to people with a shared history and experience of colonization (2).

## **CHAPTER 1**

#### 1 INTRODUCTION

This chapter provides an overview of the rationale for the study and research gaps. It also provides background information on diabetes in Canada, Saskatchewan, and Indigenous peoples. In this paper, I use the term Indigenous, to describe all Indigenous peoples in Canada including First Nations, Métis, and Inuit peoples. However, it is not possible to use only one term because the terminology is not uniformly used in the literature. Terms used in this paper reflect those used in source/referenced materials. Furthermore, the purpose and objectives of the study are stated, and this chapter describes Diabetic Retinopathy (DR) and provides a synopsis of mobile health and learning. This chapter also provides an overview of health and research in rural versus urban communities as well as research challenges, and the chapter concludes with a brief chapter summary.

# 1.1 Defining the Problem

Diabetes is a widespread population health challenge confronting the present century. Individuals living with diabetes are increasing because of globalization, urbanization, and increasing occurrence of overweight, obesity, and physical inactivity (3). In Canada, there are differences in the distribution of diabetes among populations with higher rates of diabetes present in Indigenous peoples. Earlier onset of diabetes exist among Aboriginal peoples than in non-Aboriginal peoples in Canada; and Aboriginal women are at greater risk of developing diabetes especially during reproductive years due to overweight, obesity, and gestational diabetes (4). Individuals with diabetes face multiple complications which may escalate if not timely managed and one of such complications is DR. DR is a diabetes chronic eye complication and the leading cause of vision loss among adults in developed countries including Canada (5).

DR is a progressive condition that if not well managed, can result in vision loss. Hence, the incidence of DR can be reduced by controlling blood sugar levels and undergoing regular ocular examinations. Numerous treatment and management plans improve visual outcomes in diabetic-eye diseases however, regardless of these treatment options, timely and consistent management of diabetes is essential to prevent DR complications (3). Routine eye examinations for diabetes-eye complications can decrease or postpone the complexities resulting from diabetes. However, despite its merits and success, individuals with diabetes do not access

diabetic-eye services, thereby escalating the impact of the condition on vision and daily living. Making the population aware is an essential step in the creation of a successful program to combat any health condition in a community, and it is applicable for the issue of DR (3).

The goal of the "WHO global action plan 2014–2019" is to increase eye care access across all populations, encourage individuals with visual problems, carry out and implement evidence-based practices, and address eye care across the lifespan to prevent and reduce visual loss worldwide (6, p1). At the national and provincial levels in Canada, the attention of eye care has been on eye conditions such as cataract and access to surgery rather than on preventive measures for other major eye diseases (7). Unlike cataract and refractive errors, diabetic eye diseases present many unique challenges and damage is often irreversible, which makes early detection and treatment critical. Chronic eye diseases such as DR will need a multi-faceted care plan to prevent vision loss and associated diabetes complications (8). Therefore, no single diabetic-eye intervention is sufficient instead, it requires complex treatment protocols that holistically address diabetes care because diabetes affects all aspects of health such as mental and emotional health (9, 10). Hence, constant monitoring of diabetes is required over the life of the individual.

The diabetes epidemic will remain a population health problem for Canadian health care. Given that Canadians are living longer, noncommunicable chronic (non-infectious long-lasting) eye conditions that cause vision loss, such as DR will grow substantially, thereby requiring more attention (8). Given Canada's aging population, it is imperative to develop an integrated eye health promotion strategy to address the eye care of populations at risk. Furthermore, self-management interventions tend to have positive impacts on people seeking to alter various behavioral challenges (11). Thus, mobile health (mHealth) solutions that provide a means of delivering health information may help those with the greatest need for further ophthalmic assessment (12). Mobile devices are entrenched into the lives of most people around the world and in particular, North Americans who on average use a mobile phone three (3) hours daily; hence, offering the potential for mHealth solutions and clinical support interventions (11).

Vision loss has a daunting impact on every aspect of life and activities of daily living. Without awareness of the diabetes-eye risks and complications, it will be difficult to assist in averting visual impairment among individuals with diabetes in a population (3). Keeping in mind the goal of generating awareness among the population, it is vital to understand the lacunae of

knowledge and eye care behavior concerning diabetes and eye care in individuals with diabetes and at risk of developing diabetes. The knowledge, practice, and awareness of DR among individuals living with diabetes have been examined in various populations. However, there is a shortage of information in the literature on DR knowledge and eye behavior among Indigenous peoples in Canada. To my knowledge, no study on DR knowledge and eye behavior has been undertaken in Canada.

According to Fathy et al. (2016), it is essential to explore the factors that influence eye care awareness and behavior, as well as the outcome and access disparities in among pregnant women with diabetes, women in general; and populations at risk of diabetes and development of DR (13). Nevertheless, the literature on eye care awareness and behavior in Canadian Indigenous peoples often focuses on exploring the challenges of eye care utilization in rural First Nations communities (14). Similarly, studies on DR among Indigenous populations have focused mainly on screening activities in rural First Nations communities (15,16,17). To my knowledge, there are few studies on the factors influencing diabetic-eye care behavior among Indigenous women living in urban communities. Additionally, there is limited information on factors that motivate, facilitate, and challenge DR eye care utilization in urban Indigenous communities. Few studies exist on the use of mHealth for diabetes-eye care promotion among Indigenous peoples of Canada in both urban and rural communities.

Thus, with the increasing population of Indigenous peoples in cities such as Saskatoon and the population health impact of DR among Indigenous peoples, particularly in women, it is important to know the knowledge and eye care behavior of Indigenous women living with diabetes and at risk of diabetes. Also, it is increasingly vital to understand the underlying factors influencing diabetic eye care behavior and eye service utilization by urban Indigenous women in order to possess information that can influence interventions and assist in making recommendations for a multidisciplinary patient-centered approach to ophthalmic care. There is a need for interventions that pursue an innovative way of providing targeted diabetic eye care information to Indigenous women with diabetes and at-risk of diabetes in Saskatoon. This is because, although Indigenous peoples are at high risk of diabetic complications, there are significant gaps in care among First Nations people especially among people in rural communities (18). Consequently, there is a need to improve diabetes care and management via innovative interventions. Such interventions may empower Indigenous peoples with relevant

knowledge that will influence their uptake of eye care services for early DR identification, management, and the prevention of vision loss.

# 1.2 Purpose of the study

The purpose of this study was to examine factors that motivate and constrain Indigenous women with diabetes or at-risk of diabetes in Saskatoon from adopting healthy eye care behaviors and identify the changes in DR awareness and eye care behavior as a result of a mHealth education intervention.

# 1.3 Research Questions

The study sought to provide answers to the following research questions:

- 1. What factors influence diabetic eye care use among Indigenous women?
- 2. What resources and information do Indigenous women perceive as necessary for utilizing eye care services?
- 3. How knowledgeable are Indigenous women of DR as a complication of diabetes and what is their behavior towards DR eye care?
- 4. To what extent do mHealth education intervention change DR awareness and selfreported eye care behavior among Indigenous women?
- 5. How do Indigenous women perceive mHealth as a tool for receiving health information?

## 1.4 Background

#### 1.4.1 Diabetes in Canada

Diabetes is an important chronic disease found in various populations worldwide and in Canada, type 2 diabetes is the reason for approximately 95% of diabetes cases (19). Since 2000, the prevalence of diabetes in Canada has nearly doubled with projections indicating that an estimated 3.7 million Canadians will have diabetes by 2018/2019 (20). This projected increase may be due to the increase in the aging population in Canada. Also, the risk of developing diabetes is expected to increase due to the increasing rates of obesity (20).

According to International Diabetes Federation (IDF), the North America and Caribbean region had the highest diabetes prevalence among individuals aged 20-79 years in 2017 compared with other IDF regions and this was particularly found in urban locations and due primarily to "global urbanization"; also, the prevalence of people living with diabetes in urban areas is expected to increase to 472.6 million in 2045 (21). Social, economic, environmental,

lifestyle and genetic factors affect the distribution of diabetes in Canadian populations with socio-economically disadvantaged individuals, groups, and communities disproportionately bearing the burden of disease (19).

Diabetes is a leading cause of morbidity with major complications in the kidney (renal disease), limbs (non-traumatic amputation), and eyes (retinopathy induced blindness) among Canadian adults (5). Individuals living with diabetes between 20 to 49 years of age are more likely to visit a family physician or a specialist (22). Moreover, diabetes and its complications increased health service costs on Canada's health care system and economy with approximately \$12 billion in diabetes-related expenses in 2010 (20).

#### 1.4.2 Diabetes in Saskatchewan

Saskatchewan has poor health outcomes on many health conditions, including diabetes (23). Saskatchewan residents 12 years of age and older who reported being diagnosed with diabetes was about the same as the national average (24). The Canadian Diabetes Association estimates that there are currently 75,000 individuals in Saskatchewan living with diabetes (type 1 and 2 diabetes) and that this number will increase to 111,000 (10 percent of the population) by 2020 (25). Furthermore, the financial impact of diabetes in Saskatchewan is approximately \$419 million per year and projected to rise to \$532 million in 2020 without proper diabetes-related action, necessitating urgent interventions to halt this alarming trend (26).

# 1.4.3 Canadian Indigenous Peoples

Aboriginal, First Nations, Inuit, and Métis are terms recognized in the Constitution Act of Canada 1982, Section 35, and are used in this thesis to describe the Indigenous peoples of Canada (1). Aboriginal peoples in Canada represent people who are the indigenous habitats of Canada and constitute First Nations, Inuit, and Métis people (27). The First Nations peoples are the largest number of the total population of the Northwest Territories, followed by Yukon, Manitoba, and Saskatchewan (28), and the Inuit people traditionally live in northern regions including the Arctic and Subarctic areas (29). Métis National Council refers to Métis peoples as 'individuals who self-identify as Métis, are of historic Métis Nation ancestry, are distinct from other Aboriginal peoples, and accepted by the Métis Nation' (30). Each of these Aboriginal groups has their own unique cultures, languages, diet/ foods, and their natural environment often impact the groups (31). First Nations people whose Nations have signed treaties with the crown

are accorded "registered Indian" or "Treaty status", with a "status card" that bestows Treaty rights, including access to health care services (32); as a result First Nations peoples are often legally categorized based on status (33).

Urban Indigenous peoples are those who migrated to urban areas in search of better opportunities and employment from the 1960s to present day as well as Indigenous peoples born and raised in the city and may include status and non-status First Nations, Métis, and Inuit people (34). The First Nations people are represented more in the western provinces including Saskatchewan and account for one-tenth of Saskatchewan population (35). Large communities of First Nations and Métis peoples live in Saskatoon, and these groups are the focus of this study.

## **1.4.4** Diabetes in Indigenous Peoples

The diabetes epidemic is acute among Indigenous populations and can be attributed to the rapid social, cultural, and environmental changes Indigenous peoples have undergone as a result of colonization. Previously, diabetes was not common amongst Aboriginal people in Canada, but colonialism<sup>i</sup>, the introduction of treaties, and displacement of Aboriginal people from their lands changed their lifestyle and diet, as well as influenced cultural identity and continuity which are vital to health (34). Contamination of land and water has negatively impacted wildlife, fish, water, and vegetation which were crucial sources of food. Thus, Aboriginal people have experienced and continue to undergo a change in diet with a majority of daily intake from market foods (36) and not traditional food. Therefore, urbanization, diet change, and integration of processed foods high in fat, sugar, and salt have resulted in the development of alarmingly high rates of health conditions such as obesity and type 2 diabetes that occur at an earlier age than in non-Aboriginal people (4).

Diabetes prevalence among First Nations men and women was increasingly higher than in non-First Nations men and women in Saskatchewan from 1980 to 2005, and there was unequal increasing prevalence of diabetes in First Nations peoples, particularly in women (4). Diabetes was prevalent among 17.2% and 10.3% of First Nations people living on-reserve and off-reserve respectively, and 7.3% among Métis peoples aged 15 years and above (37). However, the prevalence of diabetes among Inuit people was similar to that of the non-Aboriginal population

6

<sup>&</sup>lt;sup>i</sup> Colonialism involves the "political and economic control by a group of settlers of a dependent region and subjugation of a group of people to another" (386).

(37). Also, the 2006 Aboriginal Peoples Survey noted that about 7% of Métis people 15 years and above in Canada were living with diabetes (38). Nevertheless, a major cause of concern is the growing rate of early onset of diabetes in children (39) which predisposes them to early diabetes complications.

# 1.4.5 Diabetes in Indigenous women

First Nations women have a higher risk of developing diabetes than men, especially during their reproductive years 20-49 (4). In Saskatchewan, the prevalence of diabetes is slightly higher in females within the 30-34 years age group (40). Aboriginal women (First Nations and Métis) in Saskatchewan, are more than four times at greater risk of developing diabetes compared with non-Aboriginal women, and obesity and gestational diabetes increases the risk of developing diabetes (4). Although Gestational Diabetes Mellitus (GDM) usually resolves following birth, it increases the risk of further development of type 2 diabetes in which can occur in the mother and/or child later. Approximately 4% to 10% of GDM cases proceed on to type 2 diabetes within the first nine months after pregnancy and is a predictor for other cardiovascular diseases (41). Women with GDM are more likely than nondiabetic women to experience cesarean delivery, preeclampsia, and type 2 diabetes after delivery, and babies of GDM mothers have a higher risk of fetal macrosomia, birth injuries, and hypoglycemia compared with babies of nondiabetic mothers (42).

Furthermore, there is a higher rate of children with high birth weight among Aboriginal women living with diabetes in Saskatchewan compared with non-Aboriginal peoples (43). Therefore, GDM is likely a significant contributor to the diabetes epidemic among Saskatchewan Aboriginal women and the inter-generational effect may be observed across the years (44). As such, morbidity and complications associated with diabetes will similarly be higher (45) in Aboriginal women if not adequately addressed.

Higher rates of obesity, post-menopausal hypertension, higher metabolic syndrome, and poor response to exercise training in women living with diabetes impact the gender differences in diabetes health-related outcomes and responses to interventions (46). Therefore, there is a need for tailored gender-specific interventions to ensure interest, equal opportunity, and access to programs and services. This could be accomplished through Aboriginal health promotion and disease prevention practices addressing the problems associated with chronic health conditions (1).

# **1.4.6** Diabetic Retinopathy (DR)

Individuals living with diabetes have an increased risk of developing cataracts (degeneration of the crystalline lens in the eyes) at a younger age and are more likely to develop glaucoma (poor vision due to optic nerve damage, elevated eye pressure, and visual field loss) but, the main threat to vision due to diabetes is DR. DR is a chronic diabetic-eye complication and the most common cause of blindness, particularly among individuals between 25 and 75 years of age (47).

Using the "Early Treatment Diabetic Retinopathy Study (ETDRS)" grading standards as a reference, DR is the presence of retinal microaneurysms seen in the early stage of DR, along with lesions such as vitreous hemorrhage, exudates, neovascularization (abnormal growth of new retinal blood vessels into the vitreous), and abnormalities in the retinal veins which are often seen in the late stages of DR (48, p3). DR involves damage to the micro-blood vessels of the retina due to prolonged exposure to diabetic metabolic changes such as blood sugar fluctuations. DR occurs as a microvascular complication causing blockage, leakage, or haphazard growth of the eye capillaries and blood vessels (49). When retinopathy advances, it decreases the circulation of the blood vessels which deprives the retinal areas of oxygen, and blood vessels become blocked, resulting in retinal damage and subsequent retinal changes.

There are two key forms of DR which include the less-severe form, "non-proliferative DR" and the severe form, "proliferative DR (PDR)" (50, p348). PDR involves neovascularisation in the retina that may cause scarring of the retina and vitreous. DR is often asymptomatic in its early stages but as it progresses, DR may cause irreversible vision loss. The different forms of DR threaten vision and usually occur when retinopathy is left untreated (48).

Several factors increase the risk of developing DR including smoking, alcohol consumption, high blood pressure, and pregnancy (51). Glycemic control, blood pressure, pregnancy (with type 1 diabetes), severe retinopathy itself, and duration of diabetes similarly affect the progression of DR (52).

Among people living with diabetes, about a third of them have an extent of DR, one in ten will develop DR that threatens vision, and individuals with diabetic eye diseases report increased occurrence of physically unhealthy days and constrained daily activities (21). The Global Burden of Disease study in 2015 indicated that the primary reasons for disability among all ages were low back and neck pain and vision and hearing impairment worldwide (53). Diabetes that impairs sight has a negative impact on perceived quality of life and may give rise

to stress, feelings of vulnerability, worries about the future, and loss of independence and mobility (54); in addition to having a significant toll on the finances of individuals. Vision loss is similarly often associated with increased falls, hip fracture, and among individuals with type 1 diabetes, it may lead to limb amputation. Therefore, vision loss due to DR elevates the risk of morbidity in individuals with diabetes.

# 1.4.7 DR in Indigenous communities worldwide

In 2010, there was an estimate of about 0.8 and 3.7 million individuals blind and visually impaired as a result of DR worldwide (55). Vision loss due to DR possibly reflects the increasing prevalence of diabetes mellitus in the general population. So, individuals with diabetes tend to live to an age at which they experience ocular complications of the systemic disease (53).

The prevalence of diabetes in Indigenous populations is rising worldwide and this impacts the presence of diabetes complications in these communities. DR is the cause of 9–12% of visual impairment in the Indigenous Australian peoples (56). Also, the National Indigenous Eye Health Survey indicated that Indigenous Australians reported to have diabetes was higher than non-Indigenous Australians (57) with the reported annual incidence of DR (1.2%) in Australia and one of the highest reported incidence rates of diabetic macular edema (1.7%) (50). This high prevalence of diabetes has resulted in DR contributing to the eye challenges among Australian Indigenous people and it is more prominent than other eye conditions, such as glaucoma and age-related macular degeneration (58).

Contrary to most literature, it is interesting that the Darwin Region Urban Indigenous Diabetes Study noted that there was no difference in DR in type 2 diabetes prevalence in urban Indigenous Australians and the general Australian population (50). No explanation was given for this difference in this study. Nevertheless, the recommended eye examinations interval among Indigenous Australians is more than in non-Indigenous Australians (59), which may be because of the increased prevalence of diabetes among Indigenous peoples in Australia (58).

Similarly, there is a high prevalence of diabetes and obesity among Indigenous Māori people in New Zealand with younger age of diabetes onset, also a household survey showed that the prevalence of moderate or severe retinopathy was significantly high among the New Zealand Indigenous people (50). Zhang et al. (2010) showed that a high prevalence of DR and vision-threatening DR existed in a United States population aged 40 years and older, especially among racial/ethnic minority groups including Native American peoples (48).

#### 1.4.8 DR in Canada

DR is present in approximately half a million Canadians with about 100,000 persons having a vision-threatening form of severe retinopathy and 6,000 individuals blind due to DR (37). The increasing longevity of people with diabetes as a result of medical advancement in the management of diabetes has led to an increased risk of developing retinopathy (60).

Few studies have assessed the prevalence of DR in Canada, particularly among Indigenous peoples. However, there are more advanced forms of DR found among Canadian Aboriginal people than among non-Aboriginal peoples which may be due to the early onset of diabetes (61). Thus, living longer with diabetes will increase their risk of developing DR complications (61). A six years prevalence study from May 2007 to July 2013, from 49 communities in Manitoba showed that of individuals with DR, the percentage of people with mild, moderate, and severe non-proliferative DR was 93.5% (58.8%, 34.1%, 0.6%), and 6.5% of people were with proliferative DR (62). Kanjee et al. (2016) also indicated that persons with no evidence of DR at their initial examination, subsequently developed DR, across the six years yielding a cumulative incidence of 17.1% (62). A study that examined Cree peoples of Western James Bay, in Northern Ontario, revealed a prevalence rate of 24%, 5%, and 2% for non-proliferative DR, diabetic-macular edema, and PDR respectively (63). Also, in Southern Alberta 40% of First Nations people had background DR with many having advanced stages of retinopathy; however, DR progression occurred rapidly in men than women (52).

Women with myocardial ischemia and arteriosclerosis may be at higher risk of developing microvascular diseases such as retinopathy (64). Also, hormonal changes such as pregnancy and puberty are risk factors for the development of DR. Accordingly, diabetes will lead to a significant burden of preventable vision loss in Aboriginal communities, particularly in women if not addressed (65). Targeted care for First Nations people on blood sugar and high blood pressure control along with the utilization of retinal screening services could reduce the progression of DR, and vision loss (52).

## 1.4.9 DR Prevention and Management

DR is asymptomatic, as such, in its early stages; the most effective approach for the prevention of vision loss is early detection. Vision loss from diabetes is preventable by monitoring diabetes via regular physician visits, lifestyle modification (diet, exercise), and medication to ensure control of blood glucose within normal range of average blood sugar concentrations (A1c): 7.0%

or less and blood glucose of 4.0-7.0 millimoles per litre (mmol/L) before meals and 5.0-10.0 mmol/L two hours after meals (66). Also, diabetic vision loss is prevented by appropriately timed eye examination at the initial diagnosis of diabetes, annually, and more frequently if recommended.

The Canadian clinical practice guidelines recommend that people with diabetes undergo regular yearly dilated eye examinations for early detection and treatment. This is because with early treatment, only 5% of people with DR will become legally blind; however if untreated, 50% of people with DR will become legally blind within five years (67). The Canadian Diabetes Association recommends diabetes screening every three years in individuals 40 years of age or older with more frequent or earlier testing if the individual had one of the risk factors; including: first-degree relative with type 2 diabetes, member of high-risk populations including Aboriginal peoples, history of diabetes complications, gestational diabetes mellitus, delivery of an infant with birth weight more than 4000grams, hypertension, dyslipidemia, overweight, and abdominal obesity (68). In addition, the Canadian Ophthalmological Society recommends regular DR screening for the early detection of treatable cases (12). The current standard for DR eye care screening is a stereoscopic assessment of the retina by an eye care professional to clinically diagnose DR via ophthalmoscopy, optical coherence tomography, retinal photography, and fluorescein angiography (50).

The timing of eye examination varies depending on the type of diabetes. Persons with type 1 diabetes should have an eye examination within five years of diagnosis after the age of 15, and subsequently on an annual basis (69). While in type 2 diabetes, a comprehensive eye examination should occur at diagnosis, and after that annually (69). Hence, screening for DR is an effective method to identify treatable cases and consequently lead to early treatment of DR. This is more likely to result in a better prognosis since the effects are usually irreversible once the damage has occurred.

Although individuals living with diabetes can manage DR onset and progression utilizing different health care strategies such as regular eye examination, taking diabetes medication as suggested by the physician, and treatment when essential. However, many individuals living with diabetes do not understand the ocular complications associated with diabetes, the importance of having regular eye examinations, the importance of reporting sudden changes in the eyes to an eye specialist and prompt management of retinopathy signs/symptoms (47), all

contributing to low compliance with annual DR screening (61). In a study conducted in five Canadian provinces, it was concluded that 38% of individuals living with diabetes in the study, had never had an eye evaluation for diabetic retinopathy and another 30% had not had an eye examination in the last 2years (70). As such, there is inadequate agreement with diabetic eye screening among several individuals living with diabetes.

Urbanization and adaptation to a western diet may influence the rates of diabetes in urban populations (50); so, it is crucial that strategies for promoting eye care among high-risk groups are encouraged to reduce the development of DR. It is imperative to improve eye care practices among high-risk groups, including persons with diabetes, particularly people newly diagnosed with diabetes or found to have retinopathy and, if diabetes or retinopathy is not present, those who are at high risk of progression such as in poor glycemic control (71); and persons at risk of developing diabetes including individuals with pre-diabetes<sup>ii</sup>, gestational diabetes, and family history of diabetes. Diabetic eye disease prevention will assist in reducing the burden of disease associated with diabetes, and will likewise provide significant savings to the healthcare system (62).

# 1.4.10 Mobile Learning; Mobile Health

Mobile devices are now considered learning tools (72), because mobile devices are changing how knowledge is perceived and it is providing support for novel forms of learning. Education and health bodies recognize mobile devices as vehicles for learning, health care, and social change (73). In particular, the health care sector is taking advantage of mobile devices to promote and maintain the health and safety of patients (72). Health education via mobile platforms may increase access to information at the time needed and it provides various cues for comprehension and retention since mobile devices present information in different patterns (74).

Mobile devices open mobile learning (mLearning) opportunities for socially marginalized communities as well as for persons living in remote areas including Indigenous peoples who may not have the necessary infrastructure in their communities and areas of residence (75). According to Traxler (2009), mLearning supports personalized and targeted learning and it takes population

12

<sup>&</sup>lt;sup>ii</sup> Pre-diabetes applies to above normal levels of blood sugar but not high enough to be diagnosed as diabetes, thereby increasing the risk of type 2 diabetes (387)

diversity into consideration via the way information of interest to the user is developed and disseminated (76).

There is increasing interest to utilize mobile devices/technology to improve learning and awareness creation about health conditions and health care in general, which has resulted in the rapid uptake of mobile communication technologies in various health sectors herein regarded as mobile health (mHealth). mHealth also often referred to as telehealth and electronic health (eHealth) applies to public health practices supported by mobile devices (77), such as mobile phones, tablets, and other wireless devices.

mHealth is often user-centered since it provides convenient and personalized, timely interactions with users/patients thereby increasing active engagement in health care (78). mHealth initiatives support the changing role of health promotion (77) by raising awareness of health issues through understandable information via mobile phones, thereby assisting people in making informed health decisions.

Due to their portability, mobile phones have now become vehicles for public awareness and health promotion activities that cut across gender, age, language, literacy level, and economic status. mHealth has the potential to support health solutions at both the individual and population level, particularly for awareness, training, behavioral change (79), surveillance, and screening. Thus, the use of mHealth can improve health outcomes (80) and may reduce health disparities due to relative parity in phone access and ownership across various populations (81).

# 1.4.11 Health in Rural versus Urban<sup>iii</sup> Indigenous Communities

Indigenous peoples "living on reserves are usually referred to as living 'on-reserves' while they are referred to as living 'off-reserve' when they live away from reserves" (82, p6). On-reserve and rural are often linked as well as off-reserve and urban. Also, "a large population of Indigenous people living off-reserve live in urban cities and a small population who live 'on-reserve' are located in urban areas" (82, p6). The health needs and challenges among Indigenous peoples living in both rural and urban communities in Canada differ (82), and the social determinants of health impact them differently. For example, a key factor that influences Indigenous health in rural communities is access to care which involves the inability to obtain

13

iii In this study urban is referred to a location that has between "400-1000 people per square kilometer" (82, p6)

timely health services closer to home, transportation, and travel time to access health services. Whereas, in urban communities, access to health care may not be as significant compared to other factors. Hence, although there may be variations across rural communities, the overall health of Indigenous peoples living in rural communities is often poorer than in urban communities (83). This study focuses on Indigenous women living in the city; as such, in this study, their health care experiences would be different from Indigenous women in rural regions.

# 1.4.12 Research in Indigenous Communities

Research involving Indigenous peoples is grounded on building reciprocal and respectful relationships as well as fostering collaboration and engagement between researchers and community members (84). Researchers have a responsibility to maintain these relationships. For instance, it is imperative that community representatives are involved in the entire research process from the research concept creation to the final report completion and before finalizing all publications from the research (84).

In both rural and urban communities, representative bodies and service organizations recognized by the Métis, First Nations, or Inuit authority are responsible for protecting the welfare of the Indigenous community members as such, they are partners and oversee any study involving Indigenous research. Chapter 9 of the Tri-Council Policy Statement notes the importance of engaging with both the customary authority and formal leadership (84), but making these connections for research may be more complicated in rural communities than in urban locations. In urban communities, there are Indigenous organizations that attend to the needs of Indigenous people in cities to increase access to various services and support systems such a Friendship centres (82). The organizations have already built relationships with the urban community, and researchers can leverage on these relationships. In this study, partnership with Saskatoon Indian and Métis Friendship Centre and LiveWell Diabetes program facilitated the research and the relationships with community members.

## 1.4.13 Research Challenges and Approach

The research challenges in this study, included the inability to fully understand the complexities of diabetic-eye care among Indigenous women in Saskatoon and proffering a suitable mHealth intervention, particularly since the researcher is non-Indigenous. Hence in this study, the Medicine Wheel as described by Mussell (85) was utilized to explore DR experiences from the

perspective of the Indigenous women in the study. Also, self-determination theory (SDT) was applied as an approach to facilitate the development of the diabetic-eye health education in the study. This occurred by incorporating the SDT and the Medicine Wheel in the research processes, such as the methods, organization and assessment, the mHealth intervention, and discussion of findings.

#### 1.5 Delimitations

The study was restricted to First Nations and Métis women aged 18 years and above selected among Indigenous women at the Saskatoon Indian and Métis Friendship Centre and LiveWell Diabetes programs in Saskatoon. Therefore, the information obtained may not apply to all Indigenous women living in Saskatoon and rural communities.

# 1.6 Summary of Chapter One

There is increasing prevalence of diabetes in Indigenous women which increases the risk of developing DR. DR is an eye complication of diabetes and individuals with diabetes develop some stage of DR over time and if poorly managed can result in vision loss. mHealth refers to public health practices supported by mobile devices. The purpose of the study was to explore factors that motivate and constrain Indigenous women from adopting healthy eye care behaviors and identify the changes in DR awareness and eye care behavior as a result of a mHealth education intervention.

The next chapter provides literature related to factors affecting diabetes, and DR knowledge and eyecare behavior. Literature on mHealth is also presented.

#### **CHAPTER 2**

#### 2 LITERATURE REVIEW

# 2.1 General Scope of Literature Review

In this chapter, an overview of the factors influencing the progression of diabetes and the impact of social determinants of health on diabetes in Indigenous peoples especially as it relates to DR progression and management is provided. The chapter also describes conditions/factors affecting eye care service utilization for DR. Health education among Indigenous women is also discussed. Also, literature describing mHealth platforms, mHealth utilization for DR management in Indigenous populations, and the use of mHealth for health education and behavior change, particularly via text messages is presented. This chapter delves into the design of mHealth interventions and challenges in the design and implementation of mHealth interventions. The literature presented in this chapter supports the need for this study.

# 2.2 Variables and Factors Influencing DR

Living with diabetes increases the risk of developing DR. However, several risk factors increase the risk of DR complications along with the knowledge and behavior for eye care including: the age of diabetes onset, gender, ethnicity, income, education, and employment.

## 2.2.1 Age and DR

Type 1 diabetes is associated with childhood or yout-onset while type 2 diabetes, though type 2 diabetes usually occurs at older years, it is increasingly occurring in younger age groups across different geographical locations. Various factors especially aspects influencing infant/child development pre and post natal, further the rising prevalence and incidence of diabetes among Indigenous children such as early life events, infant nutrition, early childhood obesity, and physical inertia (86). The early age of onset of type 2 diabetes is of great concern because it results in a greater duration of exposure to hyperglycemia, and development of chronic vascular complications of diabetes during adult years (87). Individuals with young-onset type 2 diabetes often have poorer control of metabolic risk factors and are at higher risk of developing retinopathy compared with the onset of type 2 diabetes at older ages. Thus, individuals with young-onset type 2 diabetes need identification and early treatment, to prevent or delay complications of diabetes (87).

Children with type 1 diabetes below 10 years of age hardly develop DR but the risk rises after this age (88), and the DR prevalence among persons with type 1 diabetes rises rapidly particularly among post-pubertal individuals after 5 years of living with diabetes (48). Whereas, in type 2 diabetes, retinopathy may be present at diagnosis or soon after (89). Age-specific DR blindness trends between 2004 and 2013 in an Irish population in Ireland showed there was greater incidence among adults aged 18–49 years living with diabetes than there was among adults aged 50–69 years (90). Furthermore, about 50% of people with type 1 diabetes and 30% of those with type 2 diabetes have sight-threatening diabetic-retinal complications, and a higher risk of PDR (advanced retinal degeneration) in type 1 than in type 2 diabetes, while diabetic macular edema is more prominent in type 2 diabetes and all these DR complications are sight-threatening (91).

#### 2.2.2 Gender and DR

Women with a family history of diabetes are often prone to developing gestational diabetes during pregnancy. After delivery, GDM resolves but this increase the risk of both mother and child developing type 2 diabetes in the future (92). Although gestational diabetes increases the risk of post-partum diabetes in all women, post-partum diabetes is often significantly higher among First Nations women, which is usually due to socio-economic and environmental barriers to a healthy lifestyle (93). Moreover, women experience anxiety and uncertainty about their health when they receive a diagnosis of GDM particularly around having a diagnosis of diabetes later in life (94), which may be an additional stressor. Also, DR tends to accelerate during hormonal changes such as pregnancy and puberty (91). However, Ghaemi et al. (2016) indicated that although diabetes is observed more often in menopause women, retinopathy did not change with menopause (95).

Women are often primarily responsible for their family in many populations and are the primary seekers of care and diabetes information, but often lack adequate diabetes care themselves (13). A study that examined eye care knowledge and self-efficacy related to utilizing eye screening among women living with diabetes showed that there were substantial gaps in diabetes-eye complications awareness and knowledge (96).

# 2.2.3 Ethnicity and DR

Ethnicity is a compound diabetes risk factor as well as a risk factor in the development of DR; thus, information and opinions from one ethnic group cannot be transferred to other ethnic groups (50). Ethnic differences exist in the prevalence and risk factors of DR with the prevalence of various forms of DR higher in people of South Asian, African, Latin American, and Indigenous people compared to people referred to as the "white" population i.e. these may be people whose ancestry originate from the Middle East, Europe, or North Africa (50). Also, there is a higher prevalence of DR and diabetic-macular edema among Indian Singaporeans compared with the Chinese and Malays (97). On the other hand, some groups may encounter health risks and health disparities which are primarily connected with experiences in the environment and communities they live (98).

In the United States and Canada, microvascular complications are connected to microalbumin and urinary sialic acid levels along with elevated serum levels in Indigenous peoples (50). Several factors such as marginalization, loss of identity, language, and culture largely contribute to health risks (99) in Indigenous peoples.

Since the region-based prevalence of DR around the world varies, it is vital to explore factors that influence the development of diabetes and subsequently DR progression along with a focus on examining facilitators and barriers to DR care specific to Indigenous peoples. Barriers and facilitating factors are often linked to social, economic, political, and environmental factors. These factors often have a more far-reaching impact on diabetes among Indigenous peoples.

## 2.3 Social Determinants of Health and Diabetes

Social determinants of health influence the health status of all Canadians, but their negative impacts are more prominent in Indigenous peoples and related to historical and contemporary experiences.

#### 2.3.1 Colonization

Colonialism is both a health determinant and a key influence on other health determinants making it more difficult for Indigenous peoples to maintain optimum health and wellness due to limited opportunities and access to resources (100). As a result of colonialism, systemic racism, and discrimination, Indigenous peoples are often wary of accessing health services, and in some communities, there is limited access to the resources and conditions necessary for health care

(101). Colonization appears to be the origin of most health events that have influenced and still influence Indigenous peoples.

Social determinants of health are inseparably linked to the health inequalities of Indigenous peoples in Canada and health conditions are often complex as a result of underlying factors such as poverty, housing, food insecurity, community infrastructure, health and education systems, racism, and social exclusion (102). These interacting factors directly and/or indirectly influence health and are the causes of health inequities between populations (103). The factors have similarly resulted in a disproportionate distribution of ill health causing Aboriginal people to have worse health indicators than non-Aboriginal people (104). The social determinants of health impact a range of health conditions, health decisions, and health management among Aboriginal peoples in Canada with Aboriginal people facing higher rates of unemployment, limited economic opportunities, poor housing, and lower educational attainment than non-Aboriginal people (105). This impacts access to resources such as nutrient-rich foods that influence diabetes (106), in addition to the management of diabetes and its complications.

#### 2.3.2 Stress and Diabetes/DR

The experience of colonialism, racism, and social exclusion leads to stress among Indigenous peoples. Stress occurs from living and coping with stressors such as insecure employment, low income, poor housing quality, food insecurity, and discrimination (as a result of Aboriginal status, disability, or gender) (107). In addition, adverse childhood experiences are linked to the development of several chronic conditions in childhood and adulthood (108), which in Aboriginal people occur due to intergenerational trauma and stressors that affect child development due to the accumulation of stress before, during, and after pregnancy (109).

Indigenous peoples living with diabetes and having low financial security lack access to resources to aid them to manage the condition thereby increasing stress, anxiety, and diabetic complications. Continuous anxiety from these factors will weaken their resistance to diseases and increase vulnerability and progression to diabetes through physiological and behavioral pathways (110). Moreover, stress can be "diabetogenic" via endocrine mechanisms resulting in high levels of the stress hormone "cortisol" which results in elevated blood sugar levels causing chromosomal damage (110) that subsequently influences the rate and progression of diabetes among vulnerable populations. Therefore, stress is a strong risk factor for type 2 diabetes among Indigenous peoples (111), and stress is a predictor for depression often prevalent in persons

living with diabetes and associated with increased severity of diabetes complications, including retinal abnormalities (112).

Stress leads to depression, which is significantly higher among women with diabetes than men, and depression in individuals living with diabetes is associated with poor metabolic control and the use of more health care resources (64). Stress is common to many populations, but Indigenous women may have higher stress levels than other populations due to their inequitable experiences of the social determinants of health. As a result of high levels of stress, people generally adopt coping behaviors, such as the excessive consumption of alcohol, smoking, and unhealthy food consumption in an attempt to deal with stress (113). The stress hormone cortisol increases cravings for food (114) which frequently consists of food with a high rate of sugar and carbohydrate (107). Thus, when individuals face stressors that are difficult to manage, they often rely on emotion-focused coping strategies such as stress-eating, even if the stressor cannot be eliminated (113) which eventually causes negative health consequences, increases diabetes risk, as well as its complications.

The physical and psychological stress of managing diabetes (115) and the financial challenges of living with diabetes affect the progression and impact of diabetes complications. Also, trauma, violence, and historical factors such as colonization and forced acculturation are stressors that impact diabetes risk, development, progression, and management (116), which likewise influence DR progression and eye care. For example, perceived discrimination in healthcare, as well as negative differential treatment, produces stressors/pressures that can be chronic and associated with elevated diabetic outcomes and impacts the management of diabetes and complications (117). Nevertheless, the National Report of the First Nations Regional Health Survey shows that First Nations peoples report their mental health as strong and have physical, emotional, mental, and spiritual balance most of the time (118). This shows the resilience of Indigenous peoples despite health challenges and other life experiences.

# 2.3.3 Food Insecurity and Diabetes/DR

Food insecurity is a vital determinant of health that exists when people do not have access to safe, healthy, and adequate food to meet their needs (119). Therefore, food must be readily available, and individuals have to be able to obtain food in a socially acceptable way. Food insecurity results in diet-related illness, thus it is a population health issue for marginalized groups including Aboriginal peoples (120).

Traditionally, Indigenous peoples met their food needs by living off land resources, but, due to colonization and the resulting displacement of Indigenous peoples from their land as a result of the Indian Act in 1876, Indigenous peoples have undergone a nutritional transition from a diet consisting of traditional foods to the reliance on store-bought highly processed foods, which may not be readily available, affordable, and may have poor nutrient content. This is a contributing factor to the incidence and prevalence of type two diabetes (121), and the risk of developing DR.

Urban Aboriginal women/ mothers face various food security barriers including financial, loss of the knowledge regarding preparing traditional foods, and transportation to obtain appropriate food as a result of this, affecting traditional food systems (122). In addition, food deserts exist in Canadian cities and the lack of access to supermarkets also result in less access to culturally healthy or essential foods (123). Thus, residents are more dependent on smaller food stores which are more expensive and less likely to offer a range of healthy foods options, affecting not only food security but also the risk of developing diabetes and ability to manage the condition. Also, Aboriginal people experiencing food insecurity are more likely to have increased stress rate which can predispose them to ill health (120).

Nevertheless, food insecurity is interlinked with other health determinants including employment status and income. This is because these factors determine the ability to purchase accessible and affordable culturally appropriate food for good health.

## 2.3.4 Work Status, Education, and Diabetes/ DR

Income, education, and employment are indicators that determine the socioeconomic status (SES) of an individual or household, and is indirectly related to health and life expectancy (124). SES plays a key role in determining the health of people because it influences health behavior, food security, health care access and control over other proximal health determinants. Research shows that among Aboriginal people, socioeconomic disadvantage is associated with cardiovascular risks (125).

Higher education status frequently relates to better employment, income levels, health choices, and opportunities (126). This affects the availability of resources and the purchasing power for healthy eating to prevent or manage diabetes and its eye complications. SES has a major role in diabetes onset, eye complication development, and eye care in individuals living with diabetes since income influences the ability to manage diabetes and DR (127). Hwang and

colleagues found that in Canada, gender, age, duration of diabetes, and income were significantly associated with visual impairment (127).

In Canada, private health insurance for eye care services which employers may provide is a predictor of regular eye care services (127). But this is more frequently found in higher paying jobs. The absence of private insurance coverage may lead to reliance solely on the provincial health insurance which does not cover many critical eye services.

The social determinants of health are intertwined with several conditions that hinder the utilization of eye care services by Indigenous peoples and have the potential to reduce the motivation to seek eye care. Exploring factors influencing diabetes-eye care behavior is a vitally important step in the development of a successful initiative to address DR among Indigenous women in Saskatoon.

# 2.4 Factors influencing eye care service utilization for DR

Despite the benefits of DR screening, individuals living with diabetes often do not access regular eye examinations. Approximately 66% of individuals with diabetes had an eye exam between 2010 and 2011 as recommended in the clinical practice guidelines (37). In Canada, lack of awareness of diabetic eye complications, fear of treatment, guilt about poor diabetic control, health beliefs (culture, attitudes and values), resources, limited personal mobility due to poor overall health, and accessibility (difficulty related to transportation from remote regions) significantly affect eye care access (128). In addition, factors associated with nonadherence to eye examination for DR include low health literacy, lack of access to care, and pregnancy are present in different populations (13). Showing that one or a combination of factors can influence the DR eye care use.

## 2.4.1 Knowledge/Awareness

In population health, health behavior is the result of three steps: having correct knowledge, having suitable attitude or belief and acceptance, and having the capacity to act (129). Knowledge is the basic requirement for any behavior. If there is no knowledge, one cannot perform any directional practice. On the other hand, a population disadvantaged in social determinants of health such as in Indigenous populations, irrespective of the presence of knowledge, may not be able to practice what is learned, thereby ceasing the behavior change process especially for individuals who confront poverty challenges daily (130). Poverty is a

prominent determinant of health experienced by many Indigenous peoples that influences the ability to make decisions and access health care services (102). For instance, although individuals may possess knowledge of the importance of visiting eye doctors for regular eye care, they may not visit the doctor, especially when they are struggling to take care of basic life needs such as food, clothing, and housing. If eye care is not a primary need, they may visit an eye doctor only when signs and symptoms occur.

Nevertheless, low awareness of the asymptomatic and blinding nature of DR (131) is a factor that deters the uptake of DR care. A lot of individuals with diabetes do not realize that a large extent of vision loss from DR is preventable.

DR and diabetic-eye care knowledge and behavior vary across different populations, including persons living with diabetes, persons at risk of diabetes and even among healthcare practitioners, with each group having different levels of DR knowledge and behavior. For instance, a DR barometer study showed that a majority of adults with diabetes saw a healthcare professional for their diabetes, but less than half had gone for an eye examination in the last year while ophthalmologists reported that most individuals with diabetes attend an eye clinic when visual problems have already occurred due to insufficient knowledge of the risks (132). Similarly, the 2005 Canadian Community Health Survey of Canadians with diabetes showed that 68% of respondents had ever had an eye examination (12). Also, many low-income and racial/ethnic minority people with diabetes underuse testing facilities mostly due to financial burden and depression along with not seeing the need for screening, cultural beliefs, denial, language issues, fear, and transportation (133).

A study in India showed that persons living with diabetes possessed better knowledge about diabetes than about DR (134). On the other hand, individuals with diabetes in some populations are knowledgeable about DR; for instance, diabetic patients in a study in Saudi Arabia, showed that most patients were aware that diabetes could cause eye disorders and equally showed good attitude and practice for regular eye checkups by consulting eye professionals for the prevention and management of DR (3). A survey of diabetic-eye care knowledge and behavior in respect to DR among final year nursing students training to be the paramedic care providers, showed that although awareness of diabetes-related illnesses was favorable in a majority of the students; however, more than two-thirds of the students were unaware that DR eye damages are not reversible (135). Although the above studies in this

paragraph are not from Indigenous communities in Canada, they show the variations in the knowledge and awareness of DR in different population groups.

Investigating DR knowledge and eye care behavior is crucial because it is an indicator of awareness of systemic diabetic microvascular complications, as well as a sentinel indicator of the impact of diabetes in a population. Therefore, inadequate knowledge becomes a key barrier to seeking immediate eye care at critical periods when treatment can halt the disease progression, resulting in adverse complications (136). On the other hand, being knowledgeable of DR could equally demotivate individuals with diabetes from accessing diabetic-eye care. This is because when individuals living with diabetes are aware of diabetes related complications, this sometimes causes anxiety, disappointment in diabetes management, and denial which often result in non-adherence to treatment and management plans (137). Not accessing diabetic-eye care may also be due to a poor history of care with eye health professionals and the ability to pay for eye care services. Hence, as much as awareness influences eye care, other underlying factors influence the eye care behavior of Indigenous peoples.

#### 2.4.2 Income/ Health Insurance

Income and available health insurance influence the ability to pay for eye care services which in due course, influence the utilization of eye care services. Although clinical need, not an individual's ability to pay for services is the principle of the Canadian health care universal access system (138), it does not guarantee comprehensive coverage for all eye examinations. In many situations, people would need to rely on private insurance. Aboriginal people utilize specialty healthcare services such as eye exams at a lower rate than other Canadian populations (139). This may be because the provincial health plan does not cover these services. Also, many people do not have private health insurance and, unfortunately, provincial health plans do not cover out-of-pocket expenses for eye care (140).

Access to and cost of eye services depend on the presence or absence of diabetes, age, area of residence of the individual, in addition to status or non-status Indigenous identity. The Non-Insured Health Benefits (NIHB) provides coverage of health care services for First Nations people with treaty cards but the NIHB does not cover health expenses for Indigenous people without treaty cards and Métis people (33), rather they rely on the provincial health plan. Despite this, there is a divide in the access to health care services in urban versus rural areas (82). Also, Individuals between 20 and 64 years of age are not covered for routine yearly eye examinations

by many Canadian provinces (141). Although the Government of Saskatchewan covers annual eye examinations for individuals living with diabetes in the province (142), it does not cover eye exams of adults "at-risk of diabetes". In Saskatchewan, status First Nations women would have some eye examination coverage through the Non-Insured Health Benefits (NIHB) while non-status First Nations and Métis women would not have similar coverage. Therefore, the NIHB is a challenge to equal access to health services because Métis and non-status First Nations people are excluded from benefiting from this health plan (101). Hence, Indigenous women not covered by NIHB may be making out-of-pocket payments or accessing health coverage through private or employer insurance.

## 2.4.3 Health care access in Urban Indigenous populations

Many Aboriginal people have moved to the cities for better opportunities (104). With the majority of the Canadian population living in urban regions and the availability of health services in urban cities, it reduces the challenge of accessing health services. Nevertheless, several personal and system-related barriers affect the use of health services among urban Aboriginal women and these factors may either be facilitating or constraining factors including; transportation, accessibility, and location of health services and care provider qualities (143). In Canada, although there are more health care services in cities compared to rural areas, there are still obstacles to accessing and the use of health care services in cities among Indigenous peoples due to long wait times, quality of care provided, and experiences of racism and discrimination (144,145).

Several eye care centers are situated in the cities, and although travel time and distance are short, the waiting times to see an ophthalmologist can be lengthy (17). In Saskatchewan, there may be up to 8 weeks wait from general practitioner (GP) referral to see an ophthalmologist and another 12 weeks wait before treatment (146), which may discourage/demotivate eye care examinations.

## 2.4.4 Cultural Competency

Aboriginal peoples access health care with a collective history of colonial relations and stories about how people before them have been mistreated before and still continue to be mistreated while seeking health care (147). Issues of cultural competency among health practitioners may be a barrier to eye care service utilization by Indigenous peoples (101). This may be due to a

deep mistrust of health care institutions stemming from a history of culturally unsafe care endured by Aboriginal peoples (139) often resulting in dissatisfying experiences that partially meet their needs.

Health care services use by Aboriginal women are often difficult and shaped by racism, discriminatory attitudes, a lack of culturally relevant services or understanding by health care professionals, and stereotypical thinking (148). A service is culturally relevant to an Indigenous person when health practitioners respect the individual, are attentive to their needs, include the individual in health care decision making, and provide timely care (148). Nevertheless, when urban Aboriginal women access health services, their concerns are often ignored or disregarded; hence, they may delay seeking needed health advice and service or set aside their health concerns (149). This decision may subsequently endanger the women's personal health and the health of their families since they are often key in household health decision making.

Although some Aboriginal women living in cities may feel lost in a place that is so far from their culture, they remain the main caretakers of their children, struggling to feed, educate and comfort them, and often put off their own health problems for another time in the future (145). As such, due to the combined fear of judgment by healthcare providers and women's decisions to seek health care (148), Indigenous women may be discouraged from accessing health care in the cities.

# 2.4.4.1 Interaction with health care practitioners

Indigenous women may differ in their traditions, age, and education background, but irrespective of these differences, they share many historical experiences embedded in colonization. In addition, social determinants overwhelmingly impact their lives. Also, Aboriginal women are commonly victims of discrimination and abuse in a variety of forms and these experiences have an enormous impact on women's formation of trusting relationships (150).

The power imbalance between Aboriginal women and health practitioners as well as the manner of communication from a health practitioner can make women feel disempowered, hinder rapport, and keep women from expressing their opinions or asking questions particularly when health professionals do not consider their opinions (151). Individuals generally want to be respected, listened to, and in control of their health decisions (150). "Visibility" as an Aboriginal person in the patient—health practitioner relationship relates to being respected and "listened to" particularly in regards to health needs, and contributes to providing a culturally safe health care

experience (147). As such, it is important that when providing health advice/information to them, health practitioners utilize methods that are culturally congruent and collaborative in order to enhance learning such as trauma-informed practice.

# 2.4.4.2 Indigenous women and health education

Aboriginal women appreciate support in making healthy choices but they would resist being judged and dictated to (151). Thus, if a health practitioner uses an authoritarian approach to educate Aboriginal women, it may influence their self-esteem and confidence which can prompt resistance to advice provided (151). It takes time to establish rapport, and it develops from interaction and relationship building which will foster engagement and empowerment. It is essential that health practitioners are culturally sensitive when relating with Indigenous women and providing health education to enhance autonomy, self-efficacy, self-determination, and subsequently motivate them to use health services and make informed health decisions.

Health insurance/cost, asymptomatic ocular diseases, lack of perceived benefits of eye care services, urbanization, and cultural competency of health care professionals, impact the use of diabetic-eye care services. Many people at increased vision loss risk, are not accessing eye care services (152) due to these factors. The uptake of eye care services affects the ability of eye health professionals to deliver the right eye care and information (153). Thus, careful planning for education that is appropriate is the key to the success of the promotion of any health behavior (129). Technology-based behavioral interventions such as via mobile phones have shown great potential in assisting with diabetes prevention and management (46).

## 2.5 Mobile Phones and mHealth Platforms

In 2013, mobile phone penetration was estimated at 96% globally and 128% in developed countries (154). 'Basic phones' have voice telephony and SMS as their main functions while 'feature phones' have additional features including, Multimedia Messaging Service (MMS) functionality which may include a camera and MP3 music player, some internet access, and may be able to run some applications (75). Mobile phones are becoming more technically sophisticated and have evolved across the years, becoming 'smarter', however the basic features of a phone which include text and calls are still present. Hence, the new generation 'smartphones' have all the above features, along with the ability to access Wi-Fi and better internet connectivity functions.

Various mHealth platforms are available via mobile phones, including SMS (Short message service), USSD (Unstructured Supplementary Service Data), IVR (Interactive Voice Response), Web link, and APP (application). Of all the mHealth platforms, SMS platform is the most accessible irrespective of the type of phone. SMS transmits messages between phones and as the name implies, SMS provides information in a limited form with each message less than 160 characters in length, to fit into the required message length (155).

Text messaging is a targeted and cost-effective method (156) since it is relatively inexpensive to deliver messages to a large number of mobile phone users, notwithstanding how 'smart' the phone. Therefore, SMS platform is often utilized for mHealth interventions in consideration of the varying socioeconomic status found in populations to ensure that the information is equally accessible irrespective of the ability to own and maintain internet services in a more expensive "smart-phone."

## 2.5.1 Health Education and Behavior change via mHealth

mHealth has proven to be a well-received and useful medium for delivering health education to patients (157) in addition to delivering information in a culturally acceptable and traditional way (158). Since people experience digital interventions differently due to culture and demographics (159), text messages can be customized to the preferred needs of the recipients (160). mHealth educational interventions assist users overcome the barriers of access to health care by tailoring disseminated information to address the special interests and needs of diverse populations in order to change behavior (161).

With more than 90% of individuals worldwide using mobile phones (154), mHealth interventions can reach numerous populations to promote health care and encourage behavioral change. Literature shows that mHealth interventions are used in different populations for a range of public health priorities and behavior change objectives by providing information in an individualized and engaging manner (162).

SMS-based interventions can aid in changing health behaviors through automated text messages (163) and encourage the utilization of health care services (164). mHealth text messaging interventions are used to improve health literacy, provide greater access to health service, support self-management of general health conditions, and enhance communication with health practitioners (165). Also, tailored text messaging reminders have also been used to trigger physical activity and weight loss (166).

As smartphone ownership increases, the number of people going online to get health information has similarly increased and mobile technology is increasingly popular for health education and awareness creation particularly among the younger population (167) in Indigenous communities. Therefore, mHealth platforms may provide an innovative and novel approach in improving access to services, screening, and management of DR in Indigenous populations.

## 2.5.2 mHealth for DR management in Indigenous Peoples

The Romanow Report in 2002 from the Royal Commission Committee on the Future of Health Care in Canada recommended improved access to health care for marginalized populations, especially those in rural and remote areas. The report further suggested the utilization of the internet and information technologies that might support administrative needs and medical information technologies, such as telehealth (168). Internationally and across Canada, numerous government programs are using mHealth services to assist in health care delivery in Indigenous communities (169) and to bridge the gap in primary care and health care access to secondary and tertiary care services (optometry and ophthalmology services).

Teleophthalmology (telehealth) for DR removes geographical distance as a barrier to receiving health care. Telehealth is used to connect health service providers with patients in rural, remote, northern, and Indigenous communities, for health advice, exchange of health information, access to health care services, and delivery of DR screening (17). Telehealth screening for DR has lowered the barriers to screening and created opportunities for eye assessment for persons with diabetes who typically would not have been able to access DR screening facilities (170). Also, telehealth can increase support while providing diabetes education (171). Therefore, mHealth initiatives are being used in Indigenous communities in various capacities in Canada.

## 2.5.3 Developing/Designing mHealth education for Indigenous Peoples

Telehealth use with Indigenous populations produces mixed results. Though telehealth improves access to health care, some Indigenous people are skeptical about the cultural appropriateness and the privacy of telehealth services (172). Unlike telehealth, mHealth is a relatively new platform for the delivery of health care interventions in Indigenous populations.

The "Framework for the Rational Analysis of Mobile Education (FRAME) model" by Koole (2009) shows learning as an interplay of the mobile device/technology and social and

personal aspects of learning, including, learning ability and social interaction (74, p25). Also, to enhance ease of mobile technology adoption, particularly for health education, the model shows how adapting technology to the inherent strengths of the culture, such as oral tradition can increase empowerment and self-determination in the community.

Thus, meaningful user involvement is necessary for mHealth design. Furthermore, mHealth messaging service that is explicit, practical, positive, non-fear inducing and non-oppressive, acknowledges cultural and traditional practices, the social determinants of health, and the diversity of cultures within a population will impact the success/ effectiveness of a mHealth intervention. This will also enhance cultural safety and usability, capability, opportunity, and motivation for behavior change in Indigenous populations (173). For instance, the Dream-Global project, which developed culturally safe text messages (SMS) for hypertension management in Indigenous populations noted the importance of messages that adapt to local socioeconomic and geographic conditions (173). The adaptation was done by providing practical suggestions/messages based on the availability of resources in the community.

Procuring information from the target intervention users is essential for concept creation, designing, and implementing mHealth interventions (174). In Indigenous communities, it is necessary to consider the development, adoption, implementation, and sustainability of mHealth interventions while paying particular attention to community engagement, respect, and equity across all three considerations (174). Thus, consultation with community members will highlight community needs and ensure that the mHealth initiative is relevant and appropriate.

In the FRAME model, active learning via mobile devices occurs through the integration between the device, the learner, and the social aspects of the mLearning process (175). Therefore, in designing mHealth interventions, it is important to take into consideration the technological characteristics of the devices owned by the Indigenous population, cognitive abilities, social interaction, and motivation of the population (76).

# 2.5.4 Challenges in designing and implementing mHealth intervention in Indigenous communities

Cost can be a limiting factor for mHealth intervention uptake. Affordability is relative because what one person regards as affordable expenditure on mobile device services may be different from another person (75). Also, mobile service cost may be expensive among some individuals

due to limited finances; hence they manage mobile cost by choosing pre-paid options over monthly plans, sharing devices with family members, and other cost management strategies (176). Mobile service cost will subsequently impact the success of mHealth interventions in Indigenous communities since only persons able to afford mobile phone services would benefit from the intervention. Nevertheless, sharing mobile devices raises another issue of privacy because mHealth is often personalized and targeted to a specific individual which in some situations may be addressing a sensitive health condition. Sharing phones reduces the privacy of mHealth interventions and may introduce harm to the intended user.

Although Canada is not in the frontline of innovative development and implementation of mobile initiatives in support of Indigenous education (177), mobile technologies create opportunities for societal changes and can improve health and education services. People will adopt technology if the technology plays to the strengths of their culture and if the technology evokes a high degree of motivation, easily accessible, and easy to use (178).

# 2.6 Summary of Chapter Two

Several risk factors affect DR knowledge and eye care behavior and increase the risk of DR complications including, the age of diabetes onset, gender, income, and education. Although social determinants of health influence the health status of all Canadians, their impacts are more prominent in Indigenous peoples and related to historical experiences. Diabetic-eye services use is affected by health insurance/cost, asymptomatic ocular diseases, lack of perceived benefits of eye care services and cultural competency of health care professionals. Involving users of a mHealth intervention in the design is important Although the cost of mobile services may be a limitation of mHealth use, mobile technologies can enhance health services. Taking into consideration the factors affecting diabetes and DR care, this study sought to identify factors that influence the use of preventive diabetes-eye services and explored the use of text messages to encourage Indigenous women to prevent, manage, and improve their diabetic-eye health.

The next chapter discusses the study design and methods. The study phases, the process of data collection, and analysis are also discussed.

#### **CHAPTER 3**

#### 3 METHODS

## 3.1 Overview

This chapter provides an overview of the use of mixed methods in the study and the philosophical underpinning of the study. It also describes the study design, the theory, and framework that guides the study, along with the study population, and inclusion criteria for the selection of participants. In this chapter, the methods, measures, intervention, data collection phases and procedure are discussed; as well as, the data analysis procedure. Portions of the content development section in this chapter have been formerly published in a conference proceedings (179)<sup>iv</sup>

# 3.2 Justification of using Mixed Methods

This study had several research questions which were best answered via different methods. Hence, a mixed methods design was used in this study.

Mixed methods is a research approach in the social, behavioral, and health sciences wherein the researcher obtains both quantitative and qualitative data, integrates the two, and draws interpretations from both the qualitative and quantitative data to understand a phenomena or research problems (180). The mixed methods approach also promotes the combination of methods so as to foster engaging in the research process and enable examining questions through different lenses (181).

Indigenous research supports the use of different methods to tell a story and share knowledge via numerous forms such as stories, visual symbols or metaphors, song, and dance (182). Mixed methods approach equally supports the use of words and pictures to enhance the interpretation of figures and numbers (183). In addition the mixed method approach utilizes more than one method to study the same phenomenon, to complement study findings by obtaining a clearer understanding of the research problem, and to create and expand studies (183).

iv Development of text messages for mobile health education to promote diabetic retinopathy awareness and eye care behavior among Indigenous women. In H. Chen, Q. Fang, D. Zeng, & J. Wu (Eds.), Smart Health (pp. 107–118). Cham: Springer International Publishing (179). All excerpts from the published article that are used in this thesis were written by Valerie Umaefulam and Kalyani Premkumar. Valerie Umaefulam and Kalyani Premkumar are the copyright holders of all of the excerpts.

Health experiences are connected to social relations and cultural influences. Social support and cultural influences are not easily measured via quantitative approaches because their meaning varies across different cultural contexts, showing the importance of combining both quantitative and qualitative research strategies (184). The mixed methods design approach in this study is suitable since diabetes care needs various methods. In addition, mHealth utilizes various approaches and platforms to address the management of health conditions (185).

# 3.3 Philosophical underpinnings

Mixed methods typically use both quantitative and qualitative research approaches in a single study with both approaches having different beliefs and assumptions that guide approaches to research. All researchers bring their understanding of the world and assumptions about what information needs to be collected for the study of a phenomenon (180). Thus, the values and beliefs of the researcher shaped the orientation to research and collection of data as described in the preface.

The research was inductive, and this defined the combination of core and supplemental components of the methods (186) with quantitative methods having a secondary role while the emphasis was on understanding people's views based on their own experiences. Furthermore, the qualitative-driven approach aligned with the researcher's social constructionist epistemology that sees knowledge as that which generally "originates from interactions among people in a community" (187). Knowledge may change when individuals become more informed due to social interactions, which may affect their learning approach, decisions, and what they consider essential in respect to their health.

In addition, the medicine wheel, representative of an Indigenous worldview was utilized in this study to collect, organize, and assess data. Many Indigenous worldviews accept that knowledge is not fixed hence, "cannot always be quantified" (188, p23).

## 3.4 Study Design

The study utilized a concurrent embedded mixed methodology design (QUAL-quan) (189). Accordingly, qualitative and quantitative data were collected at the same time. This study was a one-group pretest-posttest quasi-experiment (190) and there was no control group. This design has been used by various studies to assess the impact of interventions including change in knowledge (191), skills (192) as well as the feasibility and short-term outcomes of interventions

(193). Hence, this design was utilized to evaluate the benefits of the study intervention. This design was used because a randomized controlled trial was not a viable method to use (194). Also, randomized controlled trials often require a large number of participants (195) which was not possible to achieve in this study. Furthermore, it was not ethical to restrict the intervention to a selected group of people because this intervention was relevant to the entire population of participants. Also, in public health and Indigenous based research, there are ethical concerns regarding carrying out accountable research that is relevant to the population, particularly among vulnerable populations (84, 196).

The use of the embedded mixed methods design was based on the assertion that different research questions need to be answered by different types of data (190) at the same data collection phase. The design is an interplay between qualitative and quantitative approaches to capture the best of both and provide enriched data. In this study, the two methods were combined for complementary purposes that is by improving one method by the use of another method (197).

Creswell (2003) agrees that researchers can use different worldviews within a study, but researchers should consider the research epistemology concerning the design being applied (198). In this study, the interest was to explore and understand the experiences of participants. Since there is little research on this subject area, the qualitatively driven strategy allowed for the discovery of unexpected issues and exploration of participants perceptions of DR eye care.

Before the intervention, qualitative data was obtained to inform the intervention design and post-intervention to evaluate and understand the intervention outcome. The quantitative method was primarily used to evaluate the intervention. Figure 3.1 shows an outline of the study design.

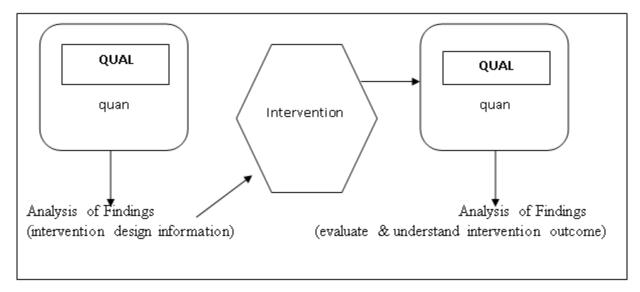


Figure 3.1: Visual representation of the Concurrent Embedded study design

# 3.5 Theoretical perspective

Possible behavior change theories that have been leveraged for mHealth studies in Indigenous populations were explored. The use of theory in studies depended on the research questions, population context, and intent of the change. For instance, a social cognitive theory-based mobile intervention was used to change smoking behavior (199) among young Maori adults. The Stages of Change behavior theory was leveraged to develop a mHealth intervention among Māori and Pacific peoples in New Zealand to reduce alcohol-related harm (200).

Considering the history of research and colonization in Aboriginal communities in Canada, research, programs, and interventions often emphasize promoting self-efficacy and self-determination among Aboriginal peoples (201). This is because self-efficacy affects the motivation to act and is an important factor associated with knowledge acquisition, attitudes, skill development, and behavior (202).

Self-determination refers to the right of Indigenous peoples to be involved and participate in decision-making (203). Self-determination is a distal determinant of Indigenous health which influences the extent to which Indigenous people can take control of their lives (102), as well as manage other health determinants. Thus, self-determination theory was a suitable fit as a guide for this study to carry out research that would support autonomous control over health decisions among Indigenous women in the study. In self-determination theory (SDT), intrinsic motivation, self-efficacy and identity, autonomy and actualization of needs fulfillment are related (204). Self-

efficacy, autonomy, identity, and community support are essential factors in empowering Indigenous peoples (102).

Human behavior theories often fail to explain the factors involved in stimulating attitudes and behavior; so, SDT portrays motivation as "psychological energy directed at a goal" (205, p2). SDT suggests that motivation for behavior can be self-determined and various motivation types such as intrinsic and extrinsic motivation can result in different outcomes. SDT explains behavior and attitude and is a guide to the issues that are important to examine by providing an approach to understand how fulfilling the need for autonomy, competence, and relatedness impacts health behavior.

Autonomy indicates the need to feel responsible and the originator of one's actions rather than carrying out actions that are enforced and controlled. Thus, understanding individuals concerns are important and influence the information or advice provided as well as the approach used to share information, and when the information is provided without judgment, this prompts a supportive autonomy environment for the individual and promotes autonomy in behavior (205). Competence fulfillment involves confidence in the ability to engage in behavior changes, carry out actions, achieve desired outcomes (similar to self-efficacy in social cognitive theory), and the perception that it is possible to make these changes within an individual's social and cultural context (206). Competence also involves identifying barriers that influence behavior (205). Relatedness refers to understanding, relationships, and connection to individuals such as family members, health care practitioners, community members, friends, and other significant others (205). Relatedness support involves empathy for ones' concerns and providing a consistently warm interpersonal environment. Connection and relationships with family and community play an essential role in supporting health and wellness among Indigenous peoples (207). SDT postulates that satisfaction of the three needs in a given context would increase motivation (208) which would in turn, encourage individuals to become proactive and engaged with the management of health conditions.

Various health behaviors benefit from autonomous motivation (209) and autonomous motivation explains a variety of phenomena and health-related behaviors, including the use of health service use as well as uptake of screening services across various age groups and cultures (210). SDT emphasizes the importance of not controlling the decision making of individuals but to provide a safe and supportive environment for individuals to make health decisions. Health-

care professionals can provide information on health conditions and practices but, this information should not try to scare the individual, instead, provide encouraging details that can assist making informed choices (211). For example, focusing on the fear of diabetic eye complications may intimidate individuals without helping them internalize values that promote actual behavior change. It may also introduce a sense of bleakness that may further prevent seeking eye care (206).

In the self-management of type 2 diabetes and its complications via mHealth, the information on diabetes care should support the need for autonomy, competence, and relatedness which may increase confidence in managing and controlling the health condition and can influence decision making. Therefore, behavior is self-determined when it originates autonomously (212).

mHealth technology via reminders and text alerts was used to improve wellness based on self-determination theory (213). Since this study sought to promote self-management of diabetes and subsequently diabetes eye complication via increasing awareness to prompt behavior change. In this study, self-determination theory was used mainly in the development of the mHealth intervention to encourage/promote self-determination and empowerment, respectfully provide support, and enhance confidence to encourage behavior change among Indigenous women. Autonomy, competence, and relatedness, the three explanatory factors of the theory, directed the development of the mHealth text-content, especially the "tone/language" of the mHealth content as well as how to implement the intervention (mobile platform). The intention was for the intervention to help participants feel confident in their ability to manage diabetes and its eye complications.

## 3.6 Framework

Just as it is important to adapt population health interventions to the population context, it is equally important to use frameworks that align with the research population (214). Indigenous peoples have diverse cultural practices, beliefs, customs, languages, and ceremonies. As such, Indigenous peoples have different worldviews to address health and well-being. An example is the First Nations holistic policy and planning model (215). Thus, this study utilized and integrated a medicine wheel (Figure 3.2).

The medicine wheel as described by Mussell (2005) symbolizes an Indigenous worldview (85), representing the interrelatedness and interconnectedness of humanity (216).

There are many ways to use this model in wellness. For this study, the medicine wheel was utilized to address DR from a holistic perspective. It was used to collect, organize, and assess the data taking into consideration the physical, emotional, mental, and spiritual aspects of wellbeing.

Mussell describes the physical aspects of health to include air, water, food, clothing, shelter, exercise, and sex. Emotional aspects of health address recognition, acceptance, understanding, love, privacy, discipline, and limits. Mussell describes mental health to include concepts, ideas, thoughts, habits, and discipline. Finally, spiritual health is described as being connected with other creations of the Great Spirit (85).

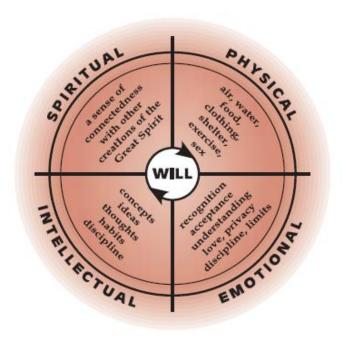


Figure 3.2: A Medicine Wheel

Source: Warrior-Caregivers: Understanding the challenges and healing of First Nations men, Retrieved December 10, 2018, from <a href="http://www.ahf.ca/downloads/healingmenewebrev.pdf">http://www.ahf.ca/downloads/healingmenewebrev.pdf</a>. Copyright 2005 by Aboriginal Healing Foundation (85).

An individual who has the ability to satisfy basic physical and emotional needs and attains mental and spiritual growth will be able to have a more rounded life and health (85). For instance, Aboriginal women living with diabetes may experience stress from coping with diabetes (107) which may similarly influence their ability to manage diabetes and its

complications. Thus, in this study, the focus is not solely on attaining physical health outcomes but also providing emotional, mental, spiritual support so that they are confident, empowered, and are hopeful in the prevention and management of diabetes and DR.

The framing from the medicine wheel in figure 3.2 was used in this study to provide a holistic approach that is congruent with the Indigenous worldview and typically, diabetic-eye care and prevention have not been explored from this perspective. Hence, self-determination theory and the medicine wheel by Mussell informed this research. The theory and framework were integrated into the research method, intervention design, and evaluation of the study to holistically address diabetic-eye care.

## 3.7 Research Location

Saskatoon has a large population of Indigenous peoples who come to the city from rural communities across Saskatchewan as well as First Nations and Métis people who were born and raised in Saskatoon. Aboriginal people comprise about 10% of Saskatoon's population wherein, 53% of Aboriginal people identify as First Nations, 45% as Métis and 2% as from other Aboriginal status (217).

LiveWell Diabetes Aim4Health program Saskatoon and Saskatoon Indian and Métis Friendship Centre (SIMFC) were partners in this study. LiveWell Diabetes-Aim4Health program is a chronic disease management program in Saskatoon that aims to provide holistic programming and "services for diabetes prevention, treatment, and management (218)" to First Nations, Métis, and Immigrant individuals and families living with diabetes or at-risk of diabetes in Saskatoon via an inter-professional team. LiveWell Aim4Health program works collaboratively with various Indigenous communities including White Buffalo Youth Lodge and Whitecap Dakota First Nation. LiveWell Diabetes program provides counseling services, individual and group education, risk assessment, exercise (fitness, food, and fun-FFF program) and food preparation programs (food experience program). LiveWell Diabetes program also provides screening services, as well as the gestational diabetes services through several initiatives (68).

SIMFC is an organization that seeks to improve the well-being of Indigenous peoples in Saskatoon via various programming and information sessions (219). SIMFC programs address various community needs and include sessions such as Independent health assessment process

sessions and networking luncheons with offers an opportunity for community members to know and learn about programs offered by different agencies/organizations in Saskatoon (219)

Before commencing with this study, the program leads at SIMFC and LiveWell Diabetes program were contacted in April 2016 to discuss the research concept and the intervention proposed. Following various conversations on the benefits, challenges, and feasibility of the proposed study, the study protocol was refined, and the two agencies indicated they would collaborate in the study. The researcher got involved with the various programming offered by SIMFC and LiveWell to engage with and build relationships with the community members by participating and volunteering at events and providing presentations at community meetings.

#### 3.8 Research Ethics

The Research Ethics Board of the University of Saskatchewan provided ethical approval and operational approval was procured from Saskatoon Health Region (now called Saskatchewan Health Authority).

#### 3.9 Methods and Outcome measures

#### **3.9.1 Methods**

# 3.9.1.1 Sharing circles

Sharing circles were used to explore perceptions of facilitating and constraining factors influencing diabetes eye care at the pre-intervention phase and at the post-intervention phase to discuss the perceptions of the participants on the mHealth intervention. Sharing circle is a method that is often used among Indigenous peoples because it is grounded in Indigenous cultures (220). Sharing circles offer a way to explore participants' insights and experiences on a topic and foster relationship building.

Feedback from meetings with Indigenous community members, LiveWell coordinators, key informants, and literature informed the use of sharing circles. Researchers have used sharing circle as a method to explore the perceptions and experience of First Nations peoples (221) and to understand the role of Indigenous knowledge and effective practices that support program utilization (222). Also, studies have used sharing circles to evaluate learning programs (223), to determine factors that enable the sustainability of health education programs (224), and to understand cultural, gendered, and historical meanings or experiences of health issues from the perspectives of First Nations women (225).

Both group discussions such as focus groups and sharing circles encourage conversation between persons having similar experiences (226). In mHealth studies, focus groups assist in improving the structure and content of interventions (227), such as the frequency of text messages and appropriate language (228). Sharing circles also provided the opportunity to obtain an insider perspective from Indigenous women involved with the intervention so as to increase cultural sensitivity during the content development for the intervention (229).

The sharing circles followed Indigenous protocols and values such as commencing and closing discussions with a prayer led by an Elder (female) familiar with the population (230) and sharing a meal with participants (188). The sharing circle often begins with a prayer by an Elder who may facilitate smudging, a cleansing ceremony where traditional medicines are burnt to remove undesirable and negative barriers (231) that can be a barrier in good conversation. Participants sit in a circle that signifies oneness and equality, and everyone has an opportunity to speak by going around the circle. The meal shared may occur before or after the sharing circle and the Elder often engages the group in a prayer to conclude the sharing circle (232). The sharing circle differs from focus group in that it seeks to build relationships and provides a respectful and safe space for conversation (233). Also, the researcher or facilitator is a part of the circle and equally shares information with the group.

Elders are crucial in sharing and passing on knowledge about culture; as such, an Elder was consulted in developing the sharing circle guide to ensure it was culturally appropriate. The Elders from SIMFC and LiveWell were met before commencing with the study to discuss the focus and objectives of the sharing circles which included to holistically explore diabetes-eye care. The Elders noted that to make the discussions in the sharing circle meaningful, it was important to limit the questions asked to one or two questions. At the end of the meetings with the Elders, the sharing circle guide and protocol was developed.

The questions asked in the sharing circle were intended to be relaxed, supportive, and free of judgment, and sought to build trust among the participants and the researcher. The Elder remained present for each session to offer support should any difficult or upsetting issues be brought up. The method showed that the researcher respected the culture of the participants so as to enhance response and engagement (181).

The researcher was part of all sharing circle discussions and created, along with the Elder, a welcoming environment that emphasized group trust and confidentiality. All sessions

were recorded with a digital recorder and a note taker observed and took detailed notes of the discussion and observations during the sharing circle sessions. After each sharing circle, the researcher, note taker, and elder discussed the outcomes of the session and a written summary of observations from the session was produced.

## 3.9.1.2 Survey

The researcher explored other research already conducted and surveys used in the field of DR and located available instruments that align with the study's research questions including surveys and interview guides. The study used a self-administered survey adapted from a DR Knowledge, Attitude, and Practice (KAP) survey (234). The instrument covered the major objectives of the study. The validity of the survey was established by assessing and obtaining feedback on the instrument from six experts in the field of diabetes education, eye care, and Indigenous health which included 1 optometrist, 1 Indigenous health researcher, 1 dietician, and 2 diabetes education experts at SIMFC and LiveWell Diabetes, and the research supervisor. The experts assessed the survey to determine if the questions could measure DR knowledge, attitude, and practice of an individual living with diabetes or at risk of diabetes (235). The experts provided feedback on the relevance, clarity, and straightforwardness of the questions (236).

Following changes made based on the experts input, the survey was reviewed and assessed the conceptual equivalence (i.e. "words with different meaning between cultures") (237, p371) with Indigenous community members at SIMFC and LiveWell. The changes made to the survey were minimal and focused on clarifying the questions so that the survey was more understandable. For instance, some changes made were: "Retina is the main part of eyes that gets damaged in diabetes" which was changed to "Retina (at the back of the eye) is the main part of eyes that gets damaged in diabetes" and "Laser treatment of diabetes is painful" was replaced with "Laser treatment of diabetes is painful".

The adapted survey consisted of twenty (20) questions (Appendix D and I). The survey questions measured aspects of knowledge, attitude, and practice regarding retinopathy. This included knowledge of eye complications of diabetes, knowledge of eye treatment in diabetes, attitude towards eye checkups, attitudes concerning the management of DR, practice for periodic eye checks, and treatment of DR.

The same survey was used for the pre and post-intervention stages. The survey was used to obtain DR KAP information in the pre and post-intervention phases. Socio-demographic

information collected included age, the presence or absence of diabetes, education level, Indigenous ancestry, and work status. Other information collected in the pre-intervention survey was blood sugar level and mobile phone number (for delivery of the intervention). Also included was an open-ended question to prompt participants to indicate the type of information they would require regarding diabetes and the eyes. The post-intervention survey was used to determine the knowledge and eye care behavior after the intervention.

The post-intervention survey contained an outline of a medicine wheel. The medicine wheel as described by Mussell (2005) was used as a tool to explore the impact of the mHealth intervention. To foster a participatory evaluation process, participants had an opportunity to evaluate the intervention by noting how the intervention impacted them in each of the four aspects of the medicine wheel (physical, emotional, mental, and spiritual health).

#### 3.9.2 Data Generated

This section provides a summary of the research questions, methods, and data generated.

Research questions one and two: the first objective of this study was to determine the factors that influence diabetic eye care practices and the second objective was to determine the resources and information Indigenous women perceive as necessary for utilizing eye care services. The first sharing circle guide was used to explore participant's diabetes experiences, as it related to their eyes and the diabetic eye-related information participants wanted to know.

Research question three: to explore the knowledge of DR as a complication of diabetes among Indigenous women and their DR eye care behavior. This was measured by the pre-intervention DR KAP survey.

Research question four: to determine the extent the mHealth intervention had changed DR awareness and self-reported eye care behavior among Indigenous women. The outcome was measured by the responses to the post-intervention KAP survey. The comparison of the pre and post-intervention KAP scores was the indicator of this measure.

Research question five: the final objective of this study was to explore the perception of participants on mHealth as a tool for receiving health information. The objective was explored through the second sharing circle discussion with participants. The second sharing circle guide explored participant's thoughts on their experience in receiving diabetic eye related messages via text messages and perceptions of receiving health information via mobile phones.

Summary of the research questions, methods, and data generated is outlined in Table 3.1.

Table 3.1: Summary of Research Questions, Methods, and Data Produced

Number	Research Questions	Methods	Data Produced
1	What factors influence diabetic eye care use among Indigenous women?	Sharing circle 1	Stories from participants on facilitating and limiting factors influencing diabetic eye care service use.
2	What resources and information do Indigenous women perceive as necessary for utilizing eye care services?	Sharing circle 1	Comments from participants on diabetes-eye related information needed.
3	How knowledgeable are Indigenous women of DR as a complication of diabetes and what is their behavior towards DR eye care?	Pre- Intervention questionnaire	KAP scores on: Knowledge of eye complications of diabetes, knowledge of eye treatment in diabetes, attitude towards eye checkup, attitudes concerning the management of DR, practice for periodic eye checks and, practice for treatment of DR.
4	To what extent do mHealth education intervention change DR awareness and self-reported eye care behavior among Indigenous women?	Post- Intervention survey	<ul> <li>KAP scores on:</li> <li>Knowledge of eye complications of diabetes, knowledge of eye treatment in diabetes, attitude towards eye checkup, attitudes concerning the management of DR, practice for periodic eye checks and, practice for treatment of DR:</li> <li>Pre and post-intervention scores were compared for change in KAP.</li> <li>Comments/feedbacks from the medicine wheel images and text were explored to assess impact of messages on physical, emotional, mental, and spiritual health.</li> </ul>
5	How do Indigenous women perceive mHealth as a tool for receiving health information?	Sharing circle 2	Feedback from participants on: - Receiving diabetic eye related messages via text messages Receiving health information via mobile phones.

# 3.10 Research Team and Roles

The team involved with this study are the researchers, the research advisory committee members, and the community members from SIMFC and LiveWell. The researchers comprise the student (primary researcher) and the research supervisor. The research team were involved in the study in different capacities. Table 3.2 outlines the different roles of the research team.

Table 3.2: Roles of Research Team

	Role	
Primary Researcher (Student)	<ul> <li>a. Developed the research questions and research protocol.</li> <li>b. Connected with community partners</li> <li>c. Responsible for mobile content development, data collection, analysis, and interpretation; and manuscript/report preparation.</li> </ul>	
Research Supervisor	<ul><li>a. Oversaw the entire research process.</li><li>b. Worked with the student during participant recruitment and data collection.</li><li>c. Reviewed themes in data analysis.</li></ul>	
Research Advisory Committee Members	<ul><li>a. Provided input in the study protocol and documents.</li><li>b. Reviewed themes in data analysis.</li></ul>	
Community Members	<ul> <li>a. Assisted with the study protocol</li> <li>b. Assisted with participant recruitment</li> <li>c. Reviewed the research instruments</li> <li>d. Assisted with the content development</li> <li>e. Reviewed themes and interpretation of data analysis.</li> </ul>	

## 3.11 Participants & Sample Size

# 3.11.1 Participants

The study participants comprised of First Nations and Métis adult women (>18 years of age) with diabetes or at-risk of diabetes. Purposive sampling was used to select study participants; therefore, all women that expressed interest (238) were included in the study. The sampling method was appropriate for this study, to identify individuals who possessed information essential for the study and this method is often used in mixed-method research (239). Also, the participant selection method ensured that rapport and trust existed, which was important so that potential participants felt comfortable to share their insights and experiences (240, 241).

Eligible participants were recruited via posters (Appendix A) placed at community venues and LiveWell program sites such as the Saskatoon Foodbank and Learning Centre, White Buffalo Youth Lodge, Westside Community Clinic, SIMFC, Aboriginal Student Center (ASC), West Winds Primary Health Centre, and LiveWell Diabetes, AIM4Health office in Saskatoon.

Participants responding to posters called LiveWell or SIMFC whereby they were connected to the primary researcher and research supervisor who provided further information about the study. Those who indicated interest signed the consent form (Appendix B).

The inclusion criteria are summarized below:

- (a) Adults (Age > = 18 years)
- (b) Female
- (c) Self-identified Indigenous ancestry (First Nations and Métis)
- (d) Living with diabetes or at risk of diabetes
- (e) Have a mobile phone to receive SMS messaging
- (f) Physically able to access SMS messaging on their phone

Participants "at risk of diabetes" pertains to women with pre-diabetes, and family history of gestational diabetes, type 1 or 2 diabetes. Participants living with diabetes included type 1 and type 2 diabetes. Diabetes was determined based on self-reported diagnosed status.

#### 3.11.2 Sample Size

Since the study was a non-randomised pre-post-study, and a formal sample size calculation was carried out. The sample size for the quantitative study was calculated based on the McNemar test which is ideal for testing the difference in "before and after" study designs (242). This study assumed that there would be a 25% positive change and 5% negative change in knowledge,

attitude, and practice of DR from pre to post-intervention at 80% power and type 1 error  $\alpha$  of 5%. Thus, the study required a minimum of 57 participants. Assuming 35% of participants were lost to follow up as seen in Pfammatter et al. (2016) (243), the intended number of participants for this study was 77 women with 50% of the total participants (28-38 women) partaking in the sharing circle and each sharing circle having not more than 8 participants. The sample size and number of participants per sharing circle were informed by similar mHealth studies using focus groups to develop content (text messages) and for formative research to modify mHealth interventions (244, 241, 245) where participants often ranged from 15–35 participants with six to eight participants per group to encourage relationship building and engagement (246). Also, Burner et al. (2014) carried out focus group discussions with 50% of persons with diabetes who had completed a text-based mHealth intervention (247).

A total of 78 participants volunteered to be part of the study. All participants provided informed consent and the researcher was present in the community at various programs to answer participant's questions about the study. Participants were provided with information about the study process, its objectives, and contact information for further questions. Figure 3.3 illustrates the number of participants during data collection via the sharing circles and survey.

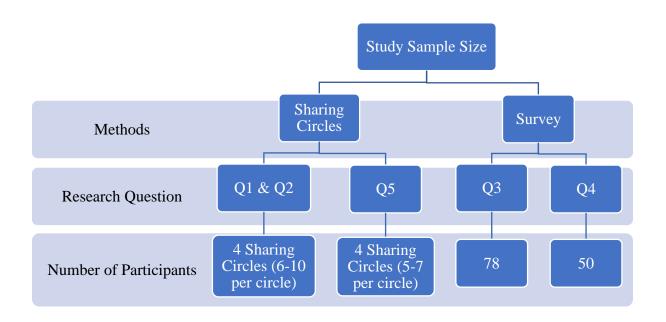


Figure 3. 3: Number of Participants during data collection

## 3.12 Intervention

The intervention involved the dissemination of diabetes-eye related text messages to participants for 12 weeks directly via mobile phone (SMS). A 12-week intervention often ensures participant retention and sufficient to provide awareness (248), enhances uptake of screening (249), and has the potential to be effective on attitude and behavior changes (250). In addition, the researcher anticipated that by sending one daily essential information would improve message effectiveness while preventing information overload (251).

## 3.13 Data Collection Procedure

The study data was collected in five stages as illustrated in Figure 3.3.

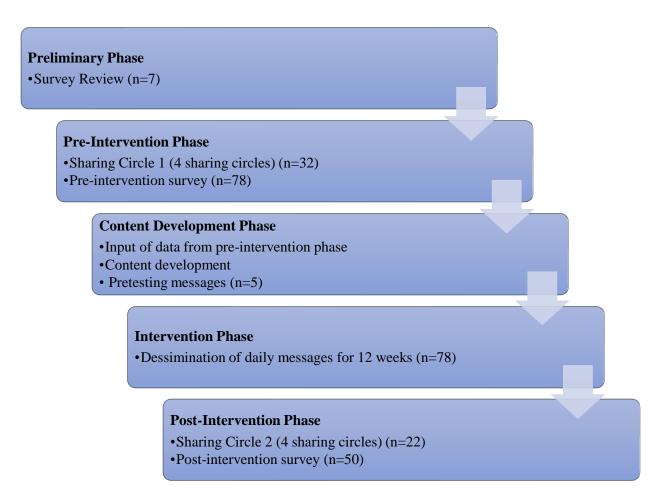


Figure 3.4: Flow Chart of Data Collection Process

## **3.13.1 Preliminary Phase**

The KAP survey developed following input from experts was pre-tested with a sample of the intended population (7 participants) who were living with or at risk of diabetes. The seven participants were not included in the study. During this phase the researcher took note of the time taken to complete the survey and any difficulties when completing the survey. Feedback provided on the first draft of the survey by the seven participants included; adding the five possible responses to the questions (fully agree - fully disagree) to each page of the survey for ease when filling out the survey. Based on feedback, alterations were made, before producing the final survey.

#### 3.13.2 Pre-Intervention Phase

All seventy-eight (78) participants completed the pre-intervention survey. All participants were encouraged to participate in the sharing circle. Ultimately, thirty-two (32) participants took part in the pre-intervention sharing circles.

In this phase, via sharing circles, perceptions of participants on DR were explored and participants had the opportunity to indicate the type of eye health information they would like to know, especially as it related to diabetes and the eyes so that it could be included in the text messages. Data was collected via four (4) sharing circles which occurred at four different locations wherein participants were recruited and occurred immediately after the community programming of the day. The locations were centres used by LiveWell and SIMFC, for example, White Buffalo Youth Lodge. The number of participants in the sharing circles depended on participant availability and ranged from 6 to 10 participants per circle.

Although there are some similarities across Indigenous cultures, each culture has unique languages, cultural practices, and protocols. Some Indigenous peoples do not practice traditional ways, and some practice other faiths and healing practices (252). As such, the Elder in the first three (3) sharing circles did not lead prayers; however, the circle at SIMFC began and ended with a prayer led by the Elder.

The session started by providing a brief introduction to the study, reiterating the goals and sharing circle process, and explaining the use of the recording device. Questions were asked following the guide (Appendix C). Also, the researcher provided brief background information of herself and reasons behind carrying out the study and was careful to prevent tainting the research process by not giving leading information related to the question asked in the sharing

circle. For each sharing circle, participants sat in chairs placed in a circle and going around the circle systematically gave every participant, the opportunity to speak or they could choose not to speak when it was their turn.

The researcher opened discussions by presenting the first question to the group, "What is your diabetes story?" followed by a second question, "What information would you like to know about diabetes and the eyes?" Probes (follow-up questions) were also strategies used, where necessary, to have an explicit explanation of the participant's experiences.

On completion, the researcher thanked participants for their contribution and asked if they had any additional comments that they wished to make. When there were no further comments, the sharing circle ended with a request to complete the pre-intervention survey (Appendix D) and socializing over a meal which also served as check-in with participants. Approximately 60-90 minutes was allocated to each session and the sharing circles lasted about 45 minutes each, which included participant sign in, brief social time with participants in the group, the sharing circle, completion of the pre-intervention survey, and wrap up. The data from the sharing circles, and field notes were reviewed consistently to ensure that data saturation was reached.

Data was collected for three consecutive weeks in November 2017. Other participants who could not attend the sharing circle completed the pre-intervention survey at SIMFC, ASC, and LiveWell program locations; hence, the survey was administered to all 78 participants in this phase.

## 3.13.3 Content Development Phase

In alignment with self-determination theory, messages were worded in a way to increase confidence, encourage, and motivate participants to make informed health decisions. Also, in line with the values of the medicine wheel as described by Mussell (2005), messages addressed aspects of physical, emotional, mental, and spiritual health.

<sup>&</sup>lt;sup>v</sup> Portions of this section have been previously published in the following conference proceedings: Development of text messages for mobile health education to promote diabetic retinopathy awareness and eye care behavior among Indigenous women. In H. Chen, Q. Fang, D. Zeng, & J. Wu (Eds.), Smart Health (pp. 107–118). Cham: Springer International Publishing (179). Found in Appendix O.

Health care organizations addressing diabetes health care among Indigenous peoples in Saskatoon and the research partners were involved in developing the content for the mHealth intervention. A multidisciplinary team of researchers, Indigenous peoples, information, communication and technology professionals; academics, health care workers and program coordinators (hereafter referred to as *team*), were involved in the development of the mHealth diabetes-eye content. The content development team consisted of a regional community health promotion manager, Indigenous community programming coordinator, diabetes control manager, health educator, and optometrists from the Canadian Diabetes Association (CDA), LiveWell Diabetes-Aim4Health program, Saskatoon Indian and Métis Friendship Center, and Saskatchewan Association of Optometrists (SAO). The team also consisted of researchers who equally had experience in the use of technology for health care.

Additionally, users are often involved in the co-development of a mHealth intervention to incorporate their values and perceptions and produce the appropriate content (253, 254). Hence, five participants were also involved in message development. Table 3.3 shows the multidisciplinary team involved in content development.

Table 3.3: Multidisciplinary Team involved in Content Development

Multidisciplinary Team	n
Dieticians	2
Diabetes experts	2
Optometrists	2
Indigenous Community Members	3
Peer leaders from the community groups	2
Indigenous Elders	2
Researchers	2
Participants	5
Total	20

The content was developed in four major phases: "content selection, participant input, review and refining of messages, and pre-testing with a sample of the participants" (179, p111).

#### 3.13.3.1 Content Selection

Content review of diabetes and eye health educational materials was carried out as well as guidelines from Optometry and Diabetes organizations in Canada via an online search of diabetes-eye educational material from 2010-2017 to capture the most recent information. The websites of Canadian Association of Optometrists, WHO, National Eye Institute, and clinical guidelines from CDA were accessed. Also, searches in diabetes organizations and health support services such as the Canadian National Institute for the Blind (CNIB) and LiveWell Diabetes-Aim4Health program and Saskatchewan Association of Optometrists (SAO) were conducted. Search terms such as "Diabetic Retinopathy" and "patient education" were used in various combinations of the keywords. All diabetes-eye related text content that was identified were included and adapted to text messaging format and when no new content was found, the search was concluded.

Materials not related to diabetic-eye care and duplicate materials were deleted. Also, content such as pictures, graphics, and treatment complexity were not included since they could not be used as text messages and would not be received by all phone types (255).

## 3.13.3.2 *User Input*

Formative research is essential in the development of mHealth intervention content, and this can occur before and during the development of the intervention to understand the needs, expectations, technology capabilities of participants phones, and abilities of participants, so as to ensure that the intervention is user-centered (256). Thus, the information obtained from the preintervention phase served as a form of formative research. The information participants requested that could motivate them to utilize eyecare services was collated from the sharing circle discussions and included in the messages. The first draft of the text messages was developed and consisted of a library of 115 messages modified to meet the 160-character count limit of SMS (Appendix E). The messages incorporated content relevant to general eye care, diabetes care, and focused specifically on DR, diabetic-eye care screening, management, and treatments. Figure 3.4 shows a flowchart of the process of message selection.

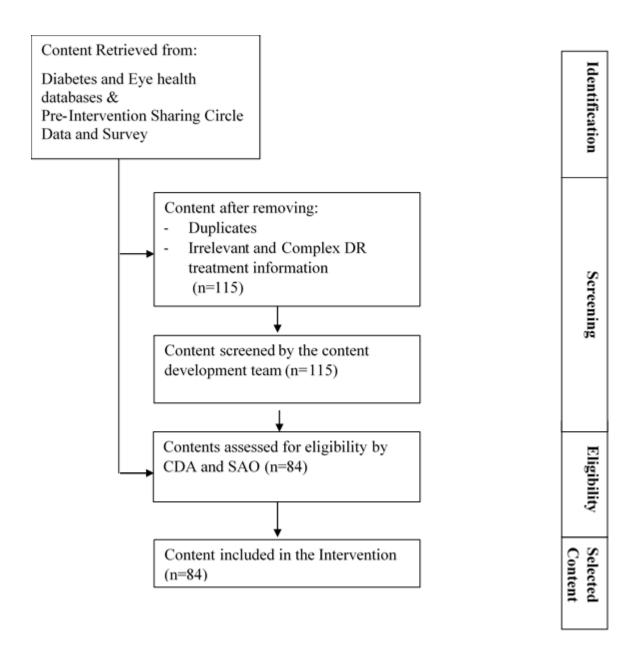


Figure 3. 5: Content Search and Selection Process

## 3.13.3.3 Review and Refining of Messages

Since it is essential that experts and users are engaged in refining, developing, and pre-testing mHealth content (257), the first draft of the library of messages was examined by the content development team. The researcher met with team members where they reviewed each message and shared feedback on their understanding of each message, as well as the appropriateness of the messages. The researcher asked questions to clarify different aspects of the feedback provided. The team provided input that the language needed to be formal, friendly, and simple for ease of understanding.

The researcher modified the content based on the feedback and recommendations and ensured that the mHealth intervention was ideal for women with varying levels of health literacy and mHealth literacy. The literacy level of information included was suitable for women with basic English literacy skills (258). The content was written in plain language. To accommodate participants with literacy limitations, each sentence expressed one thought, used simplified sentence structure, and explained uncommon words and medical jargon. Messages were tailored and personalized to participants' needs as closely as possible and based on recommendations from the survey and sharing circles to increase interest in the intervention (259). CDA and SAO reviewed the final set of messages. Table 3.4 shows a sample of changes made to the messages.

Table 3. 4: Changes made to text messages

Original Message	Changed Message
"Hello. Health Tip: Remember to add	"Hello. Health Tip: Remember to add
physical activity to your day so as to improve	physical activity to your long weekend
circulation and your general health"	activities so as to improve circulation and
	your general health"
"Did you Know: Common sight threatening	"Did you Know: An eye exam is the best way
eye problems often have no warning signs.	to find eye problems in the early stages. You
An eye exam is the only way to detect these	can't always tell when your eyes are getting
conditions in their early stages"	sick".
"Did you Know: Poor blood sugar control can	"Did you Know: Unhealthy blood sugars can
cause changes in the way you see far and near	cause changes in the way you see far and
objects and the ability to focus on close	near objects and the ability to focus on close
objects when reading"	objects when reading"

Content on diabetes-eye care, information on diabetes, and prevention and management were included. Messages were "activity-based by not solely focusing on providing educational content" (179, p114) but by incorporating messages that motivate participants to act with the aim to prompt behavior change rather than only offering information.

Since connecting and providing information on available health services and programs may enhance the uptake and engagement with mHealth services, the message content consisted

of information on diabetes services available in Saskatoon as well as how to assess eye care services, book appointments with optometrists, and regulations for eye care.

## **3.13.3.3.1 Type of Messages**

The messages consisted of the following: "informational/educational, reminder, and motivational/ support messages" (179, p114). Information/educational texts provided general information about diabetes, eye care, DR, risk factors associated with DR, management, eye-examination information, and self-care. In the context of SDT, the information text addressed the need for autonomy by providing messages that could increase their knowledge of diabetes and DR so as to prompt making informed health decisions. Reminder messages provided information that was "cues and prompts for recipients to take action, seek eye care, and to self-monitor diet and blood sugar levels" (179, p114), such as adding green vegetables in their diet and visiting an eye doctor. The messages facilitated the need for competence. Motivational/supporting texts shared information that may prompt engaging in activities that will enable participants to manage or prevent diabetes-eye conditions such as engaging in activities with friends and family. In regard to SDT, this support messages addressed the need for relationships and connections. Table 3.5 shows a sample of the types of messages.

Table 3. 5: Types of Text Messages

Message Type	Sample
Information Text	"Did you Know: Poor blood sugar control
	can cause changes in the way you see far and
	near objects and the ability to focus on close
	objects when reading".
Reminder Text	"Hello. Health Tip: When was the last time
	you had an eye exam? If more than 1 year
	ago, and you are living with diabetes, you are
	due for an eye checkup".
Motivational/supporting Text	"Health Tip: Your daily habits and lifestyle
	such as exercising could seriously help your
	eyes without you knowing it. Keep up the
	good work".

The researcher was responsible for shortening the messages to ≤160 characters while preserving their meaning. A flexible approach was utilized such that, the content was tweaked based on conditions at the period of delivery. For example, during a weekend with a public holiday, the message at the end of the week was changed to reflect the "long-weekend." The researcher designed a messaging sequence so that every week, messages provided information relating to general eye care, information targeting those with diabetes, at risk of diabetes, action-based, and connecting with health/community services.

## 3.13.3.4 Pre-Testing of Messages

The researcher distributed the text messages with five recipients for three days to ensure that the messages could be delivered to recipients using different mobile networks. They provided feedback on experiences related to the timing of receipt of messages, non-receipt of messages, and the format of the messages. After the pre-testing period, minor modifications were done before large-scale implementation in the main study. The researcher produced the final 84 messages for the intervention. A sample of the messages are in Appendix F. Figure 3.4 shows an outline of the content development process.

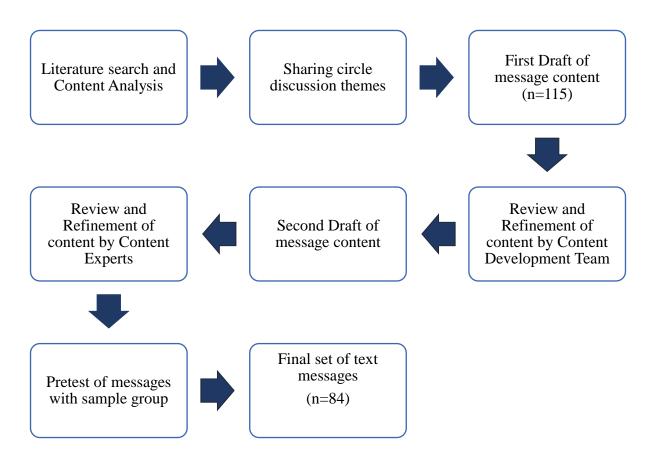


Figure 3.6: Process of developing and refining text message content.

Adapted from: Development of text messages for mobile health education to promote diabetic retinopathy awareness and eye care behavior among Indigenous women. In H. Chen, Q. Fang, D. Zeng, & J. Wu (Eds.), Smart Health (pp. 107–118). Cham: Springer International Publishing (179).

## **3.13.4 Intervention Implementation Phase**

The researcher considered the ability to track message delivery, the cost associated with disseminating messages, the messaging platform ease of use and its ability to send messages to all types of mobile devices. For this study,  $Telmatik^{\odot}$  was the messaging vendor used to send the messages.  $Telmatik^{\odot}$  is a bulk messaging communication platform that facilitates the distribution of messages via various mobile platforms and provides mobile solutions (260). The researcher entered the message for the day on the message portal daily, and the portal utilized different delivery numbers for the dissemination of messages (Appendix G). All participants received daily text messages (via their mobile phones) for 12 weeks from February 1 until April 25, 2018, between 8.30 am and 9 am daily, as suggested by the participants during the pre-intervention

phase. Participants who equally requested email messages had the messages sent via *Telmatik*<sup>©</sup> platform and the researcher provided hard copies of the messages to participants that requested hard copy printouts of the messages at different community events weekly. A text message delivery log was kept and checked daily to confirm the delivery of messages to participants. The researcher was also present every week at the various community events at the locations where participants were recruited to make sure the messages were delivered and answer any questions.

On February 28, 2018, the text message sent to participants was a reminder to participants that they could withdraw from getting the messages if they so desired. On February 28, 2018, two participants requested that the messages be stopped due to receiving too many messages. On March 02, 2018, a participant called the research supervisor asking that the messages be discontinued due to confusion and misinterpretation of the message source. She nevertheless indicated that she would be willing to join in the sharing circle at the end of the study to share her experience. On March 16<sup>th</sup> and 22<sup>nd</sup>, two participants requested to stop receiving the text messages, one indicating there were too many messages. The other participant stated that she knew the information and sees her ophthalmologist regularly. All five (5) participants that opted out of receiving the messages expressed interest in being part of the post-intervention survey and sharing circle.

#### 3.13.5 Post-Intervention Phase

## 3.13.5.1 Follow up and Study retention

The researcher contacted all participants in the study via text messages and phone calls one week before the last day of message delivery and at the end of the intervention to schedule a date for the post-intervention sharing circle and completion of the surveys. Based on the input of participants, dates for data collection were scheduled, and data collection occurred at the locations wherein the participants were recruited and occurred immediately after the LiveWell and SIMFC programs participants attended.

Dropout rates in mHealth interventions are often high and may even be as high as 80% (261), and the same was found in this study. Fifty (50) participants participated in the post-intervention phase. Over the 12-week implementation period, 36% of participants were lost to follow up resulting from participants traveling for vacation during the post-intervention data collection period, not showing up at communicated locations for data collection or non-reachable

participants. Twenty-two (22) participants took part in the post-intervention sharing circle discussions, but all fifty (50) participants completed the post-intervention survey.

## 3.13.5.2 Post-Intervention Data Collection Process

The post-intervention data collection started with sharing circles and was co-facilitated by an Elder familiar with the research and population. The researcher started the session by providing a brief introduction of the study aims, a recap of the intervention, a reiteration of the sharing circle process, and an explanation about the use of the tape recorder. Participants were able to ask questions. Questions were then asked following the guide (Appendix H). For each sharing circle, every participant had a chance to speak or they could choose not to speak when it was their turn.

The researcher opened discussions by presenting the first question to the group, "I would like you to share your story of your experience with receiving diabetes health messages via text messages. As you think of your experience, I would like you to think about what worked and what did not work with the messages you received" followed by a second question, "How do you feel about receiving health information via mobile phones?" Follow-up questions were asked where necessary to have a clear explanation of the participant's experiences.

Four sharing circles and the number of participants in the sharing circles depended on participant availability and ranged from 5 to 7 participants per circle. The sharing circles occurred between April 25 and May 9, 2018, and each session took approximately 45 minutes. Variations in the duration of the sharing circles were predominantly due to participant availability and unique contributions of the participants, with some participants providing detailed contributions and examples of experiences with the mHealth intervention while others provided short responses. The time also included participant sign-in, brief social time with participants in the group, the sharing circle itself, completion of the post-intervention survey, and wrap up. On looking at the data from the sharing circles, data saturation was reached.

On completion of the sharing circle, the researcher thanked participants for their contribution, distributed the post-intervention survey (Appendix I) and requested that participants complete the survey and to write any additional comments they had in the medicine wheel image provided in the survey. The researcher also distributed a brochure that possessed key information on diabetes and eye care along with pictures showing the different stages of DR

eye symptoms (Appendix J). The brochure was to address the request for pictures expressed during the pre-intervention phase which could not be shared via SMS.

Furthermore, when all the participants indicated that they had no further comments, the sharing circle ended with socializing over a meal which also served as check-in with participants. After each sharing circle, a debriefing process followed between the researcher and the Elder to identify common discussions/points revealed by participants. An honorarium was provided to all participants that took part in the study. The Elders were also provided with an honorarium.

#### 3.14 Analysis Overview

Analysis of the core and supplementary component proceeded with the qualitative and quantitative data analyzed separately. Each component was analyzed separately using the appropriate analytic procedure associated with that component (262). Thematic analysis was used for the qualitative data analysis, and the quantitative data was analyzed according to the strategies used, i.e. non-parametric statistics and comparing pre and post-scores. Qualitative analysis was supported by NVivo 11 and quantitative analysis by IBM SPSS statistics version 24.0.

## 3.14.1 Qualitative Analysis Procedure

The researcher did not begin analysis based on the theme/framework but inductively generated themes first and then after explored areas of alignment with the research questions, underlying self-determination theory, and the medicine wheel as described by Mussell (2005). This was done to prevent reducing the data into a pre-existing frame. Hence, not limiting the analysis to solely answering the research questions and theoretical assumptions but making the analysis broad to allow for identification of surprising data.

The audio recorded sharing circle discussions were transcribed by the Social Sciences Research Laboratories (SSRL), a research support unit at the University of Saskatchewan. The transcripts were confirmed by the researcher. The full text from each sharing circle discussion session was transferred to NVivo for data reduction, organization, and coding. The transcribed interviews were subjected to qualitative thematic analysis as described by Nowell et al. (2017) via "data immersion, initial coding, searching for and reviewing of themes/category creation, and refining themes" (263, p4).

#### 3.14.1.1 Phase 1: Data Familiarization

Qualitative data obtained from the transcribed sharing circle discussions came in Microsoft word format and did not require additional formatting. The researcher familiarized herself with the depth and breadth of the content by repeatedly reading the data and searching for recurring words, meanings, and patterns to have an idea about what information was in the data to attain a comprehensive understanding of the data. Thoughts that developed while reading the data were documented and notes were taken on possible codes.

#### 3.14.1.2 Phase 2: Generating Initial Codes

This phase involved reflection on the data, identifying aspects in the data items that were recurring across the data set, and using short phrases that captured the essence of the information. To allow for unexpected emergent codes, analysis started from the study data via an inductive analytical approach. By using an inductive approach, the codes identified were strongly linked to the data without trying to fit the codes into the study's theory and research questions (263). Descriptive coding from the words of participants was used, and data that departed from the major codes were equally included. A codebook was developed as a guide to code the entire information and organize related text (263).

## 3.14.1.3 Phase 3: Searching for Themes

Once the coding was finalized, related patterns of ideas and comments that emerged were identified to find common themes within the responses after which themes were created by comparing and grouping codes according to similarities and differences. The data were organized under themes and subthemes that explained what a series of codes mean. This process involved organizing coded sections of the transcript into themes and continuously comparing the codes in the themes within and across transcripts. Some parts of text were coded various times and organized under different themes where applicable (263).

As indicated by Rothe et al., "the key to the analysis in culturally sensitive qualitative research is to resist ethnocentric views" (264, p338). Thus, some study participants along with Indigenous peer leaders from LiveWell who assist with community programs, and community members at SIMFC were involved in analyzing and interpreting the data. At various meetings scheduled for data review, the researcher presented the initial themes based on the data from the sharing circles and survey for review and to ensure that the themes reflected the comments made.

Major themes that provided an overview of codes were decided and data that departed from the major themes were equally included.

## 3.14.1.4 Phase 4: Reviewing Themes

The coded data for each theme were reviewed, inadequacies in the initial coding amended, and some themes with limited data to support it were combined with others. Themes captured a set of ideas and summarized the data. In mHealth interventions/ studies, according to Michie et al., (2017) it is important to analyze and connect the study's theory to the intervention (265). Thus, the themes were summarized based on the study's research questions and aligned with self-determination theory and the medicine wheel.

The research advisory committee reviewed the themes to ensure the themes aligned with the data as well as expose gaps in the analysis. They also suggested revisions to the final themes and discrepancies were resolved through discussions. The researcher and research supervisor agreed on the final themes and accepted it as being representative of the data. Finally, the preliminary analysis report was written based on suggested themes.

## 3.14.1.5 Phase 5: Refining Themes and Producing the Report

Research meetings were held throughout the analysis process to allow for debriefing and to engage more with the data. Discrepancies were discussed and resolved, and meeting notes were kept keeping track of changes to the themes and interpretations. The final themes were decided on after the themes were scrutinized by the research advisory committee and community members. The themes were refined to explicitly give readers a sense of what the theme means. Direct participant quotes relevant to the themes in the analysis were included to provide context.

## 3.14.2 Quantitative Analysis Procedure

#### **3.14.2.1** *Variables*

Variables were identified from previous related research and literature. Age is an independent variable based on its association with diabetes and its progression. Other factors such as education, Indigenous ancestry, and the presence or risk of diabetes were also included as variables. As such, in this study we included the following variables: age, level of education, work status (i.e., working, not working, student, other), Indigenous ancestry (First Nations, Métis), and the presence of diabetes or at-risk of diabetes.

Age was grouped into categories (e.g., 18 -25, 26 – 45, 46 – 71 years) and level of education was grouped into four categories in order to ensure that there was an adequate sample in each category during analysis (i.e., no formal education, some high school but did not finish and other, completed high school, some college or university but did not finish, and college or university degree). In the work status category, women who identified as working were either in paid employment or self-employed, women who identified as not working were unemployed, and women who were retired or engaged in volunteer services identified as other.

#### 3.14.2.2 Quantitative Analysis Process

The results from the survey were transposed from self-completed paper or Word surveys into an Excel (version 16; Microsoft for Windows) spreadsheet and thereafter to SPSS software for further analysis. Kolmogorov-Smirnov test and Shapiro-Wilk tests were performed to test for normality. The data in this study was not normally distributed hence, the researcher reported median scores and interquartile range and used nonparametric tests. Study analyses were conducted with a 95% confidence interval and a significance level of 0.05 (5%).

Each question in the KAP survey was evaluated as a correct or an incorrect response. If the response of participants to the questions matched with the appropriate response, it was considered as correct. Categorical variables were shown as frequencies and percentages. The observations were evaluated on a percentage basis, and median scores were provided for the total points of knowledge, attitude, and practice.

For research question three (how knowledgeable are Indigenous women of DR as a complication of diabetes and what is their behavior towards DR eye care?), the description of the sample and measures in the study data (descriptive analysis) was carried out and score analysis of participants knowledge, attitude, and practice regarding DR. Kruskal Wallis test was used to analyze if an association existed between KAP and variables (age, Indigenous ancestry, diabetes status, work status, and education level), and pairwise used to test for significance between groups. Generalized linear model was used for the multivariate analysis to determine if variables were associated with the KAP scores when multiple factors interact.

For research question four (to what extent do mHealth education intervention change DR awareness and self-reported eye care behavior among Indigenous women?), descriptive analysis of participants in the post-intervention was carried out. Using Fisher's and Chi-square test, participants that completed and did not complete the study were compared, as well as compared

the KAP for completed and non-completed groups in the baseline (pre-intervention) to have an idea of the participants lost to follow-up. The score analysis of participants' knowledge, attitude, and practice regarding DR in the post-intervention was also determined.

To assess the impact of the intervention, the pre and post-intervention survey data were compared and analyzed via the Wilcoxon test for independent samples to determine the change in the KAP of participants from pre to post-intervention. Generalized linear model analysis of post-score adjusted by pre-score and independent variables was carried out to determine if the KAP is different by the age, work status, education, diabetes status, and Indigenous ancestry when adjusting for the pre-score. Finally, multivariate analysis of the pre-post-change in KAP was done to determine if the KAP difference varied between the different variables' categories.

#### 3.15 Quality Assurance

As indicated by Morse and colleagues (2002), "a research without rigor loses its value" (266). Hence, several strategies were used in this study to increase the quality of the study findings including long-term engagement with participants and member checking. Participants that best represented the research topic were chosen, the research processes were clearly documented, and the decisions made throughout the study were captured in an audit trial.

## 3.16 Summary of Chapter Three

This study is a one-group, pretest-posttest, mixed methods study with a concurrent embedded design. The study was carried out in Saskatoon, and SIMFC and LiveWell- Aim4Health Diabetes program were partners in the research. Participants were First Nations and Métis women with diabetes or at-risk of diabetes. Pre-intervention, seventy-eight (78) women participated while in the post-intervention, fifty (50) women participated. The study involved five stages: preliminary, pre-intervention, content development, implementation, and post-intervention phases. The intervention involved the dissemination of diabetes-eye related text messages for 12 weeks via mobile phone (SMS). The study is framed and guided by the philosophy of the medicine wheel as described by Mussell (2005) and self-determination theory. Data was collected by sharing circles and a diabetic retinopathy KAP survey and underwent thematic and statistical analysis.

The next chapter displays the results from the pre and post-intervention. The results are presented in alignment with the research questions answered.

#### **CHAPTER 4**

#### 4 RESULTS

#### 4.1 Overview

In this chapter, the results are presented based on the pre and post-intervention study stages. This chapter introduces the findings of the pre-intervention separately as both qualitative and quantitative in response to research questions one, two, and three. Thereafter the post-intervention results are presented based on research questions four and five. The results from question four are presented in both quantitative and qualitative format while the findings from question five are shown in qualitative format. Pseudonyms were used in the quotations. Figure 4.1 shows the sequence of the presentation of results and research questions addressed.

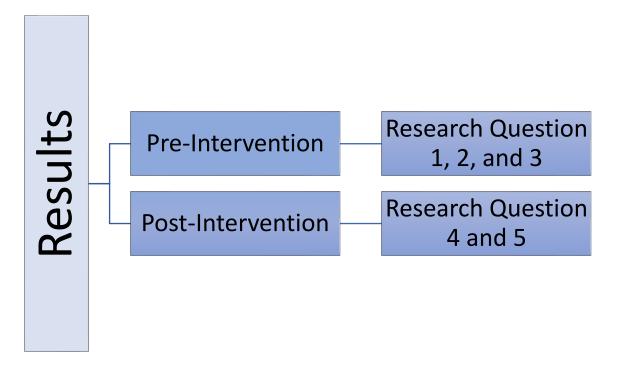


Figure 4.1: Sequence of results presentation

## **4.2** Pre- Intervention Results

Graveline recommends that data collected in sharing circles is best left unedited in order to preserve the content of the discussions by reading between the lines (267). Therefore, unedited texts from the sharing circle discussions in the qualitative results are presented. The quantitative results are presented as tables and descriptive texts.

## **4.2.1** Findings from Research Question One

**Question One:** What factors influence diabetic eye care use among Indigenous women?

Participants responded to research question one during the pre-intervention sharing circle. The themes that emerged from the data highlighted factors that motivated and constrained them from diabetic-eye care. The enabling or limiting factors were presented under three (3) major themes with accompanying sub-themes: awareness and understanding, resolve/intention, and fear. Figure 4.2 shows an outline of the themes and sub-themes.

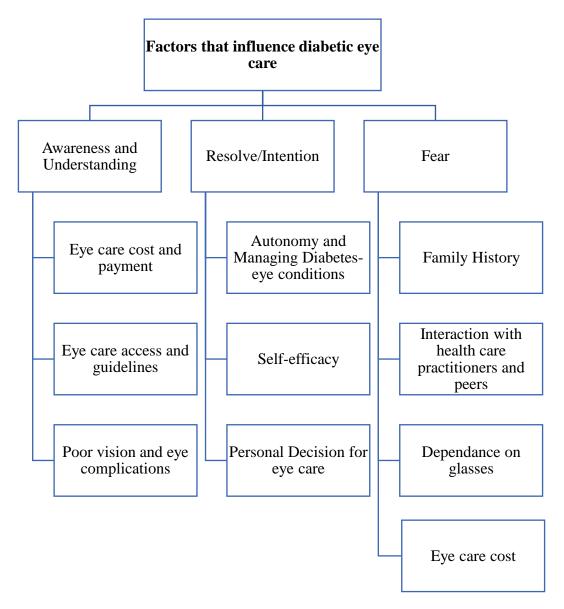


Figure 4.2: Map of Themes and Sub-themes.

#### 4.2.1.1 Awareness and Understanding

Awareness and understanding refer to the baseline of knowledge and information (knowledge base) that motivate/ constrain participants from utilizing eye care services. Awareness and understanding were discussed in various contexts including eye care cost and payment, eye care access and guidelines, and poor vision and eye complications.

## 4.2.1.1.1 Eye care cost and Payment

This theme denotes the knowledge of the costs for eye care in addition to who bears the cost of diabetic eye care. Participants regarded the cost of eye health assessment and the associated financial burden as a constraining factor to utilizing eye care services. A participant stated:

"Well uh I think I would go for eye test but um... but then again you know the resources you need to go and get it checked so unless there's a problem. I won't go."

In addition, knowledge of eye care facilities that would bill to First Nations insurance was a challenge. For instance, a participant indicated:

"Challenge I have is... um depending on the day if the um office is open so they can uh have the billing directed to uh what was it... anyway, instead of billing me um so yeah that's the biggest challenge is finding a place that will actually uh bill uh First Nations insurance."

## 4.2.1.1.2 Eye care access and guidelines

Another topic discussed by the participants was that knowledge and awareness of eye care guidelines influenced utilizing eye care services. Some participants did not know how to make an eye appointment, resulting in another constraining factor in utilizing eye care services. For example, a participant questioned:

"So, do you just have to book an appointment for an optometrist for them to check our eyes?"

Then again, access to eye care services was not challenging to some participants and they utilized eye services regularly and as required. In this regard, a participant noted:

"I don't really have any challenges in accessing eye care."

#### 4.2.1.1.3 Poor Vision and eye complications

Noticing problems or changes in one's vision facilitated seeking eye care services. As reflected in the statement by a participant who mentioned:

"I lost some of my eyesight. I was beading, sewing and then I couldn't see so I went to see an eye doctor and that was like six years ago."

On the other hand, not noticing any problems with eyes/vision made participants assume there was no need for utilizing eye care services thereby deterring them from eye care assessment.

#### 4.2.1.2 Resolve/Intention

Resolve/intention refers to experiences that influence the determination and intent of participants to seek eye care or create barriers to utilizing eye care services. Resolve/intention was discussed under three sub-themes; autonomy and managing diabetes-eye conditions, self-efficacy, and personal decision for eye care.

## 4.2.1.2.1 Autonomy and Managing Diabetes-Eyes conditions

The ability to have autonomy over health and eye care decision making was important for utilizing eye care service. Participants indicated that living with diabetes often prompted and facilitated the necessity to manage diabetes and its complications by attending diabetes programs. In this regard, one participant from the sharing circle noted:

"And this group uh .... at the uh, one of the exercise programs, we have um education and the education I find it to be very, very helpful. I learned a lot about kidneys and... sugar and salt and just on and on and on and it's something that I wouldn't, wouldn't ever have thought of you know to look into... So, I want to come here getting good, you know being good and my sugar is healthy, so I thank God."

Likewise, living with or at risk of diabetes, prompted the regular monitoring of blood sugar levels, and eye check-ups. A participant stated that:

"Every morning I take my blood and I weigh myself every morning first and I take my blood every morning for the past, since May when I had heart failure."

## 4.2.1.2.2 Self-Efficacy

Some participants were aware of the limitations in their vision, wanted to improve their vision, and were confident in their ability to improve their health and vision. Hence, influenced their use of eye care services. A participant noted that despite difficulties in diabetes-eye care, she was able to manage the condition. As stated below:

"I get my eyes checked every year and my optometrist looks for signs of diabetes in my eyes and... uh... I have to go see my doctor for my diabetic checkup. I'm trying to be good,

I'm trying to do that four times a year when you're supposed to go for your check up, but it's hard."

## 4.2.1.2.3 Personal Decision for eye care

Participants also highlighted personal decisions from daily life occurrences that facilitated taking autonomous decision to seek eye care. These included maintaining vision to retain driver's license, driving safely especially at night, and wanting to wear glasses (for fashion/identity). In addition, a participant stated going for eye care because she was worried about driving competence and response.

"I don't know how I'd look at myself if I ever hit a kid because my eyes wouldn't work right."

A participant indicated wanting to take control of diabetes and its complications.

"I just want to be able to, you know, not let diabetes control me but I want to control it you know."

Procrastination to make an eye appointment when it's not urgent, and not noticing any problems with eyes/ vision; hence, assuming there was no need for eye examination deterred participants from using eye care services. In this regard, a participant noted:

"I haven't been checked... maybe I should. I've always had good eye sight but for the past I'd say three, four years um... blurry, getting a lot of blurry visions, running into things, I have to be careful when I put things away at home because then I can't see it to know where I put it so I keep track of that. Yeah, I think I need to go back and see the eye doctor and make sure that there isn't anything wrong."

Likewise, stress present in participants' daily life was mentioned as affecting eye care and a deterrent to diabetic-eye care use. A participant stated:

"I've been going through a lot of stress and I think a lot of stress has to do with the (eye) I think?"

#### 4.2.1.3 Fear

This theme speaks to the anxiety and fear experienced by participants that influence eye care service use. Anxiety originates from different factors and were discussed under the topics of family history, interaction with health care practitioners and peers, dependence on eye glasses, and eye care cost.

## **4.2.1.3.1 Family History**

The anxiety that originated from being aware of family members with diabetes and family members who have experienced diabetes complications including loss of eyesight, amputation, and mortality from diabetes influenced the use of eye care services. For instance, participants stated:

"That's what scares me, the most scariest right there is blindness."

"I don't have diabetes... I do have family members though. And... I know my uncle has had it for over thirty years. He went into a... a coma and then... yeah one day he just went to bed and didn't wake up and that's when he realized he's got diabetes. And that was maybe thirty years ago? And now he's starting to lose his sight."

"A lot of people like both sides of my family have diabetes so and I've seen a lot of um... struggles with their eyes."

Also, the fear that resulted from participants knowing they were at risk of diabetes and experiencing eye problems themselves, motivated the use of eye care services to prevent the development of the condition. A participant reported:

"15 years ago I woke up one day and my eye was very swollen, my right eye. It was just swollen like and I couldn't even open it so I had to go right away to the hospital. They couldn't figure out what was going on... And before that I never had no problems with my eyes and them um, so they took you know they dilated my eye, they checked and they said yeah they see scars all over my eyes."

#### **4.2.1.3.2 Interaction**

This subtheme refers to interaction with health care professionals and peers. Fear of judgement over management of diabetes and eye complications was a barrier particularly when coming from health care professionals. Participants were discouraged from attending appointments so as not to invite judgement from health professionals and they were equally scared of hearing bad news from doctors. This was addressed by a participant who reported an experience with her family doctor and noted:

"Cause she usually is like this (pointing fingers) "your blood is high!, blah blah blah."

Furthermore, communication with peers on wearing glasses daunted the use of eye care services in general.

"I just think that if I've ever worn my glasses when I was little maybe I wouldn't have to wear glasses... Everybody makes fun of little kids when they had glasses, who wore glasses. So of course, you don't wear them or you wear them when nobody is looking. For years and years and years I did that, it got to the point where ah I don't care. Now I gotta wear them all the time... Who cares if they are in style or not."

## 4.2.1.3.3 Dependence on glasses

Anxiety that arose from not wanting to wear glasses. Being dependent on glasses deterred participants from utilizing eye care services. A participant stated:

"I don't want to wear glasses... This, it's... I don't like being... I don't know. I don't want to depend on it."

## **4.2.1.3.4** Eye care cost

Fear of paying for eye care assessment and glasses deterred participants from utilizing eye care services.

"Well uh I think I would go for eye test but um... but then again the you know the resources you need to go and get it checked so unless there's a problem. I won't go."

## 4.2.1.4 Summary of Findings from Research Question One

The study findings showed that awareness and understanding of eye care cost and payment, eye care access/guidelines, and poor vision and eye complications influenced eye care. Participants' resolve/intention to have autonomy and manage diabetes-eye conditions, self-efficacy, and personal decision for eye care, as well as fear that originates from family history, interaction with peers and health care practitioners, dependence on eye glasses, and eye care cost influenced diabetic-eye care.

## 4.2.2 Findings from Research Question Two

**Question Two:** What resources and information do Indigenous women perceive as necessary for utilizing eye care services?

Participants responded to research question two during the pre-intervention sharing circle. Two major themes emerged from the data on the diabetes-eye information participants were interested in which included information on diabetes-eye care and strategy for information dissemination. The first theme was further re-classified into sub-themes.

## 4.2.2.1 Information on Diabetes-Eye Care

This included information on complications, prevention, and management of diabetes and DR.

## **4.2.2.1.1 Complication**

Participants requested information on types of diabetes and its complications, how diabetes progresses, the onset and progression of diabetes eye complications, signs and symptoms of DR, and difference between eye conditions. Examples of questions posed by participants regarding the above included:

```
"And so type 2, that can still be passed down or is that more like type 1?"
```

What is that like...?"

"Do you have any information of symptoms?"

"Is it like glaucoma?"

#### **4.2.2.1.2 Prevention**

Participants also wanted to know about risk factors of diabetes, foods/drinks that are appropriate to prevent diabetes and eye conditions, how to book an eye test, and what to expect during eye tests. Examples of questions by participants regarding prevention included:

"Is it like possible let's say if you're overweight?"

"Okay so is eating a carrot helpful for your eyes or is that a myth?"

"What if you have like, if you're drinking and you have diabetes? That's worse right?"

"So do you just have to book an appointment for an optometrist for them to check our eves or...?"

"So do you think an eye doctor can tell if you're going to be diabetic from your eyes."

## **4.2.2.1.3 Management**

General information regarding managing diabetes was requested by participants as reflected in the statements below:

"How would you be able to lower your blood sugar? Do you have to walk or ...?"

"I don't quite know what age I should really start to worry about like getting tested for diabetes or if I should have already been getting... like blood sugar checked."

<sup>&</sup>quot;And so the border is like half? I still don't understand why they call it.... Borderline...

## 4.2.2.2 Strategy for Information Dissemination

## 4.2.2.2.1 Learning by Pictures

Some participants indicated that they preferred learning about DR via picture or images. A participant noted:

"I just wanted to mention that I um, I'm with Anita on the visuals, like do you have pictures I can, know how I can progress. I would be interested in seeing ...like before and after."

## 4.2.2.3 Summary of Findings from Research Question Two

Participants requested for information/ resources on complications, prevention, and management of diabetes and DR. They also requested for DR information via pictures.

## **4.2.3** Findings from Research Question Three

**Question Three:** How knowledgeable are Indigenous women of DR as a complication of diabetes and what is their behavior towards DR eye care?

Participants provided answers to research question three using the pre-intervention DR knowledge, attitude, and practice (DR KAP) survey.

## 4.2.3.1 Population Characteristics

Seventy-eight (78) women participated in this study and 83.3% of participants identified as First Nations and 16.7% Métis. The ages of participants were from 18 to 71 years with a mean age of 36± 14.79 (SD) years. 36% of participants were 18-25 years of age, 34.7% were 26-45 years of age and 29.3% were 46-71 years of age. Most participants had some college and university education but did not finish (30.3%) with 1.3% of participants with no formal education. A majority of participants were working (39.7%) with 12.8% of participants who did not identify as working, not working or students, and included women who were retired. 80.8% of participants were at risk of diabetes while 19.2% of participants were living with diabetes. Table 4.1 shows the characteristics of the study population pre-intervention.

Table 4.1: Population Characteristics (pre-intervention)

Variables	Frequency	Percentage
Age categories		
18-25	27	36.0
26-45	26	34.7
46-71	22	29.3
Indigenous Ancestry		
First Nations	65	83.3
Métis	13	16.7
Education Level		
No formal Education	1	1.3
Some high School but did not finish	9	11.8
Completed high school	15	19.7
Some college or university but did not finish	23	30.3
College or University degree	19	25.0
Other	9	11.8
Working Status		
Working	31	39.7
Not Working	18	23.1
Student	19	24.4
Other	10	12.8
Diabetes		
At risk of Diabetes	63	80.8
Diabetes	15	19.2

## 4.2.3.2 DR knowledge and eye care behavior of Indigenous women with diabetes or at-risk of diabetes in Saskatoon

## 4.2.3.2.1 DR KAP descriptive analysis as a score

## **4.2.3.2.1.1 DR KAP descriptive**

Table 4.2 shows the score analysis of participants DR knowledge, attitude, and practice. The median scores of DR KAP at baseline were 18.18 (IQR= 0-54.6), 0 (IQR= 0-40), and 25(IQR= 0-54.2) respectively. This means that of all reported knowledge scores, at least half of the population had a score less than 18.18 and the other half had scores above 18.18. Half of the reported attitude score was 0 and the other half of the central population had a score from 0-40. While for the practice scores, half of the population had less than 25 and the other half had scores above 25.

In summary, participants had the highest DR practice scores, followed by knowledge scores, and attitude scores were the lowest.

Table 4.2: Distribution of DR KAP Score at baseline in a population of Indigenous Women with or at risk of Diabetes, Saskatoon, 2017 (n=78).

	%Mean	Median	Minimum	Maximum	Interquar	rtile range	
					25	75	
					Percentile	Percentile	
Knowledge	30.163	18.18	0	90	0	54.6	
Attitude	22.564	0	0	100	0	40	
Practice	32.158	25	0	10	0	54.2	

#### 4.2.3.2.1.2 Bivariate analysis between DR KAP Score and sociodemographic variables

Table 4.3 shows the test of the association between DR KAP and variables; age, Indigenous ancestry, diabetes status, work status, and education level. There was a significant difference in medians of knowledge score by age, education, and living with diabetes.

Younger women below 18- 25 years of age had significantly lower knowledge score compared to women between 46-71 (p=0.003). Participants at risk of diabetes had significantly higher knowledge scores compared with women living with diabetes (p=0.010). Women with some college or university education had significantly lower knowledge scores compared to

women who had finished college or university (p=0.012); also, women with no formal education/ some high school education but did not finish had significantly higher knowledge score compared with women with some college or university education but did not finish (p=0.024).

Also, there was a significant difference in practice scores by age and education. Younger women below 18-25 years of age had significantly lower practice scores compared with older women above 46 years of age (p=0.008). Women with some college/university had significantly lower practice scores compared with women who had completed college or university (p=0.025).

Table 4.3: DR KAP score by Age, Indigenous Ancestry, Diabetes Status, Work Status, and Education Level in a sample of Indigenous Women with or at risk of Diabetes, Saskatoon, 2017 (n=78).

	Knowledge Sco	re		Attitude S	Score		Practice Sco	ore
	Median (IQR)	K.Wallis <i>p</i> value <sup>1</sup>	Pairwise <i>p</i> value <sup>2</sup>	Median (IQR)	K.Wallis <i>p</i> value <sup>1</sup>	Median (IQR)	K.Wallis <i>p</i> value <sup>1</sup>	Pairwise <i>p</i> value <sup>2</sup>
Ages 18- 25	9.09(0.00- 18.18)	0.004*	18 to 25 vs 26 to 45 =0.196	20.00(0.00- 40.00)	0.758	0.00(0.00- 25.00)	0.009*	18 to 25 vs 26 to 45 =0.152
Ages 26-45	27.27 (0.00- 65.90)		18 to 25 vs 46 to 71=	0.00 (0.00- 40.00)		25.00(0.00- 68.75)		18 to 25 vs 46 to 71= 0.008*
Ages 46-71	37.73 (15.91- 80.45)		0.003*  26 to 45 vs 46 to 71= 0.391	0.00(0.00- 60.00)		50.00 (0.00- 75.00)		26 to 45 vs 46 to 71= 0.797
First Nations	20.00(4.55- 54.55)	0.077		0.00(0.00- 50.00)	0.520	25.00(0.00- 66.67)	0.168	
Métis	0.00(0.00- 40.91)			0.00(0.00- 20.00)		0.00(0.00- 50.00)		
No formal Education, Some High School, Other (1)	27.27(9.09- 72.73)	0.006*	4 vs 1= 0.024* 3 vs 4= 0.012*	0.00(0.00- 60.00)	0.668	25.00(0.00- 75.00)	0.012*	3 vs 4= 0.025*  Other Pairwise =Not Significant
Completed High	18.18(0.00-		Other Pairwise	0.00(0.00-		25.00 (0.00-		C
School (2)	54.55)		=Not Significant	60.00)		25.00)		
Some college or university but did not finish (3)	0.00 (0.00- 18.18)			0.00 (0.00- 20.00)		0.00(0.00- 25.00)		

•	

College or University degree (4)	45.45(18.18- 72.73)		0.00(0.00- 60.00)		50.00(25.00- 75.00)	
Working	30.00(0.00-	0.396	0.00(0.00-	0.694	50.00(0.00-	0.620
Not Working	72.73) 9.55(0.00-		40.00) 0.00(0.00-		75.00) 12.50(0.00-	
Tion it of the same	50.00)		40.00)		68.75)	
Student	18.18(0.00-		20.00(0.00-		25.00(0.00-	
	36.36)		60.00)		25.00)	
Other	22.73(6.82-		0.00(0.00-		25.00(0.00-	
	80.00)		30.00)		62.50)	
Diabetic	18.18(0.00-	0.010*	0.00(0.00-	0.249	25.00(0.00-	0.143
	54.55)		40.00)		50.00)	
At-risk of [Diabetes	45.45(18.18-		20.00(0.00-		50.00(0.00-	
	81.82)		60.00)		75.00)	

Score: Median
\* Independent samples Kruskal Wallis test at significance level of 0.05. Significant values have been adjusted by the Bonferroni correction for multiple tests.

#### **4.2.3.2.1.3** Generalized linear Model Regression Analysis

Table 4.4 shows the variables associated with the DR Knowledge baseline score in both simple and multiple regression. Age, education, and diabetes were associated with knowledge score in univariate analysis. Only education remained associated in the multivariate analysis. Moreover, the relationship between Indigenous ancestry and knowledge score was not significant in univariate analysis but it was significant in multivariate analysis.

Multivariate analysis indicated that First Nations women had significantly higher knowledge scores compared to Métis women ( $\beta$  =19.7; 95%CI=2.6-36.78). Also, women with some college or university education had significantly lower knowledge scores compared to others with no formal education and some high school education ( $\beta$  =-27.2; 95%CI=-48.6 to -5.8).

Table 4.5 shows the variables associated with the DR attitude baseline score in both simple and multiple regression. The relationship between diabetes and attitude scores was not significant in univariate analysis but it was significant in multivariate analysis. Multivariate analysis indicated that women living with diabetes had significantly higher attitude scores compared to women at risk of diabetes ( $\beta$  =21.6; 95%CI=0.6-42.7).

Table 4.6 shows the variables associated with the DR practice baseline score in both simple and multiple regression. Age and education were associated with practice score in univariate analysis but did not remain associated in the multivariate analysis.

Table 4.4: Variables associated to DR Knowledge baseline score (Simple/multiple regression) in a sample of Indigenous Women with or at risk of Diabetes, Saskatoon, 2017.

	Univariate			Multivariate					
	Median Score (IQR)	Beta(β)	95%	CI	<i>p</i> -value*	Beta (β)	95%	CI	<i>p</i> - value*
Ages 26-45	9.09(0.00-18.18)	18.39	3.80	32.99	.013*	2.73	-16.11	21.57	.776
Ages 46-71	27.27 (0.00-65.90)	28.07	12.81	43.32	*000	5.40	-18.01	28.81	.651
Ages 18-25	37.73 (15.91-80.45)	$O^a$	•			$O^a$			
First Nations	20(4.55-54.55)	12.70	-4.73	30.12	.153	19.67	2.56	36.78	.024*
Métis	0.00(0.00-40.91)	$O^a$				$0^{a}$			
Completed High School	18.18(0.00-54.55)	-12.57	-31.19	6.04	.186	-9.52	-28.93	9.89	.336
Some college or university but did not finish	0.00 (0.00-18.18)	-24.21	-40.92	-7.50	.005*	- 27.21	-48.63	-5.78	.013*
College or University degree	45.45(18.18-72.73)	3.45	-14.04	20.93	.699	-5.06	-24.67	14.56	.613
No formal Education, Some high School and Other	27.27(9.09-72.73)	$O^a$				$O_a$			
Working	30.00(0.00-72.73)	-1.95	-22.56	18.65	.853	6.34	-13.54	26.21	.532
Not Working	9.55(0.00-50.00)	-13.83	-36.18	8.52	.225	- 13.72	-35.48	8.04	.216
Student	18.18(0.00-36.36)	-15.14	-37.28	7.00	.180	-3.92	-26.79	18.95	.737
Other	22.73(6.82-80.00)	$O^a$			•	$0^{a}$			•
Diabetes Present	18.18(0.00-54.55)	-22.01	-37.97	-6.05	.007*	7.58	-10.43	25.60	.409
At-risk of [Diabetes	45.45(18.18-81.82)	$O^a$		•		$0^{a}$	•	•	•

<sup>\*</sup>Univariate:  $p \le 0.20$ ; Multivariate:  $p \le 0.05$ Dependent Variable: Knowledge Score: Median

Model: (Intercept), Age, Indigenous Ancestry, Education Level, Work Status, Diabetes Y/N

a. Reference category. Set to zero because this parameter is redundant.

Table 4.5: Variables associated to DR Attitude baseline score (Simple/multiple regression) in a sample of Indigenous Women with or at risk of Diabetes, Saskatoon, 2017.

		Univariate					Multivariate			
	Median Score (IQR)	Beta (β)	95% CI		p- value*	Beta (β)	95& CI		p- value*	
Ages 26-45	20.00(0.00-40.00)	74	-17.13	15.65	.929	-9.52	-31.56	12.51	.397	
Ages 46-71	0.00 (0.00-40.00)	5.62	-11.51	22.76	.520	-12.55	-39.93	14.83	.369	
Ages 18-25	0.00(0.00-60.00)	$O^a$				$O^a$				
First Nations	0.00(0.00-50.00)	8.62	-10.01	27.24	.365	1.56	-18.45	21.57	.879	
Métis	0.00(0.00-20.00)	$O^a$				$O^a$				
Completed High School	18.18(0.00-54.55)	-4.98	-26.17	16.20	.645	-9.62	-32.32	13.09	.406	
Some college or university but did not finish	0.00 (0.00-18.18)	-9.79	-28.81	9.22	.313	-19.83	-44.89	5.23	.121	
College or University degree	45.45(18.18-72.73)	-1.05	-20.95	18.85	.917	-8.59	-31.527	14.35	.463	
No formal Education, Some high School and Other	27.27(9.09-72.73)	$O^a$				$O^a$				
Working	0.00(0.00-40.00)	6.58	-15.65	28.81	.562	20.35	-2.90	43.59	.086	
Not Working	0.00(0.00-40.00)	4.00	-20.11	28.11	.745	6.15	-19.30	31.59	.636	
Student	20.00(0.00-60.00)	12.42	-11.46	36.31	.308	19.65	-7.11	46.40	.150	
Other	0.00(0.00-30.00)	$O^a$				$O^a$	•			
Diabetes Present	0.00(0.00-40.00)	- 11.68	-29.19	5.83	.191	21.63	.57	42.70	.044*	
At-risk of [Diabetes	20.00(0.00-60.00)	O <sup>a</sup>				O <sup>a</sup>	•	•	•	

<sup>\*</sup>Univariate:  $p \le 0.20$ ; Multivariate:  $p \le 0.05$ Dependent Variable: Attitude Score: Median

Model: (Intercept), Age categories, Indigenous Ancestry, Education Level, Work Status, Diabetes Y/N

a. Reference category. Set to zero because this parameter is redundant.

Table 4.6: Variables associated to DR Practice baseline score (Simple/multiple regression) in a sample of Indigenous Women with or at risk of Diabetes, Saskatoon, 2017.

	Univariate			Multivariate					
	Score (IQR)	Beta (β)	95%	CI	<i>p</i> -value*	Beta (β)	95%	CI	<i>p</i> -value*
Ages 26-45	0.00(0.00-25.00)	17.59	1.11	34.07	.036*	3.54	-18.65	25.72	.755
Ages 46-71	25.00(0.00-68.75)	31.61	14.38	48.84	.000*	17.59	-9.97	45.15	.211
Ages 18-25	50.00 (0.00-75.00)	$O^a$				$O^a$			
First Nations	25.00(0.00-66.67)	13.21	-6.82	33.23	.196	15.66	-4.48	35.80	.128
Métis	0.00(0.00-50.00)	$O^a$				$O^a$			
Completed High School	18.18(0.00-54.55)	-19.65	-41.22	1.92	.074	-14.36	-37.21	8.50	.218
Some college or university but did not finish	0.00 (0.00-18.18)	-24.50	-43.87	-5.14	.013*	-24.37	-49.59	.85	.058
College or University degree	45.45(18.18-72.73)	3.95	-16.32	24.21	.703	-4.26	-27.36	18.83	.718
No formal Education, Some high School and Other	27.27(9.09-72.73)	$O^a$				$0^a$			
Working	50.00(0.00-75.00)	2.63	-21.31	26.58	.829	13.31	-10.09	36.70	.265
Not Working	12.50(0.00-68.75)	-7.69	-33.65	18.28	.562	-2.55	-28.17	23.06	.845
Student	25.00(0.00-25.00)	-8.68	-34.41	17.04	.508	2.24	-24.69	29.17	.871
Other	25.00(0.00-62.50)	$O^a$				$O^a$			
Diabetes Present	25.00(0.00-50.00)	-16.59	-35.37	2.19	.083	-4.01	-25.22	17.20	.711
At-risk of [Diabetes	50.00(0.00-75.00)	$0^{a}$	•		<u> </u>	$0^a$	<u> </u>	•	<u>.                                    </u>

<sup>\*</sup>Univariate:  $p \le 0.20$ ; Multivariate:  $p \le 0.05$ Dependent Variable: Practice Score: Median

Model: (Intercept), Age categories, Indigenous Ancestry, Education Level, Work Status, Diabetes Y/N a. Reference category. Set to zero because this parameter is redundant.

## 4.2.3.3 Summary of Findings from Research Question Three

Pre-Intervention, participants had high DR practice scores compared with knowledge and attitude scores. Younger women had significantly lower knowledge and practice score compared to women between 46-71. Although women at-risk of diabetes generally had significantly higher knowledge scores compared with women living with diabetes. Women living with diabetes had significantly higher attitude scores compared to women at risk of diabetes. Women with some college or university education had significantly lower knowledge scores compared to others with no formal education and some high school education.

#### **4.3 Post- Intervention Results**

#### 4.3.1 Findings from Research Question Four

**Question Four:** To what extent does the mHealth education intervention change DR awareness and self-reported eye care behavior among Indigenous women?

The responses from the post-intervention survey were used to examine the extent the mHealth education intervention changed DR knowledge and self-reported eye care behavior.

## 4.3.1.1 Characteristics of women that completed the study

A total of 50 women participated in the post-intervention study and completed the surveys. 79.6% of participants identified as First Nations and 20.4% Métis. There was a mix of participants across different age groups and ages ranged from 18 to 69 years with a mean age of 35 years ± 14.57 (SD). Also, 39.6% of participants were 18-25 years of age, 31.2% were 26-45 years of age, and 29.2% were 46-71 years of age. Most participants had some college and university education (38.8%) with 8.2% of participants with some high school and no formal education. In addition, participants were predominantly of working status (51%) compared to other participants who were students (12.3%). 79.2% of participants were at risk of diabetes while 20.8% of participants were living with diabetes. Table 4.7 shows the characteristics of participants who completed the study.

Table 4.7: Population Characteristics (Post-Intervention)

	Frequency	Percentage
Age categories		
18-25	19	39.6
26-45	15	31.2
46-69	14	29.2
Indigenous Ancestry		
First Nations	39	79.6
Métis	10	20.4
Education Level		
Some high school but did not finish/ No formal	4	8.2
Education		
Completed high school	8	16.3
Some college or university but did not finish	19	38.8
College or university degree	18	36.7
Working Status		
Working	25	51.0
Not Working	11	22.4
Student	6	12.3
Other	7	14.3
Diabetes Status		
At risk of Diabetes	38	79.2
Diabetes	10	20.8

# 4.3.1.2 Comparison of the baseline evaluation between women that completed and did not complete the study

There was a significant difference between the work status and education level between those who completed and did not complete the study. There were more persons not working who did not complete the study (39.3%). Among people that did not complete the study, there was a higher percentage of people with some high school but did not finish/ no formal education who did not complete the study (48.1%). There was no significant difference in Indigenous ancestry, age, and diabetes status between those who completed and did not complete the study (Table 4.8).

This information is important because it shows the ability of the mHealth intervention to engage participants with low education level and participants not working. Also, the information will affect the interpretation of the data related to education level and work status.

Table 4.8: Comparison between Completed and non-completed groups

	Com		
	NO	YES	<i>p</i> -value*
Age	n=28	n=48	0.583
18-25	8 (28.6%)	19 (39.6%)	
26-45	11 (39.3%)	15 (31.2%)	
46-69	9 (32.1%)	14 (29.2%)	
Indigenous Ancestry	n=28	n=49	$0.521^{\dagger}$
First Nations	25 (89.3%)	39 (79.6%)	
Métis	3 (10.7%)	10 (20.4%)	
Work Status	n=28	n=49	0.001*
Working	5 (17.9%)	25 (51.0%)	
Not working	11 (39.3%)	11(22.4%)	
Student	5 (17.9%)	6 (12.3%)	
Other	7 (25.0%)	7 (14.3%)	
Education Level	n=27	n=49	$0.003*^{\dagger}$
Some high school but did not finish/ No formal Education	13 (48.1%)	4 (8.2%)	
Completed high school	6 (22.2%)	8 (16.3%)	
Some college or university but did not finish	5 (18.5%)	19 (38.8%)	
College or university degree	3 (11.1%)	18 (36.7%)	
Diabetes Status	n=28	n=48	0.378
At risk of Diabetes	21 (75.0%)	38 (79.2%)	
Diabetes	7 (25.0%)	10 (20.8%)	

<sup>\*</sup>p-values <0.05 †Statistical difference assessed by the Fisher's exact test because of small cell sizes (expected values <5).

The KAP of participants who completed the study was not significantly different from participants who did not complete the study in the pre-intervention (Table 4.9). This information is important to show that participants who remained in the study were not more knowledgeable of DR and did not have better attitude and practice scores compared with participants who did not complete the study at the pre-intervention stage.

Table 4.9: Comparison of the KAP for completed and non-completed groups (in the baseline).

	Not-Completed Median (IQR)	Completed Median (IQR)	<i>p</i> -value*
Knowledge	18.18 (0.00-48.86)	27.27 (0.00-56.82)	0.823
Attitude	0.00 (0.00-35.00)	0.00 (0.00-60.00)	0.833
Practice	0.00 (0.00-43.75)	25.00 (0.00-75.00)	0.519

<sup>\*</sup>*p*-value < 0.05

#### 4.3.1.3 DR KAP post-test descriptive analysis as a score

Table 4.10 shows the score analysis of participants' knowledge, attitude, and practice regarding diabetes retinopathy post-intervention. The median scores of participants were 45.45(IQR= 25-63.6), 10 (IQR= 0-80), and 50 (IQR= 0-75), respectively. This means that of all reported knowledge scores, half of the population had a score less than 45.45 and the other half had above 45.45. Half of the reported attitude score was 10 and the other half of the central population had a score above 10. While for the practice scores, half of the population had less than 50 and the other half had scores above 50.

In summary, participants had the highest DR practice scores, followed by knowledge scores, then attitude scores.

Table 4.10: Distribution of DR KAP Score post-intervention in a population of Indigenous Women with or at risk of Diabetes, Saskatoon, 2018 (n=50).

					Interquartile Range		
	%Mean	Median	Minimum	Maximum	25	50	75
					Percentile	Percentile	Percentile
Knowledge	41.98	45.45	0	90.9	25	45.5	63.6
Attitude	36.80	10	0	100	0	10	80
Practice	45.50	50	0	100	0	50	75

# 4.3.1.4 Effect of the mHealth education intervention on DR awareness and self-reported eye care behavior among Indigenous women

## 4.3.1.4.1 Pre-post-analysis using Wilcoxon Test

Table 4.11 shows that there was a significant difference in the effect of the diabetes-eye mHealth education on knowledge, attitude, and practice. The knowledge score significantly increased by 25 (p=0.002). Although the difference in attitude median is zero, the upper limit (75th percentile) was significantly higher in the attitude score (p=0.014). The median practice score significantly increased by 12.50 (p=0.018).

Table 4.11: Effect of diabetes-eye mHealth education on Knowledge, Attitude and Practice in a population of Indigenous Women with or at risk of Diabetes, Saskatoon (n=50).

	Pre	Post	Difference	<i>p</i> -value*	
	Median (IQR)	Median (IQR)	Median (IQR)		
Knowledge	18.18 (0.00-54.54)	45.45 (25.00-	25.00 (-9.09-45.45)	0.002*	
		63.63)			
Attitude	0.00 (0.00-40.00)	10.00 (0.00-	0.00 (0.00-60.00)	0.014*	
		80.00)			
Practice	25.00 (0.00-54.17)	50.00 (0.00-	12.50(-25.00-50.00)	0.018*	
		75.00)			

<sup>\*</sup>p-values reflects Wilcoxon test < 0.05

## 4.3.1.4.2 Effect analysis using DR KAP Post-test scores as dependent variables

Multivariate analysis showed that the post-intervention attitude score for older women was significantly lower compared to younger women adjusted for Indigenous ancestry, education, diabetes, work status, and pre-score ( $\beta$  =-29.34; p=0.038). The DR attitude post-score for individuals with diabetes significantly increased compared to those at risk of diabetes adjusted for all variables and pre-score ( $\beta$  =26.68; p=0.039) (Appendix K).

The post-intervention DR practice score for older women was significantly lower compared to younger women adjusted for Indigenous ancestry, education, diabetes, work status, and pre-score ( $\beta$  =-34.59; p=0.021). Also, the DR practice post-score for women living with diabetes significantly increased compared to those at risk of diabetes adjusted for all variables and pre-score ( $\beta$ =33.59; p=0.014) (Appendix L)

Multivariate analysis showed that the practice post-score for women with college or university education was significantly higher compared with women with no formal education or some high school education when all variables and pre-score was adjusted for ( $\beta$ =38.55; p=0.009) (Appendix L).

# 4.3.1.4.3 Effect analysis using change in score as dependent variable

# 4.3.1.4.3.1 Generalized linear Model Regression Analysis of Pre-post-change in DR KAP score

Age and education were associated with knowledge score in univariate analysis but only education remained associated in the multivariate analysis. Multivariate analysis indicated that women with some college or university education had significantly higher knowledge pre-post-change score compared to others with no formal education/some high school education ( $\beta$  =35.4; 95%CI=2.2 to 68.6). Presented in Table 4.12.

Multivariate analysis did not show any association between pre-post-change in DR attitude score and variables including Indigenous ancestry, the presence of diabetes, work status, education level, and age.

Table 4.13 shows the variables associated with the pre-post-change in practice score in both simple and multiple regression. Multivariate analysis showed that older women 46 years and above had significantly lower pre-post-change in practice score compared to women 18-45 years of age ( $\beta$  = -37.8; 95% CI= -74.8 to -0.8). In addition, women who had completed high school, some college or university; and women with college or university degree had significantly higher practice score compared to others with no formal education/some high school education ( $\beta$  = 44.4; 95%CI= 4.9 to 84.0), ( $\beta$  = 42.0; 95% CI= 4.4 to 79.55) and ( $\beta$  = 46.0; 95% CI= 10.8 to 81.1).

Table 4.12: Variables associated to pre-post-change in DR Knowledge score (Simple/multiple regression) in a population of Indigenous Women with or at risk of Diabetes, Saskatoon.

	Univariate								
	Difference Median Score (IQR)	Beta(β)	95% CI		<i>p</i> - value*	Multiva Beta	95% CI		<i>p</i> -value*
Ages 26-45	9.09(0.00-27.27)	-2.05	-22.72	18.63	.846	12.54	-16.29	41.36	.394
Ages 46-69	18.18 (-18.18-54.55)	-22.02	-43.58	46	.045*	-3.83	-36.58	28.92	.819
Ages 18-25	0.00 (-20.45-13.64)	$O^a$		•		$O^a$	•	•	
First Nations	9.09 (-8.64-27.27)	7.77	-15.27	30.80	.509	5.01	-23.01	33.02	.726
Métis	0.00(-27.27-36.36)	$O^a$				$0^{a}$			
Completed High School	0.00(-36.14-13.64)	24.52	-6.50	55.53	.121	25.89	-9.12	60.90	.147
Some college or university but did not finish	4.55(0.00-34.09)	31.44	2.92	59.95	.031*	35.39	2.15	68.62	.037*
College or University degree	18.18(-8.64-50.00)	15.61	-13.14	44.35	.287	19.23	-11.91	50.36	.226
No formal Education, Some high School and Other	3.18(-19.32-18.18)	$O^a$				$0^{a}$			
Working	0.00(-11.36-25.00)	7.06	-26.44	40.56	.679	-2.61	-38.77	33.55	.888
Not Working	8.18(-4.55-34.09)	12.88	-27.38	53.14	.531	3.51	-38.70	45.71	.871
Student	18.18 (-2.05-34.09)	13.31	-22.05	48.68	.461	5.85	-34.68	46.38	.777
Other	4.55(-25.91-22.73)	$0^{a}$				$O^a$			
Diabetes Present	9.09(-8.41-31.82)	-16.74	-40.53	7.06	.168	-3.31	-33.80	27.16	.831
At-risk of [Diabetes	3.18(-25.00-9.09)	$O^a$				$O^a$			

<sup>\*</sup>Univariate:  $p \le 0.20$ ; Multivariate:  $p \le 0.05$ 

Dependent Variable: Pre-Post-change in Knowledge Score: Median

Model: (Intercept), Age, Indigenous Ancestry, Education Level, Work Status, Diabetes Y/N

a. Reference category. Set to zero because this parameter is redundant.

Table 4.13: Variables associated to pre-post-change in DR Practice score (Simple/multiple regression) in a population of Indigenous Women with or at risk of Diabetes, Saskatoon.

			Univariate 95% CI		Multivariate				
	Difference Median Score (IQR)	Beta (β)			<i>p</i> -value*	Beta(β)	95%	95% CI	
Ages 26-45	12.50(0.00-50.00)	-15.00	-41.15	11.15	.261	.08	-32.49	32.65	.996
Ages 46-69	0.00 (-25.00-25.00)	-39.74	-67.02	-12.47	.004*	-37.79	-74.79	79	.045*
Ages 18-25	0.00(-37.5-4.17)	$O^a$				$O^a$		•	
First Nations	0.00(0.00-37.50)	15.18	-14.45	44.80	.315	15.56	-16.09	47.22	.335
Métis	0.00(-12.50-12.50)	$O^a$				$O^a$			
Completed High School	-25.00(-62.50-6.25)	59.17	20.75	97.59	.003*	44.43	4.88	83.99	.028*
Some college or university but did not finish	12.50(0.00-75.00)	46.84	11.49	82.14	.009*	42.00	4.45	79.55	.028*
College or University degree	0.00 (0.00-50.00)	31.25	-4.37	66.87	.085	45.95	10.78	81.13	.010*
No formal Education, Some high School, Other	0.00(-18.75-25.00)	$O^a$		•		$O^a$	•	٠	•
Working	0.00(-25.00-25.00)	.32	-40.90	41.54	.988	-3.03	-43.88	37.83	.885
Not Working	50.00(-6.25-81.25)	41.67	-7.87	91.21	.099	34.69	-12.99	82.38	.154
Student	12.50(0.00-50.00)	16.07	-27.44	59.58	.469	16.61	-29.19	62.41	.477
Other	0.00(0.00-0.00)	$O^a$			•	$O^a$			
Diabetes Present At-risk of [Diabetes	0.00 (0.00-25.00) 0.00 (0.00-20.83)	.89 0ª	-30.47	32.25	.955	31.26 0 <sup>a</sup>	-3.19	65.70	.075

<sup>\*</sup>Univariate:  $p \le 0.20$ ; Multivariate:  $p \le 0.05$ 

Dependent Variable: Pre-Post-change in Practice Score: Median

Model: (Intercept), Age categories, Indigenous Ancestry, Education Level, Work Status, Diabetes Y/N

a. Reference category. Set to zero because this parameter is redundant

# 4.3.1.5 Qualitative evaluation from survey

CONSORT eHealth (Consolidated Standards of Reporting Trials of Electronic and Mobile Health Applications and online TeleHealth) which is a guideline for reporting of non-RCT evaluation of mHealth interventions (268), recommended that in evaluating mHealth applications, it is essential to include qualitative analysis so as to understand why results occurred. As such, an image of a medicine wheel was included in the post-intervention survey and was an opportunity for the participants to provide feedback on the mHealth intervention to explore to what extent the mHealth education intervention holistically impacted participants. This was done to get a complete picture of the impact of the mHealth intervention.

Participants provided feedback/ reflection on how the messages impacted their physical, emotional, mental, and spiritual health. The recurrent words were collated using Wordcloud to visually represent the impact of the messages (Appendix M). All comments made can be found in Appendix N.

# 4.3.1.5.1 Physical Health

Mussell (2005) describes physical health to include air, food, clothing, shelter, exercise, and sex (85). The main themes associated with physical health were exercise/physical activity, eating healthy, blood sugar control, got an eye test, helpful, and balance. The intervention appeared to motivate participants to engage in various activities to improve health care, diabetes care, and eye care. For example, some participants reported:

```
"Encouraged me, I am keeping up my medical checks."
```

"Tried working out by walking."

"Got blood sugar under control."

"Fit, feeling better about oneself."

Some participants reported going for an eye examination due to the intervention.

"I booked an eye exam. I haven't had an eye test since I was 6 years old."

"Eye exam made me feel better."

#### 4.3.1.5.2 Emotional Health

Mussell describes emotional health to include recognition, acceptance, understanding, love, privacy, discipline, and limits (85). The themes associated with emotional health were giving back to the community, feeling good, taking action, getting eye examinations, sharing

information with others, reminders, and positive emotions. A participant stated that the intervention showed her the necessity to connect with others for support.

"Talking to someone when I have problem, seeking family for support, Elders support, giving back to the community."

In addition, the intervention assisted in lessening anxiety and fear towards diabetes and eye care. Some participants noted:

"At first, I felt nothing then I began to enjoy it and look forward to texts. I would discuss and use information with others. I feel content and less anxious about my eye health." "Feeling good with more knowledge on the subject."

"Learned some information that put my mind at ease."

"Sense of fear to bad health has resolved, knowing the information I received through text."

#### **4.3.1.5.3 Mental Health**

Mental health represents concepts, ideas, thoughts, habits, and discipline as described by Mussell (85). The key words/themes associated with mental health were knowledge, awareness, education, and information. Some participants noted that the mHealth intervention impacted their knowledge of diabetes, its eye complication, and management:

"Gave me much to think about and share with my family. Will use information to help change my way of thinking/eating for better eye health. Good thoughts."

"It gave me a sense of how to control my blood sugar and prevent diabetes, so it doesn't affect my vision."

"Learned something new, going to be mindful of eye health and children's eyes" Participants indicated that they were more aware of diabetes and eye care. As seen in the comments below from two participants:

"By reading the messages, this instilled awareness of the impact of diabetes on eye health"

"Awareness, sparked my thought process about diabetes"

# 4.3.1.5.4 Spiritual Health

Mussell describes spiritual health as a sense of connectedness with other creations of the Great Spirit (85). The themes associated with the text messages and spiritual health were smudging,

thankful, awareness, and prayers. Some participants reported that as a result of the mHealth intervention:

"Got in touch with my inner soul."

"Reawaken"

"Uplifted me, felt I had an angel working with me."

Also, participants mentioned that the intervention highlighted the importance of holistic health care. In respect to this, two participants noted:

"Take care of whole self, not just aspects."

"Taking care of my body that houses my spirit."

Some participants drew images that reflected their feelings about the messages received and their health (Figure 4.3 to 4.7).

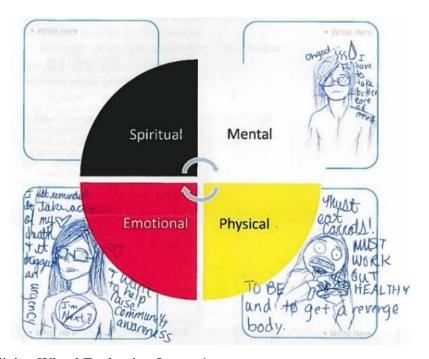


Figure 4.3: Medicine Wheel Evaluation Image 1

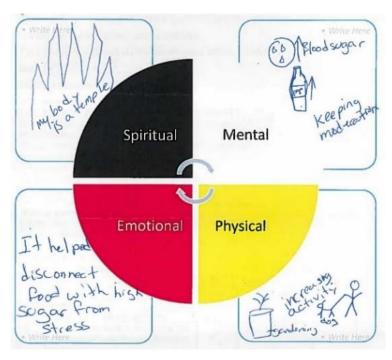


Figure 4.4: Medicine Wheel Evaluation Image 2

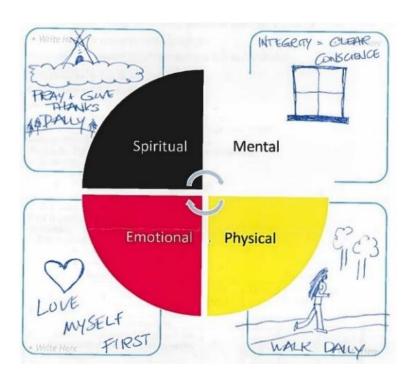


Figure 4.5: Medicine Wheel Evaluation Image 3

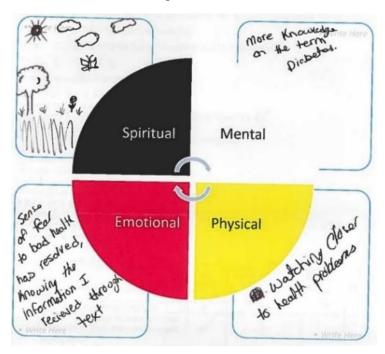


Figure 4.6: Medicine Wheel Evaluation Image 4

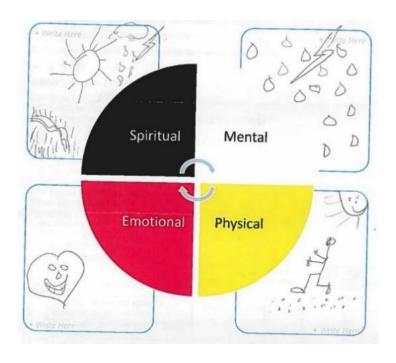


Figure 4.7: Medicine Wheel Evaluation Image 5

The images that represented physical health included phrases such as "walk daily," "increasing activity, gardening," and "must eat carrots." A phrase included in the emotional health section included "love myself first". The mental health aspect included phrases and sentences such as "more knowledge on the term diabetes," "keeping moderation," "integrity =clear conscience," and "I have to take better care of myself." The spiritual health section included phrases such as "my body is a temple," and "pray and give thanks daily."

To conclude, the images illustrated that the mHealth intervention impacted the physical, emotional, mental, and spiritual health of participants. It showed participants' perception of the intervention on diabetes-eye care, risk factors, and self-management.

# 4.3.1.6 Summary of Findings from Research Question Four

Post-intervention, participants had high DR practice scores compared with knowledge and attitude scores. Nonetheless, the knowledge, attitude, and practice scores significantly increased post-intervention. The DR attitude and practice post-score for individuals living with diabetes significantly increased compared to those at risk of diabetes. Women with some college or university education had significantly higher pre-post-change in knowledge and practice score compared to others with no formal education and some high school education. Older women 46 years and above had significantly lower pre-post-change in practice score compared to women 18-45 years of age.

General opinion was that the diabetes-eye care related text messages received by participants created diabetes-eye care awareness/knowledge. It also prompted action and change in diabetes-eye care behavior.

# 4.3.2 Findings from Research Question Five

**Question Five:** How do Indigenous women perceive mHealth as a tool for receiving health information?

Participants responded to research question five by providing feedback during the postintervention sharing circles on their experience in receiving diabetes-eye messages through text messages and on receiving health information via mobile phones in general. Five (5) key themes emerged from the discussions including; nature of message delivery, the impact of messages, interaction, content, and delivery format. Figure 4.8 shows an outline of the themes and subthemes.

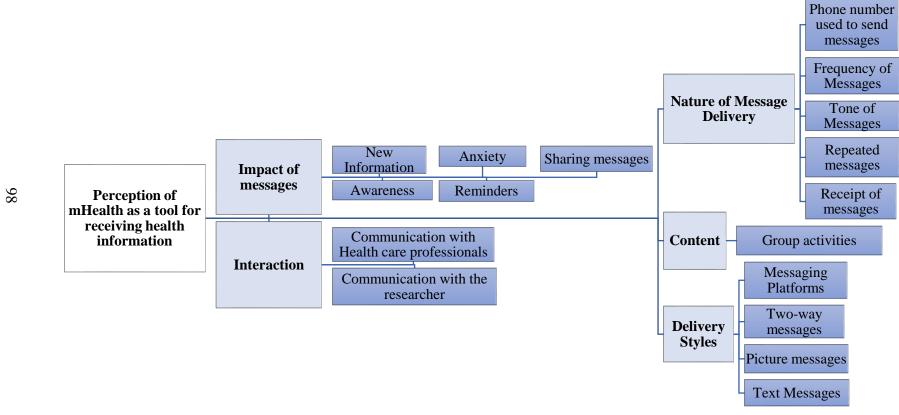


Figure 4.8: Outline of themes and sub-themes on the perception of mHealth as a tool for receiving health information

# 4.3.2.1 Nature of Message Delivery

Message delivery featured as a theme in the discussions including both the technical aspects of messages delivery that involved timing, phone number used, receipt of messages, and the aspects directly related to the nature of the text messages sent including repeating messages and tone of messages.

# 4.3.2.1.1 Phone number used to send messages

The platform used for disseminating messages distributed text messages with different numbers. Participants provided varying comments about receiving messages from different numbers. A participant noted:

"I'd hope that there would be a way to figure out how to get all the texts come from the same number."

While another participant indicated:

"It doesn't bother me to scroll and look at all the different numbers at all."

# 4.3.2.1.2 Frequency of Messages

The participants gave contrasting comments on their perception on the frequency of the messages. Some did not mind receiving daily messages as noted by a participant who stated:

"Actually, I like getting text messages every day. That could work so well for diabetes to a First Nation person and I think that would be like really good bonus to get."

Whereas some participants felt that there were too many messages: A participant indicated:

"If they were to be like that but like not every single day it would be a lot better."

## 4.3.2.1.3 Receipt of Messages

Participants indicated that they liked the routine of receiving the messages at the same time daily and often looked forward to receiving a notification every morning.

"It kinda got routine because it was like 8:30 my phone's gonna ring."

"I just found I liked the routine of getting the message around 8:30 every morning and the only time ... my phone ring something is because of the text message."

On the other hand, some participants missed receiving the text messages which was either due to change of number or providing a house phone number rather than a mobile number for the study. A participant stated:

"My number, my phone number changed so I totally missed it."

# 4.3.2.1.4 Repeated Messages

Another point the participants spoke about was repeated messages. Participants observed that some messages were repeated at different intervals during the intervention period. A participant noted:

"I thought all the messages were good. Some of them kind of repeated themselves in a different way."

Although some messages were repeated, some participants appreciated the repetitiveness. A woman voiced:

"Personally, didn't mind the daily messages or the repetitiveness. Because as you get older and when you have diabetes memory becomes an issue so when you're young, it's not an issue."

# 4.3.2.1.5 Tone of Messages

There were a number of comments on message structure/format, tone, and language.

"I like how it's, "did you know" "did you know?"

"It wasn't pushy or anything. It was just "did you know?"

# 4.3.2.2 Impact of messages

The diabetes-eye health messages had both positive and negative impacts on the participants. The messages acted as health reminders, provided new information on diabetes and eye care, influenced awareness, prompted participants to share the information. On the contrary, it equally imparted fear and anxiety.

## 4.3.2.2.1 Anxiety from messages

A participant reported been scared and anxious as a result of the messages received due to confusing the source/origin of the message. She indicated that she had seen a doctor for a medical check and various diagnostic tests had been carried out prior to receiving the text messages. She had been previously diagnosed with pre-diabetes and was worried about being diagnosed with diabetes. On receiving the diabetes-eye messages, she assumed the clinic was confirming she had diabetes and was sending her nutritional tips to manage diabetes. She stated:

"I got the texts about seeing a nutritionist from the eye study but all I saw was diabetic and I was like oh my god I'm diabetic..... So I'm just all devastated and I'm like okay,

I'm going to beat this, ... but I came back, I found out it was a urine infection. That's why the clinic was trying to call me. But I was so anxious in that whole time."

## 4.3.2.2.2 New Information

Participants commented on how informative the text messages were, and the new information gained from receiving the messages.

"There was a few that I went oh I didn't know that."

"I really find them very informational too and I picked up on a couple things."

A participant mentioned that the text messages provided information that her eye doctor had not informed her during eye care visits. She stated:

"Because I learnt so much that my eye doctor or my um eye surgeon information that they should've given me. I learned you know what to look for, you know what to do when this happens and that is just huge for me."

Another participant indicated that the messages provided some information not received from eye health practitioners.

"It seemed like you elaborated on more than what, you know, the optometrist will tell you in the office."

## **4.3.2.2.3 Awareness**

Participants reported that the messages created or increased awareness of diabetes in general and diabetes-eye related diseases. Two participants stated:

"I knew the signs to recognize it within myself and maybe other people."

"Like this study really made me more aware that age, the ethnicity, you know how it's like for Aboriginal people."

#### **4.3.2.2.4** Reminders

The messages served as reminders to several participants particularly regarding self management, maintaining health, and seeking health care. A participant noted:

"I found that it reminded me daily that I'm a diabetic cause I need to do my insulin. And that's actually how I got my blood sugar down was yeah just being reminded every day." Another participant referred to the intervention as, "it's kind of like... good nagging at you, you know to do these things."

# 4.3.2.2.5 Sharing messages

Participants reported sharing the messages with family and friends. For example, some participants noted:

"I shared them with some of my relatives."

"I shared with a lot of people over Saskatchewan. I think even B.C. too actually."

"Eight o'clock in the morning, having coffee with my dad for instance. Ding. Oh by the way dad you should go see the eye doctor. You know it's not just dry eyes or allergies, this is what you could be doing."

## 4.3.2.3 Interaction

Interaction refers to the comparison between how health care professionals provide health information and the messages received during the mHealth intervention, and the re-enforced impact of diabetes-eye care by the researcher via communication with participants.

# 4.3.2.3.1 Communication with Health care professionals

Participants commented that the relationships and communication of health information from health care practitioners in general impacted knowledge and diabetes-eye care behavior. A participant stated:

"Seeing the doctor, sometimes you just feel like another number not a person. You just feel like a number you know and you're just in and out, in and out you know, you don't have time to get that extra uh feedback and information that you need as a person being one-on-one."

#### 4.3.2.3.2 Communication with the researcher

In addition, participants appreciated meeting and conversing with the researcher during the study period. In regard to this, a participant noted:

"I also appreciate the talks in between the three months too because it showed that you actually cared. You know you're looking into our overall health in the meantime. If I had questions you were looking into it for us"

#### 4.3.2.4 Content

Another point the participants spoke about was interest in receiving more detailed content on nutritional tips to prevent diabetes and its complications. For example, a participant noted:

"But um a lot of people I find have like well I don't want to say addictions but like they drink a lot of pop like me for example. It's like what are um some more healthier alternatives."

Participants had various suggestions on future activities on diabetes-eye care. Indicating the importance of relationships and group interactions. Two participants stated:

"More um. More group activities."

"If there's even like other studies that, ...anything diabetic related would be interesting."

# 4.3.2.5 Delivery Style

This refers to the nature and type of health information messages that can be disseminated to impact health knowledge and in the long run, behavior change among participants. This involved utilizing an array of mobile phone features to share health messages in a manner that is comfortable and appropriate for the participants.

# **4.3.2.5.1** Messaging Platforms

This speaks to the use of voice, mobile applications (apps), and the internet for information dissemination. Participants expressed interest in receiving voice health messages. In addition, participants suggested that the voice messages could also be in Indigenous languages. In relation to that, a participant stated:

"Even like if it was recorded in Cree and somebody could get a message, like a voicemail."

Other participants were interested in receiving health messages via the internet either via mobile apps or the internet. Two participants indicated:

"I like the text messages but ... if there's like um a website like if for additional information, if you want to keep looking up, like look into the fact that you sent out to us."

"An app that would just like bring up a notification that tells you daily facts without it bringing up all the text messages, that would be ideal for my lifestyle I guess."

# 4.3.2.5.2 Two-Way messaging/Phrasing of Messages

There were various comments on two-way versus one-way messaging with some participants indicating interest in responding to text messages in order to make further enquiries on health

information received. The phrasing of the text messages also made participants want to respond. A participant noted:

"There were times I got a few messages, it was like "did you know?" And then I was like wondering, should I respond to it?...And then it'll give you information."

# 4.3.2.5.3 Picture and Image messages

Some participants mentioned appreciating health messages with images. In relation to that, a participant stated:

"I'm like new to the cellphone so I wish there was little pictures or bouncy things or something. I like those."

# 4.3.2.5.4 Receiving Messages via Text

Several participants indicated that there were advantages to receiving health messages via text such as it been ubiquitous, convenient, and easy to read and share.

"It's convenient though."

"You could choose to keep the messages if you want. You could look back on them when you need to. I think that's a really good way of, like sharing health information."

A participant indicated that receiving health information via text was beneficial for some Indigenous peoples who are uncomfortable visiting doctors. She stated:

"I think it's a good idea because then there's a lot of First Nations people that or Indigenous people that don't like going to doctors."

Some participants preferred receiving health messages by text rather than other platforms. They noted:

"I think it's like a good medium to use because everyone is always, has their phone or is on their phone so it's the best way to get the information."

"I think it'd be a lot easier for like text messages rather than emails because I got text messages and emails and somedays I forget to check my emails... So text messages were very easy."

# 4.3.2.6 Summary of Findings from Research Question Five

The mHealth intervention provided new information on diabetes and eye care, created awareness, and prompted participants to share the information. Although the intervention

relieved anxiety and diabetes stigma, on the other hand, it also increased anxiety. Interaction with health care professionals and the researcher re-enforced the impact of the intervention.

Participants indicated that the nature of messages such as the timing of message delivery, phone number used, receipt of messages, repeated messages and tone of messages were important in mHealth interventions. Also, the message content, group activities, and delivery format such as via voice messages, mobile applications, internet, two-way messaging, text messages were noted as essential in using mHealth as a tool for receiving health information.

# 4.4 Integration of Qualitative and Quantitative Results

An approach to integration of qualitative and quantitative results is by "data merging" which is where both data are combined and reported together in the discussion section of a study, such as reporting first the qualitative findings and then reporting the quantitative results that either support or challenge the qualitative findings (269). The discussion section in this study was used to integrate the study results.

In the next chapter, the findings from the pre-intervention study phase regarding the factors influencing DR eye care behavior, the findings of the DR KAP survey, and the information requested by participants are discussed together. The post-intervention results from the quantitative and qualitative data on the impact of the mHealth intervention are integrated by exploring findings that provided clearer understanding of the impact of the intervention. The perceptions of participants regarding mHealth as a tool for health information are discussed separately in the next chapter.

#### **CHAPTER 5**

#### 5 DISCUSSION AND CONCLUSION

## 5.1 Outline

In this chapter, the study results are discussed in relation to the literature and aligned with the study's theory and framework. The approaches to maintain rigor in the study are described and the strengths and limitations of the study reviewed. This chapter discusses the practice and policy implications of the study and presents the researcher's reflections on the use of self-determination theory and the medicine wheel framework in the study and on the research journey. The recommendations and directions for future research are discussed. The final section in this chapter wraps up the thesis with the summary and conclusion.

#### 5.2 Discussion of Results

The results are discussed under three major headings to integrate the study results: the factors influencing DR eye care, the impact of the mHealth intervention, and the perception of mHealth as a tool for health information. The results from the pre-intervention phase are integrated and discussed under "factors influencing DR eye care". While the post-intervention results are discussed under "impact of the mHealth intervention and the perception of mHealth as a tool for health information".

# 5.2.1 Factors influencing DR eye care

# 5.2.1.1 Awareness and Understanding

The study revealed that awareness and understanding of the cost associated with eye care, particularly regarding coverage of eye examinations influenced diabetic eye care use among study participants. In the literature, it has been discussed extensively that financial burden and concern over health insurance coverage of eye examination costs are barriers to diabetic eye care (133, 270, 271, 70). Similarly, the reason for poor diabetic-eye practice and attendance at eye clinics is often related to inadequate funds (272). Among Canadian Indigenous peoples, financial constraints have been identified as a barrier to health care service access (273).

A prominent study finding was that participants' limited understanding of the eye care procedures covered by NIHB, the provincial health insurance coverage, particularly for individuals living with diabetes and children, as well as eye care cost for women without status

(who wouldn't have NIHB) deterred women from using eye care services. The Government of Saskatchewan covers annual eye examinations for individuals living with diabetes in the province (142). Individuals living with diabetes with a health card in Saskatchewan can have DR screening yearly covered by the Saskatchewan health plan. This also applies to Indigenous women with or without a status card. For individuals above 18 years of ages without diabetes, NIHB and the provincial health plan covers bi-yearly eye examinations while children under 18 years of age can have yearly eye examinations covered (274). However, it appeared that there was limited knowledge among study participants of the DR vision care benefits in Saskatchewan. This indicates the need for better communication of information regarding insurance coverage of eye care/health services in Saskatchewan, particularly the NIHB and Saskatchewan health plan coverage for individuals living with or at risk of diabetes. Increased awareness of coverage will aid in reducing the anxiety experienced due to concern over eye care costs, as well as encourage the uptake of diabetic-eye care services.

Several women in the study indicated that access to eye care services was not a constraining factor for diabetes-eye care, which may be because Saskatoon is a city with several eye care facilities. In urban communities, individuals living with diabetes rarely report DR access barriers due to better transportation within the cities (133).

Consistent with similar research, in this study several participants indicated that the inconvenience of making appointments and not knowing how to make eye appointments deterred them from diabetic eye care. Individuals living with diabetes are frequently not familiar with guidelines for diabetes management (275), and their nonadherence to eye examination guidelines commonly occurs due to lack of understanding of eye care recommendations, resources, and physicians' limited time for communication with patients (276). The study findings support that there was limited communication of diabetic eye screening guidelines and the availability of resources on diabetes-eye care via different channels including diabetes health teams, diabetes community health programs, and most importantly by physicians.

Furthermore, consistent with research on DR, this study found that asymptomatic eye conditions were a deterrent to the utilization of eye care services as most study participants were unaware that, even if they had no eye difficulties, it was important to have regular eye examinations. The literature shows that having no symptomatic ocular problems, referral to an eye doctor, and not knowing the necessity of a periodic eye check up even when good vision is

present are commonly mentioned eye care barriers (134, 272). Inadequate understanding of diabetes, complications, beliefs concerning the need of obtaining an eye examination, and whether diabetic eye diseases are detected by an eye examination contribute to differences in adherence to preventive eye care services including diabetic-eye screening (13, 270). In the same way, diabetes eye examination barriers shared by both young and older adults include beliefs about diabetes consequences and DR knowledge misconceptions (271).

On the other hand, this study had a unique finding as it revealed that DR awareness that originated from having poor vision and eye complications served as a motivating factor for the women to utilize eye care services. This finding is concerning as, eye complications may have already resulted in irreversible vision loss, thereby becoming another source of stress and burden for Indigenous women. Due to the high prevalence of vision loss and blinding eye diseases in Indigenous populations worldwide (277), awareness and promotion of preventive diabetes-eye care practices among Indigenous peoples living with or at risk of diabetes should be a priority rather than waiting until vision loss occurs.

The pre-intervention study findings revealed limited understanding and awareness of eye care guidelines and knowledge of eye treatment in diabetes. The findings showed that participants had better DR practice scores than knowledge and attitude scores.

Additionally, the study results revealed that participants generally were aware of diabetes and its eye complications, but their knowledge of eye examination was limited. This was likewise observed in Alberta, where First Nations peoples' showed that they possessed more knowledge about complications of diabetes than knowledge about screening for complications (278). Inadequate diabetes-eye knowledge was also observed in related studies where poor knowledge of the eye complications of diabetes and DR was noticed among persons living with diabetes with none mentioning DR as a possible complication (272), along with poor results in the assessment of DR attitude and practice (279).

Furthermore, age impacted DR knowledge and eye care behavior where younger women 25 years and below had significantly low knowledge and practice scores compared with women aged 46 and older. This result corresponded with a previous study which showed that young age and limited formal diabetes education were factors related to nonadherence to DR screening (71). Likewise, a study in Saudi Arabia regarding DR KAP and retinal examination among a group of people living with diabetes showed that the age group (35-50) had a better attitude and practice

toward DR rather than the younger age group below 35 years of age (279). A similar study in India noted that awareness of DR causing impaired vision was higher among persons 30 years and above (280).

A significant finding in this study was that women with some higher education such as college or university education had significantly lower knowledge scores compared to others with no formal education and some high school education. This finding was contrary to related study where respondents with high education level such as secondary and university education had high diabetes and DR KAP scores compared to participants with low education levels (279). However, the finding in this study may be because age was associated with the educational level of participants as older women had lower education levels than younger women in the study.

Due to the limited understanding and knowledge of DR and diabetes-eye care, study participants requested that the mHealth intervention included information on funding for eye care costs, DR related symptoms/issues versus other common vision problems (e.g. how DR is different from glaucoma or cataracts) to address the understanding and awareness of DR. Mostly, participants required basic diabetes information such as types of diabetes, diagnosing borderline or pre-diabetes, as well as diabetes in children, and the complications of diabetes on vision.

In the context of self-determination theory, awareness and understanding are vital steps to aiding informed decision making and can be an intrinsic motivation for individuals to be encouraged to manage and prevent diabetes and DR. Also, thoughts, concepts, and ideas that originate from awareness are essential features for mental wellness (85).

#### 5.2.1.2 Resolve/Intention

The study findings support that having control over decisions regarding diabetes-eye care management influenced eye care service utilization due to the resolve to live a healthy and productive life. In addition to that, individuals living with diabetes tend to seek eye care to prevent vision loss from DR and becoming a burden to family members (271).

In this study, findings showed that stress affected the diabetes-eye care behavior of participants. Living with diabetes is associated with several stressors which may be due to the treatment plan, emotional burden of diabetes, stigma of diabetes, powerlessness, self-management challenges, ability to obtain appropriate food to maintain health (117). It may also be due to negative differential treatment often present in Indigenous health care, which in turn can produce and worsen general chronic stressors that elevate diabetic outcomes and impact the

management of diabetes and its complications (117). People living with diabetes and in stressful situations have a higher risk of developing DR than individuals living with diabetes without stress, accordingly, stress is a common barrier to eye care by persons living with diabetes (133). However, stress coping strategies depend on the individual and support in the community/environment.

The study showed that although Indigenous women may find it difficult to maintain their diabetes-eye care plan and have regular check-ups, they were confident and determined to control/manage diabetes and its eye complications. In the words of a participant, "I want to not let diabetes control me, but I want to control it." This resolve motivated some participants to utilize eye care services.

Nevertheless, irrespective of the reported resolve by participants to take control of their eye care, the study findings showed that the attitude to diabetic eye examinations and control of risk factors among participants were less than their DR knowledge scores. Similar findings were found in a KAP assessment of individuals living with diabetes in Jamaica, which indicated that even among people already diagnosed with DR, knowledge scores were good but their diabetic-eye care practice was inadequate (282).

This study also revealed that younger women 25 years and under had significantly lower DR practice scores compared with older women above 46 years and above. It appeared that older adults were more likely to adhere to eye care recommendations compared to younger adults. Relatedly, the relationships between age and time of diabetes diagnosis to first diabetic eye screening and severity of DR across England showed that individuals aged between 18 and 34 years of age were less likely to attend eye screening after a diabetes diagnosis with a higher risk of presenting at eye clinics with DR during their first eye test (283). Similarly, young adults with type 2 diabetes were least likely to initiate DR screening promptly after a diabetes diagnosis, exposing them to a high risk of severe DR at their first eye examination (271). On the contrary, increasing age was associated with a reduced lower likelihood of attending eye examination for Indigenous and non-Indigenous Australian people with diabetes (59).

The pre-intervention findings regarding the influence of age on DR attitude and practice were of concern, especially with the increased rate of Indigenous peoples in Canada developing diabetes at a younger age with higher risk of retinopathy complications (86). Thus, it is important that young Indigenous women have improved DR eye care behavior.

As such, study participants indicated that information on the prevention and management of diabetes was important. The study participants were interested in knowing about ways to prevent diabetic eye complications. Related studies showed that encouraging prevention was important, especially promoting the knowledge that DR and vision loss can be avoided by early diagnosis, management, and treatment as well as the importance of annual eye examinations among individuals with pre-diabetes, uncontrolled blood sugar levels, persons living with diabetes including individuals that are newly diagnosed with diabetes (282, 270).

In addition, participants requested information on the frequency of eye examinations which was consistent with Foster and colleagues (2016) who concurred that knowledge about the timing and frequency of eye examinations is crucial to aid in early diagnosis of diabetic retinopathy since in its early stages, it can be asymptomatic (282). However, a difference between this study and previous studies regarding information required is that participants in this study requested information on how to book an appointment and with whom and eye examination procedures such as; what occurs at the appointment, what the eye doctor is looking for, and some of the issues that may arise from the appointment.

Furthermore, the study participants required resources on genetic and behavioral risk factors such as age, weight, family history, diet, exercise, and general lifestyle information. Participants also requested general information about diabetes complications and blood sugar control. A study noted that topics relevant to diabetes management, such as risk factors of diabetes, diet, exercise, stress management, and blood sugar monitoring, as well as visiting a general practitioner regularly and having an annual eye and limb check must be incorporated in a diabetes self-management support intervention for people at risk of diabetes and with diabetes (285).

Another finding that stood out in this study was the request for diabetes-eye care information via pictures. This may be due to the traditional and preferred way of communication and learning of Indigenous peoples which is via oral tradition and art (songs, pictures, dance). Nonetheless, individuals may generally prefer learning by pictures and according to Mayer's multimedia principles, "a combination of words and pictures fosters deeper learning than from words alone" (286, pix). Also, the request for pictures may be due to the influence of technology such as smartphone which is amenable to images. Memon et al. (2015) suggested that DR

behavior change materials include pictures where possible, particularly for females and young persons (281), as images may increase engagement with the information being presented.

All these resources and information were essential to support and encourage Indigenous women in this study in their resolve/intention for diabetes-eye care. Fostering awareness and knowledge of diabetes and DR (mental outcome) can influence the resolve to seek preventive diabetes-eye care services, build confidence in one's ability to manage or overcome diabetic-eye challenges and make changes towards diabetes-eye care behavior (physical outcome). Nevertheless, in the context of self-determination theory, this change in behavior will not be impactful and sustainable without a supportive environment that would build confidence and alleviate anxiety.

## 5.2.1.3 Fear

In this study, diabetes caused feelings of anxiety and fear among participants particularly regarding complications such as blindness, amputation, and mortality. A key finding was that fear resulting from personal experiences such as having a family member living with diabetes and its complications, and accounts from relatives about experiences of living with diabetes, motivated participants to seek eye care and utilize other diabetes prevention and management services. The pre-intervention findings showed that women living with diabetes had significantly higher attitude scores compared to women at risk of diabetes. It appeared that the experience of living with diabetes influenced eye care behavior while persons at-risk of diabetes were not equally motivated to utilize eye care services because they were not directly affected by diabetes.

In connected research, in females without diabetes, there was inadequate knowledge of diabetes and DR whereas attitude scores were higher among study participants living with diabetes when compared with nondiabetic participants (281). Additionally, related studies in Saudi Arabia and Nepal showed that individuals with more than eleven years living with diabetes had higher DR KAP scores than the others (279), and individuals living with diabetes, irrespective of whether they had DR or not, were more aware of DR than individuals without diabetes (287). In London, Ontario, Canada, individuals living with diabetes had seen their eye physician or any health practitioner more often in the past year than those without diabetes (288).

Older adults with living with diabetes have fears of several complications of diabetes including amputation, kidney complications, blindness, and other diabetes co-morbidities that may be grounded in experiences of living with diabetes, thus influencing self-management (289).

But among women, this anxiety may originate from their experiences and observations as caregivers (289). Family members of individuals living with diabetes are involved in the management of diabetes in many ways and experience many concerns, fears, and worries connected with diabetes for both the present and the future. In many cases, diabetes is regarded as "more severe by family members than by individuals living with diabetes" (290, p5). Likewise, pregnant women living with type 2 diabetes of American Indian origin possess significant dread, fear, and anxiety surrounding the health and well-being of the unborn child, blindness, amputation, and death (291). This shows the need for social, behavioral, and health professionals working with persons living with diabetes to include family and friends' networks in the understanding and management of diabetes and its complications to reduce anxiety.

Another major factor that affected eye care service use found in this study was the fear of judgment, particularly from healthcare providers. The willingness to seek eye care, such as attending a referral to an ophthalmologist, and subsequently, the potential to prevent visual loss due to DR, depends on how physicians interact with their patients and not merely on whether a referral was made (127). Therefore, not being understood by health professionals and inadequate empathy and concern for Indigenous women's opinions and feelings hinder the utilization of eye care services.

Providing a warm interpersonal environment is crucial in health care because the doctorpatient relationship is integral in influencing health behavior and service utilization.

Communication between health practitioners and patients is essential for the uptake of DR screening and in facilitating the use of other diabetes care (292). As indicated by Cavan and colleagues (2017), there is often a concern among individuals living with diabetes and undergoing eye treatment about the poor communication between them and their doctors, and the authors suggested the need for "multi-directional and multi-disciplinary communication", involving the patient, the primary care provider, and the ophthalmologist (132, p22).

For many Indigenous peoples, access, and utilization of health services are compounded by low trust, safety, and control rooted in both historical and lived experiences (273). The relationship between the health care provider and Indigenous peoples is vital in addressing the power dynamics in the health care of Indigenous peoples and can provide an avenue to alleviate past harms (293). Therefore, looking at the experiences of the study participants from a cultural safety lens, the encounter and interaction between the health care provider and Indigenous

peoples highlight the power imbalance found in healthcare grounded in colonialism (144). It is essential that Indigenous women feel safe when assessing health care and that interactions with health practitioners do not trigger or stir memories of negative experiences. Negative authoritarian interaction such as, "lecturing and finger-pointing" will result in distrust, avoidance, and resistance to health care providers if the communication is not uplifting and supportive.

The physician-patient relationship is reciprocal, and both parties are accountable to each other hence, it is not enough for physicians to tell persons living with diabetes to seek eye care without providing the necessary justification. Explaining the reasons for eye care promotes relationship building and adherence to eye care advice because the individual can make informed health decisions. Communication, relationship building, and trust are important for eye care management to be effective (294).

Research support that appropriate education from practitioners during consultations is essential for eye service utilization and adherence to treatment regimes. For instance, eye doctor-patient communication and education about how to administer glaucoma eye drops increased confidence and increased eye drop daily use (295). In Canada, interactions between health professionals and individuals living with diabetes about eye complications is an important determinant of whether a patient will obtain an eye examination (127). Not being involved with diabetes care, anxiety about diabetic-eye screening and limited information are patient-level reasons for never attending DR screening (296). Likewise, limited respect of patients by health practitioners and inadequate holistic care (275) influences health care among persons living with diabetes. Accordingly, it is important to provide a supportive health care environment.

Another main finding was that some study participants associated diabetes eye examinations with the prescription of refractive glasses. Although eye specialists may observe during DR screening the need for eye glasses to assist with vision correction and prescribe glasses, diabetic-eye care and DR screening is not focused on prescribing eye glasses but on the health of the retina and eyes in general. In this study, fear of depending on eye glasses due to the misunderstanding that seeing an eye doctor would result in wearing glasses along with a reluctance to wear glasses and dependence on glasses hindered the utilization of eye care services. The study showed that some women were skeptical of wearing eye glasses due to the fear of losing their present sight and stigma associated with wearing glasses from peers when

they were children. As seen in related studies, fear and stigma are linked to the use of eye glasses and fear of the glasses being detrimental to vision (297), along with a perception that children wearing eye glasses would be blind in the future (298).

Individuals are influenced by their community and social circles (299). Thus, social and peer pressure can be both facilitators and barriers to seeking diabetes-eye care (271). Worry and concern regarding the opinion of peers can have a lasting effect on health decisions and deter eye care service use.

Since fear was connected to worry and misconceptions about self-care, family eye history, and eye care treatments/management. Participants highlighted the need for information on DR signs and symptoms and if symptoms were gradual or immediate. Also, participants requested to know whether vision loss in DR was inevitable/reversible or whether prevention and management can make a difference. Knowledge of diabetes-eye symptoms can alleviate the fear of DR and is crucial for prompt DR eye examination since limited awareness of the asymptomatic nature of DR in early stages results in severe prognosis (294).

In respect to self-determination theory, experiencing fear from personal and family experience of diabetes, dependence on glasses, and interaction with health care practitioners can result in amotivation and lead to poor autonomy over health decisions. Health care behavior can be influenced by anxiety and fear and some individuals may deny the presence of a health condition "as a coping mechanism" (291, p259). In addition, poor interaction with health care practitioners can create "relatedness frustration" (300, p203), and undesirable health outcomes. It likewise negatively influences the feelings of hope, dignity, and respect of the values of individuals, and reduces feelings/emotions regarding empowerment, confidence, and self-determination.

In summary, the factors that influenced DR eye care behavior among Indigenous women vary with an interplay between social, cultural, economic, and institutional factors. The study findings showed that to address DR knowledge and eye care behavior among Indigenous women living with or at risk of diabetes, diabetes-eye care promotion strategies that are supportive and encourage the women to make informed health decisions was essential for overall diabetes care.

# 5.2.2 Impact of DR mHealth Intervention

mHealth interventions impact health outcomes and behaviors in various ways. As support in the management of diabetes, it enables users to maintain health goals by providing useful information and guidance (301).

The mHealth intervention in this study aimed to provide information that will impact DR knowledge and diabetes-eye care behavior. Since diabetes and DR affect all aspects of one's life, the medicine wheel by Mussell (2005) was used as a tool to assist with the organization of the data on the impact of the DR mHealth intervention. Thus, the impact is discussed based on its effect on participants' physical, emotional, mental, and spiritual health.

## 5.2.2.1 Physical Health

As mentioned by Mussell (2005), within the medicine wheel worldview, physical health represents food, shelter, exercise (85), and it also represents action and behavior (302). The intervention enabled participants to recognize their physical health needs and via self-awareness took the responsibility for making positive changes. The impact of the mHealth intervention on physical health is discussed based on its influence on physical activity and personal wellness, and diabetes-eye care behavior.

# 5.2.2.1.1 Physical activity and personal wellness

Most individuals living with diabetes fail to engage in regular physical activity despite it being highly recommended for better control of glucose and other risk factors, and improved quality of life (303). Thus, the mHealth intervention sought to find ways to encourage and incentivize physical activity. Study findings support that the intervention provided insights on the importance of personal wellness and consistent with other mHealth based studies, the intervention had a key impact on physical activity behavior as reflected by participants' report of increasing physical activity via walking and weekly exercises to maintain health (304, 305).

Findings from this study suggest that the mHealth intervention encouraged participants to engage in physical activities and enhanced control regarding personal wellness, which are essential for health care (273). The study findings support similar health messaging research in that it enhanced changes in participant's physical activity behavior via providing support and prompting self-monitoring (305). Also, the results support mHealth intervention as a useful tool

for patient empowerment due to message prompts that fostered taking-up various forms of physical activities (306).

Although the study findings support that the intervention inspired participants to engage in various activities for personal wellness via reported self-management actions, it is difficult to clearly infer that the intervention improved healthy lifestyle.

# 5.2.2.1.2 Diabetes-Eye care Behavior

A change in DR eye care behavior was observed following the mHealth intervention. The comparison between the pre and post-practice score showed that post-intervention practice score significantly increased. Related findings from SMS intervention studies for chronic disease management equally indicated improved adherence to treatment and disease prevention actions due to mHealth interventions (307, 308).

In contrast to Lee et al. (2014), who indicated that participants 40 years of age or older in Miami with a self-reported diagnosis of diabetes were more expected to report seeing an eye care provider if they indicated a history of receiving diabetes education (309). A major finding in this study was that older women had significantly lower DR attitude and practice score post-mHealth intervention compared to younger women. In addition, older women 46 years and above had significantly lower pre-post-change in practice score compared to women 18-45 years of age. Hence, the older the woman, the lower the DR eye care behavior score.

This may be due to some reasons one of which could be because older adults are usually anxious towards using health information technology; however, older adults who overcome this anxiety, tend to possess confidence in managing their health and health care (310). Another reason could be because older women may find it difficult to read text messages due to reduced visual acuity. Also, they may not have read the messages every day and missed key messages. The study findings demonstrated that early mHealth interventions among women living with or at risk of diabetes may have a better impact on the DR eye care behavior than when introduced at an older age. Given that older women are more likely to develop DR and older adults with vision loss are more probable to have more health complications (311), it is imperative that mHealth interventions can equally motivate older adults living with diabetes to prevent and control DR.

Another key finding in this study was that the DR attitude and practice post-score for women living with diabetes significantly increased compared to those at risk of diabetes. The experience of living with diabetes may have encouraged engagement with the mHealth

intervention and influenced eye care behavior. This is consistent with a study in Alberta, Canada, which supported that the presence and duration of living with diabetes affected the uptake of mHealth applications (312).

Furthermore, the study findings suggest that women with higher education background had better DR practice score compared to others with no formal education/some high school education. Although there was no significant difference in the post-intervention DR knowledge score based on educational background, it is important to note that low education and literacy level are common characteristics associated with limited health technology use (313) and influence the uptake and impact of mHealth interventions. Thus, illuminating the importance of tailored mHealth intervention content to meet the literacy level of all participants so that the intervention is impartial.

As a result of the intervention, some participants watched sugar intake, began to control blood sugar, and one participant stated she felt, "fit, feeling better about herself." Participants had their eyes tested, one of the women booked an eye exam despite not having an eye test since she was six years old. Others mentioned that as a result of the intervention, they were keeping up with medical check-ups and would see their optometrist, dentist, and doctor regularly. Others indicated that they would make an eye appointment.

Additionally, participants described that the messages reminded them to take their medication or to check blood sugar levels and that they received support from knowing that the researcher was thinking about and responding to their requests. This was consistent with related mHealth based diabetes studies where participants felt positive, optimistic, encouraged, and supported as a result of receiving helpful reminders to check blood sugar and/or to take medication (304, 314), as well as a regular physical activity reminder (305).

The impact of the intervention on the diabetes-eye care behavior of participants aligned with some text-messaging intervention studies that improved the self-management of diabetes and various health outcomes among individuals living with diabetes (315, 316, 317). On the other hand, it is important to state that not all diabetes mHealth initiatives produce a positive outcome on diabetes management and outcomes.

Nonetheless, the study findings showed that the mHealth intervention had an impact on physical health and the diabetes-eye care behaviors among participants. In alignment with self-determination theory, the health changes may have originated from participants having autonomy

and control over health decisions. The mHealth intervention did not require participants to carry out activities such as sending health data on weight or physical activity while on the study. Hence, participants had control over decisions made.

#### 5.2.2.2 Emotional Health

Within the medicine wheel worldview, emotional health represents understanding, acceptance, privacy (85) and relationships (302). The mHealth intervention became a source of emotional support and motivated participants to improve diabetes-eye care of self and others.

Emotional support for users is often present via text-based mHealth applications (314) and participant's confidence in decision making tends to increase due to gaining knowledge regarding diabetic-health conditions obtained from various sources including technology platforms (301). As such, in this study, the emotional impact of the intervention varied.

# 5.2.2.2.1 Anxiety from messages

The study results uniquely revealed that the mHealth intervention resolved the perception of fear due to diabetes, enhanced feelings of hope, relief, positive/good feelings. One participant verbalized she felt, "content and less anxious about eye health". Other participants indicated that the intervention provided information that reduced the stigma and anxiety around diabetes.

On the other hand, an unanticipated outcome of the intervention was an increased feeling of anxiety over health status. This is noteworthy and should be of utmost consideration when utilizing mHealth for marginalized populations. Indigenous peoples are resilient, nevertheless, they are exposed to more stressful situations in their daily lives such as marginal economic conditions when compared to the general population. The anxiety may have been as a result of a design flaw in the intervention, given that the messages were delivered using different numbers which can produce unwanted and unanticipated user experiences and influence use of the mHealth intervention (318). The literature suggests too that the anxious feeling associated with the use of mHealth intervention can reduce health service use (319). Therefore, mHealth interventions for marginalized populations should be implemented/designed in a way to reduce and not heighten fears/anxiety.

As such, the study findings established the importance of communicating with participants during the intervention, whether in person or via the mHealth platform. For example, a message such as, 'If you are experiencing anxiety from these messages, please contact this number', could have been sent at intervals during the intervention. Also, regular one-on-one

interaction with mHealth intervention users could be beneficial, so that worries can be addressed, and appropriate support provided. This interaction may be feasible if the mHealth intervention is integrated with regular workshops or programs that foster social support and the strength to cope with anxiety and improve health in general (320).

# 5.2.2.2.2 Sharing messages

Technology is frequently used for communication and/or for sharing of information, and a major outcome of this study was that information from the mHealth intervention was shared with family and friends. Another key study result was the impact of the mHealth intervention on participant's perception on the importance of connections and relationships in health care management that inspired them to build relationships to "help raise community awareness" of DR and give back to the community. Here, emotional needs were met by connecting with family and friends. For instance, one participant stated she shared the messages with some of her relatives.

Relatedness from community, friends, family as well as from health care providers is essential for diabetes care among Indigenous peoples (321). In addition, family and community relationships and connections play a critical role in supporting health and well-being among Indigenous individuals (207).

Participants used and shared the information with family members and others and saw the importance of seeking family and Elders for support when they had a concern. The study findings showed the potential of mHealth in promoting engagement with community members while aiding health education and promotion.

## 5.2.2.2.3 Communication with Health care professionals

Another outcome was that the mHealth intervention provided extra support that the women considered important for diabetes-eye care which during regular health care visits, was not provided (158). Participants reported that interactions with health care providers were frequently brief and in the words of a participant, health care providers made them "feel like another number, not a person". Hence, the results revealed that it is essential for health care professionals to create opportunities to interact with Indigenous women living with or at risk of diabetes about diabetes-eye care.

Interpersonal communication is an important influence on health care access and service utilization. Treating Indigenous people like "another number" discourages them in managing and controlling diabetes, along with demotivates the use of health services (293). In respect to self-determination theory, understanding and support of health care providers enable building relationships and connections that motivate individuals to make positive changes in health behavior.

Compliance with treatment regimens and management of health conditions such as utilization of DR screening for prompt diagnosis, is fostered by relationships and improved interactions between health care providers and service users (322, 296). Therefore, it is essential that there is ongoing and continuous communication. The study findings showed that health information via mHealth intervention can be used to not only increase health literacy but also support and strengthen patient-doctor relationship and communication during one-on-one visits (323).

## 5.2.2.2.4 Communication with the researcher

The study findings showed that the researcher's interactions with participants during the intervention reinforced the impact of the mHealth intervention. The findings showed that technology-driven interventions should maintain an element of "human" connection and the relationship developed can encourage participant interest, use, and engagement, as well as influence health care. Therefore, a SMS-based mHealth intervention may require support with additional personal contact (166). As evidenced in related studies where inclusion of counselling and in-person contact/human support in text messaging interventions increased women's knowledge and fostered improved health practices and provided a social presence in a way that encouraged the continued use of the mHealth intervention (324, 325).

In the frame of self determination theory, the mHealth intervention appeared to encourage relationships, communication, and connection with family, friends, and health care professionals. This relatedness fosters intrinsic motivation to make health changes and is essential for emotional wellness.

#### 5.2.2.3 Mental Health

Within the medicine wheel worldview, as stated by Mussell (2005), mental health refers to thoughts, concepts, and ideas (85). These cognitive needs provide a means to expand thinking skills and make meaning of life experiences (85).

Increasing the health education and awareness of the risk of vision loss from DR is an eye-health promotion strategy for individuals living with diabetes (55), by providing essential information that will enable individuals reach and sustain health care goals, along with providing reassurance (301). Hence, it was fundamental that the mHealth intervention improved awareness and was relevant.

The post-intervention findings indicated that the mHealth intervention increased awareness of DR, diabetes, and eye care in general. The intervention evoked feelings of hope and "good thoughts", and stimulated participants thoughts regarding diabetes-eye care, and management and prevention of diabetes-eye complications. The post-intervention study findings showed that the mHealth intervention significantly increased participant's DR knowledge, attitude, and practice scores compared to the pre-intervention scores. Consistent with a related study which observed that mHealth messages led to improvement in patients' knowledge (326). Thus, the mHealth intervention in this study, facilitated knowledge/education of DR and diabetes-eye care which impacted their behavior towards diabetes-eye care.

Another outcome of the mHealth intervention was that participants voiced that the mHealth intervention delivered novel information and improved knowledge of DR. This may have been due to incorporating their requests from the first sharing circle pre-intervention, as such, the information was useful to the participants. Connected research noted that these factors influence the way individuals utilize mHealth services (327). Also, a timely, novel, and up-to-date information, is usually considered desirable, relevant, and engaging (328).

An outcome of the mHealth intervention was that it provided more information than was usually received from health care practitioners. This was similarly observed by Watterson et al (2018), where participants felt that compared with information received during health appointments, they received more extensive information via mHealth messaging services/interventions (314). This shows the potential of mHealth initiatives in providing adjunct health service to users. Nevertheless, it raises concern that health care practitioners are not providing enough counselling and information to patients during health appointments, which is best practice and essential for the prevention and management of diabetes complications.

Furthermore, another outcome was that the mHealth intervention served as a medium for providing diabetes-eye care related reminders to participants. It appeared that reminders as a result of the mHealth interventions was important for daily health care and the development of

self-management habits. Consistent with related research, text messaging due to the instant delivery, provided testing reminders, and strengthened diabetes self-management (329).

In alignment with self-determination theory, the mHealth intervention provided participants with the tools to develop insights about DR and empowered them with the competence to make autonomous decisions to prevent/manage diabetes-eye conditions. From the literature, autonomy is closely related with empowerment (330). Empowerment is vital to health care because empowering populations at risk facilitates autonomy and control through self-management (331). Self-management via mHealth is more than information exchange rather, by supporting autonomy, and providing guidance and advice for better care, mHealth provides navigational help, reminders, recommendations, and encouragement (299).

# 5.2.2.4 Spiritual Health

For the purpose of this study, spiritual wellness is defined as connectedness with creations of the Great Spirit (85). A person's spiritually is connection to the land, the people, and the community.

Research showed that SMS-based mHealth interventions often stimulate self-reflection (159). The same was observed in this study along with other key findings where the mHealth intervention reawakened in participants the importance of balance and taking care of "whole self, not just aspects" in diabetes-eye care. The intervention encouraged participants and they shared that they engaged in the following activities that enriched their spiritual health, offering tobacco, meditation, being with nature, smudging, connecting with Elders, pow-pow, and giving thanks daily to the creator.

The mHealth intervention appeared to be holistic and aligned with concepts described in the medicine wheel. Perhaps the use of the medicine wheel as a tool in the evaluation provided participants an opportunity to discuss their spirituality, and it brought to light how many of them were practicing spiritual practices.

Participants expressed they felt, "lifted, reawakened, and heartfelt". Thus, the mHealth intervention uplifted participants, promoted hope, and served as a support in their health, diabetes-eye care, and experiences living with or at risk of diabetes.

# 5.2.2.5 Summary points regarding impact of the mHealth Intervention

The findings from the effects of the mHealth intervention are congruent with self-determination theory. In the frame of the theory, the mHealth intervention provided diabetes-eye care

information to study participants that up-lifted and motivated participants, in addition to, supporting autonomy and confidence regarding diabetes-eye care. The mHealth intervention provided a holistic approach to support of diabetes-eye care. Holistic care respects autonomy and provides support for self-efficacy (332).

The mHealth intervention created awareness about diabetes-eye care, provided information previously unknown and served as health care reminders. Indigenous women in the study identified with values during the intervention which empowered them to engage in behaviors including eating healthy, taking medication as prescribed, having regular medical and eye check-ups, and building relationships in the community.

# 5.2.3 Perception of mHealth as a Tool for Health Information

Mobile health services are regularly delivered via various mobile technology platforms (268). Advances in mobile phone designs have created the ability for messages to be creatively offered in multiple formats across different populations. An understanding of how populations engage and use these technologies is important (333) as it will illuminate various factors to take into account when developing and implementing mHealth interventions in Indigenous populations.

# 5.2.3.1 Delivery Style

mHealth utilizes different stimulus types that align with various platforms for dissemination. The stimulus types are linked with the delivery styles such as text, voice, sound, or image (334). However, there is insufficient evidence as to which delivery style/method is best at increasing uptake of mHealth interventions because a delivery method that is suitable for one population may not be appropriate for another (334).

# **5.2.3.1.1 Mobile Apps and Internet**

This study showed that the preference of the mHealth platform varied by individual choices and characteristics. For instance, in this study, some participants highlighted the need for mobile applications (apps) rather than text messages for better and prolonged engagement with the educational context. This was suggested by several young women in the study, which may be due to digital knowledge and use of advanced mobile technology by younger women. Hence, adapting mobile apps for diabetes-eye health education to better meet the needs of the young population may increase the use of apps for self-management of diabetes and eye care, via

improved engagement (312). Nevertheless, the ability/inability to use mHealth apps can create a gap in care especially between the younger and older population.

Some participants suggested the use of the internet for mHealth initiatives. This is promising as age is becoming less of a barrier to the use of mobile technology as evidence has shown that internet adoption among older adults is climbing. Stellefson et al. (2017) indicated that a majority of older adults use the internet for various needs (310). Individuals living with diabetes are obtaining diabetes information via the internet (335). In addition, Aboriginal people living with diabetes in Australia used the website "How's Your Sugar" for health promotion (284).

Nevertheless, in Canada, internet access as well as the use of apps is affected by income (313). Also, worldwide, one of the countries with the highest wireless data cost is Canada (336). Using the internet or mobile apps for the dissemination of health messages may limit the access and use to people who can pay for internet services and afford/own smartphones for the download of mobile apps, thereby introducing inequity.

## 5.2.3.1.2 Voice/Audio Messages

Another major study finding was the use of audio messages in distributing health messages. Several participants suggested voice messages in different Indigenous languages, buttressing the need to incorporate cultural components when developing mHealth interventions. This can occur by using targeted strategies such as audio versus text messaging. Voice/audio messages in various languages could also compensate for literacy difficulties.

In addition, cultural continuity and preservation are instrumental to health and self-determination; and defined as "the preservation of traditional culture and often assessed by the knowledge of Indigenous languages" (337, p2). So, including Indigenous languages in the design and implementation of health messages may also aid in the preservation of Indigenous languages. DR screening initiatives may be improved by utilizing traditional languages in the intervention (338). Also, research showed that there is a positive relationship between preservation of culture and diabetes prevalence among First Nations peoples (337).

Nevertheless, although voice messaging has many advantages, in many situations, messages sent via voice platform cannot be saved for future reference and may not be received by the intended recipient on time. Text messaging on the other hand, can be saved and referred to later. Hence, it may be a better method of message delivery than voice messages (305).

## 5.2.3.1.3 Two-Way messaging

The study findings revealed that mHealth interventions that enabled users to send questions and receive a timely reply would enhance mHealth usage and engagement. This was observed in similar research which concurred that limited targeted feedback while using mHealth services reduced its impact on diabetes self-management (339). It is important to mention that a mHealth intervention with the capability of two-way messaging, could reduce anxiety and provide support to users.

There is interest in bi-directional messaging with health care providers in mHealth interventions (340). For instance, a mHealth intervention *EpxDiabetes* (341) was developed on the premise that personalized feedback from health care providers is essential for mHealth uptake and engagement. Similarly, there is high interest in mobile applications that allow for scheduling doctor appointments and two-way communication with health providers (342). But, there may be no difference between the impact of one-way messaging versus two-way messaging (316).

## 5.2.3.1.4 Picture/ Image messages

The study findings showed that participants were interested in picture health messages sent via mobile phones. mHealth initiatives that provide a visual representation of the information tend to enhance understanding and acceptance among users particularly if the images were requested. Based on Mayer's multimedia principles, combining images and words enhances knowledge acquisition and learning (286). Furthermore, the use of diagrams and pictures to explain health conditions and instructions improve communication in health care (343). But not all phones have the capability to receive picture messages; hence, sending health messages solely as images would impede equitable access to the health information among individuals with basic mobile phones.

#### 5.2.3.1.5 Text/ SMS Messages

The study findings indicated that irrespective of other mHealth platforms, text messaging was considered reliable, easy to use and easily accessible, which are all essential components and objectives of mHealth initiatives. Despite the potential of mHealth in health care management, it is vital to ensure that the intervention is available to all populations equally (344).

mHealth interventions has the potential to both reduce and increase health inequalities because, within the same population, effective mHealth design for one group could bring about negative and unforeseen consequences for another group with different characteristics (313). For instance, younger people often obtain smartphones compared with older people (345). Hence, mHealth interventions that leverage smartphone platforms such as mobile apps would be unavailable to individuals who do not own a smartphone. It may result in variations in the management and outcome of health conditions among individuals within the same population. In order to provide an equitable mHealth intervention, content would have to be made available for various platforms.

A systematic review assessing the impact of mHealth interventions in different health conditions found out that SMS was the most widely used platform addressing chronic disease management and showed a positive impact on clinical outcomes, treatment and care, and health behavior (346). Studies showed that irrespective of age or gender, text messaging are often preferred in health messaging. A case in point, Dobson et al. (2017) suggested that mHealth via SMS was preferred for the management of diabetes due to its convenience (329). Also, women would rather use cell phones rather than computers to receive health information (345), and women tend to react better to text messages than email messages (347). This may be because of the privacy of messages, ability to retrieve and refer to text messages (348), and share text messages with family and friends.

#### 5.2.3.2 Nature of Message Delivery

The results showed that the participant's interest and engagement with the mHealth intervention in this study was influenced by the consistency of the number used to send the text messages. This indicates that being able to relate to and connect a phone number to a mHealth service can influence intervention use. Number consistency may also reduce anxiety on receipt of messages since participants would be aware of the source of the message.

Furthermore, study results showed that daily receipt of text messaging could support interest and use of the mHealth intervention. Related research showed that the regularity of text messages was vital in mHealth education interventions (349), and some users preferred receiving health messages at least once daily (329). Nevertheless, the messaging frequency should be modified based on the perceived importance of the intervention in the user's life (334). It is crucial to explore the "dose-response effects" (251, p1) of the mHealth intervention and make

sure that distributing high doses of the intervention does not result in information overload and over burden the users.

Also, the findings showed that some participants were unable to partake in the mHealth intervention due to change of mobile phone number, providing a house phone number, and non-reachable numbers. Inability to reach individuals is often present in health care management, for instance, in the UK, individuals living with diabetes did not attend a diabetic-eye screening programme due to inability of health practitioners to contact more than 50% of patients and many patients had phone numbers that were not in use (296). This supports the importance of using different approaches to reach out and contact individuals.

Finally, although there is a high rate of mobile phone ownership worldwide, some individuals manage mobile phone cost by sharing mobile phones with family members (176). This may deter the receipt of messages by the intended user and reduces privacy. Non-receipt of mHealth messages poses a concern for the use of mHealth interventions in disseminating health messages because it will hinder the intervention.

### 5.2.3.3 Message Content and Format

The study showed that disseminating repeated messages, the inclusion of specific health information/tips, and integration of mHealth interventions with group activities was crucial when using mHealth as a tool for health information.

Pushing out repeated messages was welcomed by some participants as it served as a reminder of key information. Adults generally benefit from repeated reminders, especially older adults in order to improve memory (350). However, the repetition of messages may lead to boredom among users (351). A possible suggestion would be to provide the option for users who require more information to request for it.

The content of the mHealth intervention was considered as very important. Some participants suggested specific nutritional tips that could enable them to make better informed choices in preventing and managing diabetes. Indicating the importance of tailored and personalized messages which a study showed increased satisfaction with text messaging interventions in Indigenous populations (352). Yet, sending personalized messages will make the delivery of the intervention more complex and could increase cost.

Furthermore, a finding that stood out in this study was that integration of group activities into mHealth interventions was integral in health information dissemination. Some study

participants expressed the desire to attend other diabetes programing to continuously keep them informed about diabetes and its complications, thereby indicating they valued learning from peers and the support present in group activities.

Social support is important to health care and influences health outcome. Gathering together and participating in activities is familiar and uplifting for Indigenous women; it provides support and is an opportunity for women to share health experiences and stories (353). Health promotion events that provide connections and support groups are relevant (354). Thus, the study findings showed that, along with providing health information, mHealth interventions should be combined with group activities to create an environment of encouragement and social support.

Participants voiced a preference for more relatable and less formal tone of messages. Similarly, participants indicated that providing supportive, suggestive, and non-pushy health information, enhanced engagement with the mHealth intervention. Also, participants related to the messages and were motivated to take informed action towards improving their health.

Individuals respond to different tones of health messages, whether it be empathetic, authoritative, or motivational (355). People generally respond well to a kind word or encouraging message; hence, in the context of self determination theory, positive and supportive messages would be preferred as this type of message is not forceful and threatening, but rather empowering and impacts confidence. It is essential to explore the favoured tone and the preferences of the intended user population and pretest the messages before distribution.

# 5.2.3.4 Summary points regarding mHealth use for health information

The findings revealed some unique perceptions of using mHealth for health information among Indigenous women. Although the perceptions mentioned here regarding using mHealth as a tool for health information represented the views of Indigenous women in this study, the suggestions may be transferable to various populations. mHealth interventions must be designed to be culturally appropriate and acceptable to intended users so that it can promote uptake and engagement with the intervention for sustainable health care. This can occur from the use of a single or a combination of mobile platforms, repeating key messages, distributing messages using an identifiable number, ensuring that the content of the messages addresses the population's need, sending the appropriate frequency of messages, utilizing supportive and encouraging messaging tones, and including group activities in the design of the mHealth intervention, for an enriched and equitable use of the health information.

## **5.3** Summary of Discussion of Results

The study findings provided insights on factors such as limited understanding of the eye care procedures covered by NIHB and provincial health insurance, poor vision and eye complications that influenced DR eye care. In addition, fear and anxiety as a result of personal or family experience with diabetes and its complications as well as fear of judgment, particularly from healthcare providers affected the DR eye care.

The mHealth intervention impacted DR awareness and diabetes-eye care behavior of participants. The intervention motivated participants to make changes regarding diabetes and eye care such as exercising and visiting healthcare practitioners. Participants also shared the messages with family.

The study findings articulated that factors such as the message content, the delivery platform, the format of the messages, and the tone and frequency of messages need to be considered in the implementation of mHealth interventions among Indigenous peoples.

## 5.4 Quality and Rigor

To ensure the study findings were trustworthy and valid throughout the study, a systematic approach was utilized to recruit study participants and carry out the research (356). A clear description of decisions made in every phase of the research was provided.

# 5.4.1 Rigor and Trustworthiness in Qualitative Study Phase

Research with Indigenous peoples encourages a reconsideration of the meaning of validity; thus, when reflecting on the quality of the study, validity issues are often different compared to a non-Indigenous based research (182). Chapter 9 of the Tri-council policy statement notes that in research with Indigenous peoples community member should perceive the research as relevant (84). Thus validity in Indigenous research takes into consideration the ability to ethically carry-out research that is relevant to the community and gives back to community (357).

In this study, the researcher leveraged the three criteria of validation when using a qualitative approach as suggested by Kvale and Brinkman including validity as: the quality of craftsmanship, communication, and action (358). Validity as quality of craftsmanship infers that the credibility of the researcher impacts the reliability of the findings reported. In this study, validity as quality of craftsmanship was established by providing a clear description of study

stages, transparency, following up on surprises that presented in the study, exploring rival explanations, and getting feedback from community members and study participants.

"Validity as communication" was established by assessing the information/knowledge shared during the study alongside dialogue with participants and community members in order to clarify and validate the information (358). Indigenous research should give back to the community and support well-being (182). Here, "validity as action" is the application of the study and acting on the interpretations (359, p32). Thus, the mHealth intervention provided needed information to support health, and upon request from some participants and research partners, the researcher provided workshops at different community events in Saskatoon to address the DR knowledge gap.

Terms such as credibility, transferability, dependability, and confirmability are used in qualitative research as qualitative terminology roughly corresponding to the quantitative terms for internal validity, external validity, reliability, and objectivity in quantitative research (360). Hence, the trustworthiness of the qualitative data in the study was described based on these terms.

# 5.4.1.1 Credibility

Credibility involves showing that the results and interpretations truly represent the data (361). Extended engagement with participants enabled the researcher to interact and build trust with community members, learn more about the culture, and provided the opportunity to check for misinformation that may originate from the researchers' bias and prejudices. Different sources were used to provide supporting information that clarified the impact of the intervention. Diabetes and eye health care professionals revised and validated the mHealth content to increase content credibility. In addition, community members reviewed the messages to enhance its cultural acceptability and relevance.

Although member checking with community members may result in different and sometimes conflicting interpretations (359), it was important that participants and community members were included in the analysis and interpretation of research. Creswell (2009) suggests that member checking is carried out using themes from the data rather than the actual transcripts (190). As such, the researcher presented preliminary findings of the study to the community members and some participants and obtained feedback on the findings. This was carried out to

ensure proper interpretation of the data, reveal missing information that was not addressed, and confirm that the data interpretation aligned with participants' views.

To strengthen the credibility of the analysis, transcripts were coded by the researcher and the derived themes were reviewed by the research supervisor, research advisory committee, and community members.

## 5.4.1.2 Transferability

Transferability refers to the extent the qualitative findings is applicable or can be transferred to other context with other populations (362). Generalization is not solely the ability to draw inferences from samples to populations, but also the ability to apply concepts derived from the study of an occurrence in one group to the understanding of a similar occurrence in a different group (363).

As such, a rich description of the research process was provided. The researcher ensured that participants' perceptions were clearly included in the study, in order to show how the study findings can be transferred to other settings and assist in making decisions regarding transferability to other settings (360).

## 5.4.1.3 Confirmability

Confirmability refers to the ability of other researchers to confirm study findings (361). Field notes were kept to document decisions in the research process such as choosing the intervention, refining the survey, content development, analyzing the data, and interpreting the results. The SSRL team transcribed the sharing circle discussions and the researcher confirmed the transcriptions.

#### 5.4.1.4 Dependability

Dependability speaks to the fidelity in data collection, data analysis, and interpretation, and shows that the findings are consistent (364). The methods and research processes were carefully and explicitly documented, and the instruments included in the appendices, thereby providing sufficient detail to ensure the reproducibility of the study findings (365).

Debriefing was carried out with the community members and research supervisor during data analysis and involved exploring and clarifying interpretations. According to Creswell and Poth (2018), this review process provided an external check and impacts the dependability of the data (360).

A good-quality digital recording was used, and word-for-word transcription ensured that the data was reliable. The same guide was used for all sharing circles to ensure consistency in data collection. Nevertheless, the sharing circle discussions were fluid and follow-up questions were asked based on the direction of the discussions in the groups.

## **5.4.2** Quality in the Quantitative Phase of the study

Establishing the quality of the quantitative phase of the study was based on an assessment of the research design, methods, processes, and procedures in the study. The study design and methods were adequate to answer the research questions. Also, there was no change in the measures/methods used in the pre and post-study.

During data analysis, confounding variables were controlled for using multivariate analyses. Included in the study were the common and known factors for DR knowledge and eye care behavior based on literature. However, there may be some other unmeasured potential confounding variables in this study such as the duration of diabetes and the presence of other eye conditions. This could have influenced the reported DR knowledge and eye care behavior of participants since the longer the duration of diabetes, the more likely the individual would develop eye complications, the individual may have visited an eye doctor for DR, and therefore be more knowledgeable about DR. Also, if participants are already seeing an eye specialist for other eye conditions such as glaucoma or age-related macular degeneration, their eye care behavior may be more frequent than people without other eye conditions.

Furthermore, many of the associations between KAP of DR may not have been statistically significant due to the small sample size used for analysis especially in the post-intervention. There were several threats to validity in the study due to the pre-post-study design and mixed methods approach; these are discussed in the next section.

## 5.4.2.1 Threats to Validity due to Study Design

A limitation associated with pretest-posttest study design is that the outcome can change over time for various reasons apart from the intervention. These factors could masquerade as an effect of the intervention or hide an effect that exists (366). A case in point, participants with ongoing eye disorders may have already scheduled eye tests scheduled and attended eye appointments within the intervention period. Irrespective of receiving the intervention, the participant would have increased eye care behavior as a result of visits to the eye doctor. Making the intervention

appear to have caused a change in eye care behavior, even when it was not responsible for the behavior.

Although the study design was suitable to access the impact of the mHealth intervention, it was difficult to explicitly show causation because the change documented may not solely be as a result of the intervention. This study was a single group pre-post-test as such, there was no control group to compare the impact of the intervention; thus, limiting our assessment to participants' reported accounts in the survey. Nevertheless, participants provided rich descriptions of the outcome of the intervention and their experiences that increased our understanding of the impact of the intervention.

Moreover, the changes may have occurred due to other factors apart from the mHealth intervention such as Hawthorne effect (367). Since participants knew that they were participating in a study and experiencing the novelty of it, participants could have reported a change in behavior that did not exist; thereby, showing a trend that the intervention impacted DR awareness and eye care behavior though it did not.

Furthermore, simultaneous co-interventions could have affected the study findings. Co-intervention bias may have occurred because some participants may have received two or more interventions during the study such as attending other diabetes care programs in Saskatoon for instance programs provided by SIMFC and LiveWell, and there may have been a carryover effect between interventions. Information about other diabetes programs occurring during the mHealth intervention was not collected. Therefore, the effect observed in this study may be partially/totally related to other programs happening at the same time with the mHealth intervention.

## 5.4.2.2 Threats to Validity due to Mixed Methods Approach

Mixed methods approach often has sampling challenges such as having inadequate sample sizes for quantitative analyses and estimating appropriate sample sizes for both phases due to both quantitative and qualitative designs having separate sampling principles (186). In this study, threats to validity arose from decisions regarding sample size for the quantitative phase of the study since participants were recruited based on qualitative sampling approaches. Participants were purposefully selected, and the selection criteria prevented coercion because participants voluntarily indicated interest in every phase of the study. Nonetheless, the selection of participants for the quantitative phase of the study did not meet the requirements of quantitative

sampling (262) and may have introduced selection bias in the quantitative phase of the study. Participants were not randomly selected; thus, the population does not represent all individuals living with or at risk of diabetes in Saskatoon. Volunteering for the study may have also introduced "volunteering bias" because the participants who volunteered may have been different from women who were not willing to participate.

Another major source of selection bias in this study was the loss to follow-up and non-response during the post-intervention study phase which may reduce the validity of the result (368). Based on the analysis of the difference between participants in the pre and post-study, there was a differential loss of participants as a result of education and work status. Therefore, data from women who were less educated and women not working were not equally represented in the post-intervention study and may have distorted the findings. If the women lost to follow-up stayed in the study, it may have changed the study results. However, the DR KAP scores of participants who completed the study were not significantly different from participants who did not complete the study pre-intervention.

### 5.5 Other Strengths and Limitations of the study

## 5.5.1 Strengths

A strength of this study was having a diverse study population with participants across different age groups, at various risks of diabetes, with type 1 and 2 diabetes, as well as both First Nations and Métis women of various education levels and working status. Since the research population was small, it would follow that the study was not aimed at delivering broad generalizations about all Indigenous women with diabetes or at risk of diabetes living in Saskatoon. However, the findings provided rich insights into the perceptions of Indigenous women in the study population and their DR awareness and eye care behavior.

Additionally, the theoretical basis of the research and content development was a strength. SDT theory informed the research processes and the tone and manner of the messages formed. Also, the mHealth intervention reinforced messages from standard diabetes and DR care in Saskatoon. The intervention used a basic message delivery platform; hence, the intervention was uniformly accessible to all participants irrespective of the type of phone they possessed. The research design and procedures enabled participants and community members to provide input in the research process and mHealth intervention.

#### 5.5.2 Limitations

It can be challenging to explore the impact of mHealth interventions especially regarding accurately including the appropriate participants (265). As such, a limitation of the study was the self-identification of diabetes status and the use of self-reported data for ascertaining KAP; the possibility of self-reporting bias cannot be excluded. Nevertheless, self-reports are commonly used for accessing DR KAP (234, 279, 135).

Granted that member checking with participants would prevent misrepresentation of interpretations from the study discussions (369), the researcher was unable to carry out detailed member checking because it was not possible to reach all participants that were part of the sharing circle discussions. In addition, this study was limited to the Indigenous population in urban areas. Health care accessibility, technology services, and population demographics are different in rural areas.

Limited information technology infrastructure to provide services as required deters mHealth implementation (370). For example, the content delivery was pretested for three days before message dissemination to resolve and fix technical bugs and make improvements in the portal used for delivering the text messages. Despite that, some participants did not receive some messages on the first two days of distribution. Nevertheless, messages were re-sent to participants who did not receive the first two messages.

Also, the portal used did not distribute messages using the same phone number instead, four different numbers were used to send out the messages for the entire 12 weeks. This may have been confusing to participants; however, to ensure that participants recognized the origin of the text message received as from the study, each message began with "Diabetes-Eye Study."

Some participants provided their landline rather than mobile numbers as such, were unable to receive the messages. The researcher corrected this mix-up for most participants by meeting with them at various LiveWell and SIMFC programs during the implementation of the mHealth intervention. Two participants did not receive any message throughout the entire 12 weeks and were only able to do so during the post-intervention study phase. Also, some participants who changed their mobile number during the study period did not inform the researcher of the change and did not receive some messages. The researcher ensured that the participants received the messages during the post-intervention sharing circles via text, print, or

email as requested. Also, they all received the flyers with key messages. Also, the inability to have two-way communication with participants via the mHealth platform used limited this study.

### 5.6 Implications on Population health, Practice, and Policy

This study provided information about DR knowledge and eye care behavior that can serve as a foundation for development and implementation of future health promotion initiatives and contribute to the advancement of DR knowledge among urban First Nations and Métis people living with or at risk of diabetes.

Population health interventions regarding diabetes will benefit from prevention, self-management of diabetes and its complications, and equity in diabetes care (371). This study showed that mHealth was feasible for diabetes education and eye health promotion. The intervention can augment diabetes health care by providing additional support to individuals living with or at-risk of diabetes particularly between doctor visits to improve diabetes care and encourage the use of diabetes care services. This could lead to improved long-term clinical outcomes for persons living with diabetes.

The study identified socio-cultural factors influencing diabetic-eye care service utilization. The factors provide important insights about changes that could be focused on in population health interventions/programs to increase awareness of DR and diabetic-eye care among Indigenous peoples living with or at-risk of diabetes.

The process of developing the diabetes-eye care mHealth intervention can support future developments of health promotion strategies for several health conditions. In addition, although the study articulated features that would influence the use of mHealth interventions among urban First Nations and Métis women; nonetheless, the same features may likewise apply to the implementation of mHealth interventions in other populations.

There are limited epidemiological studies exploring vision loss and DR rates in Canada (62), and this limits planning population eye health programs. This study provided evidence that can enable researchers, health care practitioners, and policy makers to understand the current landscape of DR, and the actions required in order to promote diabetes eye care service uptake and inform prevention programs. The study also showed the use of mHealth in context which can be incorporated into present diabetes services provided in Saskatchewan.

Additionally, since more educated people remained in the study post-intervention, it has important implications for practice and for the future design of mHealth interventions because

the intervention may not have met the needs of less educated people. So, integrating mHealth intervention with other programs/services in the community and presenting health information via other mediums rather than only using text messages such as through group activities or workshops may widen reach, interest, and engagement. An integrated diabetes care strategy along with diabetes-focused stress management interventions may be promising to improve diabetic-eye care and lead to an overall decrease in diabetes outcomes in Indigenous populations.

#### 5.7 Research Contributions Summary

There is limited information regarding health promotion of diabetic-eye care among Indigenous peoples in Canada. This study makes various contributions to science by adding to the literature on DR and diabetic-eye care in Indigenous populations by identifying factors influencing eye care among Indigenous peoples in urban areas. In addition, this study has contributed to the process of creating text messages based on population characteristics.

While text messages have been used extensively in diabetes and chronic disease management in Canada, text messaging has not been used for eyecare. Hence, this study contributes to the literature on eye health management via mHealth.

This study also makes contributions to healthcare by providing information that can be utilized in designing mHealth interventions for Indigenous populations. Furthermore, the study highlights the importance of ongoing and continuous communication between health care practitioners and clients. As such, it demonstrates the various mHealth platforms such as via voice, text, mobile applications that health care practitioners can utilize to provide additional support for the prevention and management of chronic conditions and its complications.

# 5.8 Researcher reflections on the use of SDT and the Medicine Wheel framework in the study

The self-determination theory (SDT) and the medicine wheel as described by Mussell (2005) were useful as a guide for the development of the mHealth intervention messages. Since SDT is associated with triggering intrinsic motivation, I focused on ensuring that the tone of the messages was respectful and non-pushy, and I depended on the insight of community members in deciding whether the messages were appropriate and motivational. Also, I concentrated on creating messages that would generally address diabetes-eye care, build the confidence of participants, encourage engaging with relationships with family, friends, and health professionals by promoting feasible positive outcome expectations. By focusing primarily on these areas, I

found out that there were limited messages on stress management which is information that is important particularly among individuals living with diabetes. Other researchers can improve on the use of SDT and the medicine wheel as a frame for developing mHealth messages by ensuring that there is a balance in the messages developed and that messages clearly align to an aspect of the theory and the medicine wheel.

The medicine wheel was a great framework to use for this study because it enabled me to focus on not only the physical impact of diabetes on the eyes but showed the importance of a holistic approach to addressing DR. In addition, the medicine wheel worked well as a tool in the evaluation of the mHealth intervention. By including it in the post-intervention survey, I was able to understand how participants perceived the text messages and how well I was able to meet my objective of creating and disseminating messages that were valuable and relevant. Future researchers can use a different approach in evaluating the impact of mHealth interventions. This can be done by carrying out the evaluation as a group activity using a large outline of a medicine wheel and suggesting that participants write their comments on the same outline. This may increase interaction between participants and provide a richer evaluation of the intervention.

# 5.9 Researcher reflections on the research journey

Community engagement is crucial in population health research (372) and Indigenous health research is built on relationships (357). Relationships with community partners assisted in fostering trust and providing an introduction to community members. Accordingly, I worked in close collaboration with community members at SIMFC and LiveWell during all stages of the study. I had prolonged engagement with the study participants to observe, build trust, be aware of various contextual factors, and prevent misinformation.

When non-Indigenous researchers carry out research with Indigenous peoples, there is the possibility to learn and share as well as the likelihood of limited understanding of experiences. As a non-Indigenous person, I have obtained education on Indigenous health and the impact of colonization on the health of Indigenous peoples, but I still failed to understand these connections fully. Forging respectful relationships through listening and dialogue (373) enabled me to understand the views and behavior of participants. I was culturally humble and listened to the input of the Elders and community members during the entire research period.

Indigenous research is based on relationships thus, I desired to have an ethical, accountable, and responsible relationship with the community members and study participants

(374). As such, to ensure that I researched in an appropriate way, I adhered to the "4 Rs" in Indigenous research: respect, relevance, reciprocity, and responsibility (375) which are all essential features of any healthy research relationship (357). It was essential that the research was relevant to the community; thus, I provided the reason behind the study and consulted with community members in the research concept development stages. They understood the relevance and focus of the research and this increased interest and support of the study.

An integral part of the development of the mHealth strategy was community participation, and it was important to provide participants and community members the opportunity to ask questions and raise concerns before commencing with the intervention (376). Hence, I consulted with community members regarding the mHealth intervention to get their input on the mHealth design. Furthermore, I spent time getting to know the participants, which led me to constructively explore and analyze ways to meet their needs with the mHealth intervention and ensure their opinions and suggestions were included in the study. Participants were involved in the research process in a respectful way (377), by obtaining consent and not coercing them to be part of the study.

It is vital that researchers maintain engagement with the community not only during the research period but also post-research (84). Prior to participant recruitment and during the research, I was present every day of the week for eight (8) months at the various programs organized by LiveWell and SIMFC. For instance, on Mondays and Tuesdays, I was at the LiveWell FFF program, on Wednesday, at the LiveWell food experience program and on Thursdays and Fridays, I was present at SIMFC for meetings and community gatherings.

My presence at the various locations provided me with the opportunity to meet with the participants before commencing with the study. During the study, it served as check-in to ensure that participants received text messages, answer any questions and interact with the group. I have continued engagement by participating in different programs and providing eye-health promotion presentations/workshops in several community programs where several study participants attend.

My journey from the inception to completion of this research has been a learning process and has afforded me the opportunity to experience carrying out research with Indigenous peoples in Saskatoon. It has shown me the importance of seeing the person behind the research and carrying out research that is beneficial to both the researcher and participants. In addition, this

study has empowered me with tools and competencies such a relationship building, cultural humility, and interpersonal skills which I will leverage in my personal and professional life.

#### 5.10 Recommendations

The results from this dissertation lead me to other recommendations.

The "WHO Universal Eye Health Global Action Plan for 2014-2019" (6, p1) commends that eye and vision care including management of chronic eye conditions, be the focus of countries worldwide. Although Canada has universal access to health care and DR services and treatments are available and publicly funded (70), in Canada, there are eye care gaps that will increase across time if not addressed soonest (8).

Since, DR is a global health problem (378), Canada should have an action plan at both federal and provincial levels to prevent and manage DR among high-risk populations. The action plan should focus on increasing the care process for diabetic-eye care as well as DR awareness (338).

Health care providers have a key role in creating awareness of DR and diabetes complications. They have a responsibility to provide health education to persons living with diabetes regarding various health complications associated with diabetes and encourage them to seek care from appropriate specialists. In addition, health practitioners should ensure that they integrate trauma-informed care in health service delivery with Indigenous peoples by being respectful and non-judgemental when communicating and educating Indigenous women living with or at risk of diabetes. As well as creating safe environments that foster confidence in the ability to make health care decisions and manage health conditions (379).

There is a harmful relationship between poor diabetes control and DR (380) this is because, poor diabetes control may lead to the development and progression of DR while the presence of severe DR may in turn, result in poor diabetes control. Also, DR is not only important due to the possibility of vision loss, it can be used to predict other diabetes complications. It may be a warning of other complications due to the connection between the management of diabetes and the development of diabetes complications (381). Hence, diabetes-eye health should be included in broader diabetes management frameworks, which can contribute to initiatives addressing equitable diabetes health care outcomes in Indigenous communities.

Population health researchers/professionals should explore novel approaches to promote DR knowledge, provide diabetes-eye information, and increase eye service use among populations at risk. This can be via mobile technology involving the use of text or voice messages in different languages via different platforms along with group activities to foster social support. Diabetes health services and programs should develop innovative solutions targeted across the life span including prenatal, during pregnancy (gestational diabetes), postnatal, diabetes or obesity in childhood, adolescence, and adults. These programs should also include diabetes-eye education as best practice for diabetes care.

Lastly, the researcher recommends the development and integration of tailored diabeteseye care messaging into diabetes health resources such as brochures which should be made available for all persons living with or at risk of diabetes in order to improve awareness on key diabetes-eye care information, such as; eye examination guidelines and NIHB/ provincial health insurance covered diabetes-eye care benefits in Saskatchewan.

#### **5.11 Future Research Directions**

The impact of the mHealth intervention on DR knowledge and eye care behavior in the current study are noteworthy. However, the study used a one sample pre-post-test design which has several limitations. Future studies should design a controlled two sample pre-post-study in order to increase the ability to detect the impact of the intervention, and to control for secular trend (382). Also, more studies are needed to explore the best strategies to address the reported barriers of diabetes-eye care and to promote eye care among Indigenous women in both urban and rural areas.

Future researchers should ensure that there are several mHealth system tests done early in the design and development phase. This will allow time to fix the limitations of the portal and delivery system before the service users experience it.

Strategies to keep this study relevant and sustainable include advocating for interaction with study partners, eyecare, and diabetes organizations to utilize the study data in the provision of their services. For example, SIMFC and LiveWell have the mHealth content and the brochures developed in this study available for distribution to their clients.

### **5.12 Summary and Conclusion**

Diabetes is a chronic disease which if not adequately managed eventually results in micro and macrovascular complications including DR (383), which could subsequently lead to vision loss (384). DR visual impairment in individuals may contribute to difficulties with engaging in regular activities of independent daily living, poor quality of life, anxiety, and isolation/loneliness (311).

The increasing incidence and prevalence of diabetes among Canadian Indigenous peoples raise the risk of DR in this population making it imperative to develop innovative solutions targeted at knowledge/education, prevention, treatment, and care as well as self-management (1) of diabetes, and its eye complications. Consequently, health promotion via mHealth is frequently used in health institutions and organizations, and if employed suitably, it could create a means to promote awareness of DR and empower people to make informed health decisions among various populations in Canada.

The study sought to understand the diabetes-eye care needs of Indigenous women, identify factors that influence/motivate the use of preventive diabetes-eye services, and presented an opportunity via text messages to encourage Indigenous women to prevent, manage, and improve their diabetic eye health, along with facilitating diabetes-eye care and general well-being. This study provided insights into some of the underlying factors influencing diabetes-eye care behavior among Indigenous women in Saskatoon living with and at risk of diabetes. These factors included understanding eye care cost and NIHB/ provincial health insurance coverage for eye care, awareness of how to access eye care services, resolve and intent to control diabetes, and fear associated with personal and family history of diabetes and anxiety associated with interaction with health care practitioners. The mHealth intervention was designed and developed based on the recommendations of the study participants to address their information and resource requests.

The DR knowledge and eye care behavior among Indigenous women in the study population improved after the mHealth intervention. The impact of the mHealth intervention was observed in the increase of the KAP scores, and it prompted participants to take care of self, induced feelings of hope, provided new information on diabetes and eye care, created awareness, encouraged participants to share the information and engage in various activities to improve

diabetes-eye care, relieved stress and worry over diabetes-eye care as well as caused anxiety in one participant.

The way that information and communication technology is used by populations worldwide varies (385). Thus, in this study, different facets such as the platform used to distribute the health information, whether via text or voice, content and tone of messages, and group activities, were important when using mHealth as a tool for health information among Indigenous women. These factors could also be applicable in other populations for the self-management of several health conditions.

This dissertation contributes to the existing literature on mHealth use in Indigenous populations for the management of diabetes and DR. The findings support that, Indigenous women living with or at risk of diabetes will benefit from enhanced communication as well as targeted programs/interventions regarding diabetes and eye care. mHealth messaging interventions might offer a useful means of providing information between clinic visits, and encourage them to have regular eye examinations, access DR screening, and have early treatment for DR.

In conclusion, the study demonstrated the importance of providing diabetes-eye care information to bridge knowledge gap and empower Indigenous women to make informed eye health choices. This will in the long run, prevent vision loss due to DR and its associated sequelae and improve the quality of life of Indigenous women living with or at risk of diabetes.

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#### **Appendix A: Research Poster**

# Department of Community Health and Epidemiology University of Saskatchewan

## PARTICIPANTS NEEDED FOR

a study of

Impact of Mobile Health (mHealth) in Diabetic Retinopathy (DR) awareness and eye care behavior among Aboriginal Women in Saskatoon.

As a participant in this study, you would be asked to partake in a sharing circle and complete a questionnaire. After which you will receive daily text messages on your phone for three months. This will be followed up with a sharing circle and completion of a questionnaire for feedback on the mHealth intervention.

In appreciation for your time, you will receive a \$20 Gift card.

For more information about this study, or to volunteer for this study, please contact:

Valerie Umaefulam
Department of Community Health and Epidemiology
at 306-229-9782 or

Email: ovu015@mail.usask.ca

or

The LiveWell Diabetes Office at – 2409-22<sup>nd</sup> Street West or Call: 655-LIVE (306-655-5483)

This study has been reviewed by, and received approval through, the Research Ethics Office, University of Saskatchewan.



#### **Appendix B: Consent Form**

**Project Title:** Impact of Mobile Health (mHealth) in DR (DR) awareness and eye care behavior among Indigenous Women in Saskatoon.

**Researcher:** Onyinyechi Valerie Umaefulam, PhD Student, Department of Community Health and Epidemiology, University of Saskatchewan,

Email: ovu015@mail.usask.ca

<u>Supervisor</u>: Dr. Kalyani Premkumar, Department of Community Health and Epidemiology, +1306-966-1409, kalyani.premkumar@usask.ca

#### **Purpose(s) and Objective(s) of the Research:**

- 1. To determine factors that influence diabetic eye care use among Indigenous women.
- 2. To determine resources and information Indigenous women perceive as necessary for utilizing eye care services.
- 3. To ascertain the knowledge of DR as a complication of diabetes and behavior towards eye care among Indigenous women.
- 4. To determine the impact of mHealth education intervention on DR awareness and self-reported eye care behavior among Indigenous women.
- 5. To explore Indigenous women's perceptive about mHealth as a tool for receiving health information.

#### **Procedures:**

- The first phase of this study involves participating in sharing circle discussions and filling out a preintervention questionnaire at the LiveWell program locations where participants will be recruited, and will take about 60-90 minutes to complete.
- The second phase involves mHealth education herein; participants will receive text messages containing diabetes-eye care related information, DR risk factors, prevention and treatment daily via mobile phone for three months.
- Immediately after the intervention, participants will be invited to partake in a sharing circle discussion and fill out a post-intervention questionnaire. These activities will all occur at LiveWell Diabetes Program locations where participants were recruited and will take about 60-90 minutes.
- The sharing circle discussion will begin with a prayer and smudging led by an Elder. A meal will be shared after the discussion.

#### **Potential Risks:**

• There are no known or foreseen risks or discomfort to you by participating in this research. However, participants may become emotional during the sharing circle discussions which the Elder will address.

#### **Potential Benefits:**

- The study will promote eye care knowledge spurring behavioral change that can result in better diabetes self-management and diabetes retinopathy blindness prevention.
- The awareness created via this research will significantly reduce the associated ramifications that occur as a result of DR blindness, including falls, mental health conditions and poor quality of life.
- The study will be beneficial in providing culturally appropriate eye care to Indigenous peoples in order to bridge the knowledge gap and empower Indigenous people to make informed eye health choices.
- The study will also provide insight into some of the underlying socio-cultural factors influencing eye care service utilization.

• It will contribute to the evidence base for mHealth and can augment health care services by providing additional support to individuals with diabetes or at risk of diabetes so as to change health care practices in the long run.

#### **Compensation:**

• Participants will be given a gift card of \$20 pre-intervention and \$30 post-intervention in appreciation for their time on the study.

#### **Confidentiality:**

• The researcher will undertake to safeguard the confidentiality of the discussion, but cannot guarantee that other members of the group will do so. Please respect the confidentiality of the other members of the group by not disclosing the contents of this discussion outside the group, and be aware that others may not respect your confidentiality. The researcher will also safeguard your confidentiality when presenting study results in PhD dissertation and conferences.

#### Right to Withdraw:

- Your participation is voluntary and you can participate in only those discussions that you are
  comfortable with. You may withdraw from the research project for any reason, without explanation or
  penalty of any sort. Should you wish to withdraw, you may leave the group meeting at any time;
  however, data that have already been collected cannot be withdrawn as it forms part of the context for
  information provided by other participants.
- If you choose to withdraw from the study, this will have no penalty or effect on the services you receive from LiveWell

#### **Data Dissemination:**

Research data will be used for PhD, conference presentations and journal publications. The data will also be shared with the First Nations and Métis communities.

#### Follow up:

• The researcher will make the results available to the women through LiveWell and the results will be in lay language.

#### **Questions or Concerns:**

- Contact the researcher using the information at the top of page 1;
- This research project has been approved on ethical grounds by the University of Saskatchewan Research Ethics Board. Any questions regarding your rights as a participant may be addressed to that committee through the Research Ethics Office <a href="mailto:ethics.office@usask.ca">ethics.office@usask.ca</a> (306) 966-2975. Out of town participants may call toll free (888) 966-2975.

Your signature below indicates that you have read and understand the description provided; I have had an opportunity to ask questions and my/our questions have been answered. I consent to participate in the research project. A copy of this Consent Form has been given to me for my records.

Name of Participant	Signature	 Date	
Researcher's Signature	 Date		

A copy of this consent will be left with you, and a copy will be taken by the researcher.

#### **Appendix C: Sharing Circle 1 Discussion Guide**

This sharing circle discussion guide shows the main areas for discussion. The questions will evolve and undergo refinement before it is administered. The sharing circle will occur at the different LiveWell Diabetes program sites were participants will be recruited.

#### Sharing Circle Procedure:

- ➤ Participants will be seated in a circle and the sharing circle discussion will begin with a prayer and smudging led by the Elder.
- ➤ Warm up: I would like everyone to introduce themselves. Can you tell us your name and the community you associate with?
- ➤ Introduction of the study and Rationale for the sharing circle:
  - Thank you for giving me your time and participating in our study. I hope we will have an interesting conversation today. The aim of this discussion is to explore your perception on factors that influence diabetic eye care use and what information you would need in respect to DR. This will assist in the design and implementation of the content of the mobile health messages which will be sent to you in this study. Thus, for that purpose we want to learn from your expertise and experience.
- Researchers' background: The researcher will share her story and reason for carrying out this study.
- > Question 1: This will be a narrative;
  - I would like you to share your story of diabetes particularly as it relates to your eyes. As you think of your experience with diabetes, I would like you to think about your experience in regard to getting help, what motivates or encourages you to seek eye care, what would prevent you from assessing eye care.
- ➤ Since you have already filled the consent form, I know that you agree to participate, but I just want to go through some points with you, is that okay with you?
- 1. Participation in this study is completely voluntary.
- 2. You can decide not to answer a particular question if you feel uncomfortable doing so.
- 3. You can speak if you are holding the sacred object.
- 4. Please don't interrupt anyone holding the sacred object. The group should listen silently until the speaker has finished.
- 5. Do you have any question before we start the discussion?

➤ Repeat Question 1 and proceed with discussion by passing the sacred object to participants.

The sacred object will be passed around twice, in order for participants to be able to have another opportunity to make their input.

#### ➤ Question 2:

I feel you would like to know of how diabetes affects the eyes, the causes and symptoms of DR, and prevention and treatment for DR. However, I would like to know what you would like to know about diabetes and the eye?

#### Conclusion

That concludes our sharing circle discussion. Thank you so much for coming and sharing your thoughts and opinions with us. We hope you have found the discussion interesting. Your opinions will be valuable to the study. We have a short questionnaire that we would like you to fill out. If you have additional information that you did not get to say during the discussions, please feel free to write it on this form. Before you leave, please hand in your completed questionnaire.

- The Elder closes the discussion with a prayer.
- > Share a meal with the participants.

### Appendix D: DR Knowledge, Attitude, and Practice Survey (Pre-intervention)vi

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110	п	W.

diabetes

Diabetes is a condition that affects different parts of the body including the foot, kidneys, eyes and skin. It impairs hearing, affects the nerves, causes sexual dysfunction and increases the risk of cardiovascular conditions. This survey however, is specific to diabetes and the eyes.

This questionnaire will help us understand your knowledge, attitude and practices in respect to DR. Please fill out the questionnaire to the best of your ability. Please note that you can decide not to answer certain questions.

The 11	iformation collected via this questionnaire	will be c	onfidenti	al.		
Date:	//					
Socio	-demographic Information					
How	old are you? [ ]					
I self-	declare as: First Nations [] Métis []					
	you been diagnosed with diabetes by a doc	tor Yes [	] No []			
	is your Blood sugar level: mmol/L			]	After you ea	t [ ]
I don'	t know []	-			-	
Phone	e number:					
	ork provider:			I	don't know	7[]
What	is the highest level of education you have	complete	ed?			
0 = N	o formal education					
1 = Sc	ome high school but did not finish					
2 = C	ompleted high school					
3 = Sc	ome college or university but did not finish	L				
4 = C	ollege or university degree					
5 = Ot	her (please specify)					
What	is your work status?					
$1 = \mathbf{W}$	orking					
2 = N	ot Working					
3 = A	re you a student					
4 = ot	hers (please specify)					
	Question			Respons	es	
		Fully	Agree	Can't	Disagree	Fully
		Agree	_	Decide	_	Disagree
Kno	wledge					
1	Diabetes can damage eyesight					
2	Retina (at the back of the eye) is the					
	main part of eyes that gets damaged in					

vi Adapted from: Khandekar, R., Harby, S. Al, Harthy, H. Al, & Lawatti, J. Al. (2010). Knowledge, attitude and practice regarding eye complications and care among Omani persons with diabetes - a cross sectional study. Oman Journal of Ophthalmology, 3(2), 60–65. https://doi.org/10.4103/0974-620X.64228

3	Eye doctor will examine eyes using				
3	special equipment to find effects of				
	diabetes				
4	Timely treatment can prevent/ delay				
-	damage due to diabetes in eyes				
5	Control of Blood sugar makes eye				
	treatment effective				
6	Poor control of diabetes increases the				
	risk of eye complications				
7	In diabetes, one eye may be affected				
	first followed by the other eye				
8	Children with diabetes also have risk of				
	eye complications				
9	An eye with DR if successfully treated				
	will not need treatment again				
10	Treatment of diabetes is painful				
11	If vision is damaged due to diabetes, use				
	of 'low vision' aids helps in daily work				
Attit		1	ı	1	1
2.1	If my vision is good, my eyes are not				
	affected. So, I do not need annual eye				
	testing.				
2.2	If my blood sugar level is controlled, I				
	do not need annual eye tests				
2.3	The information on eye problems due to				
	diabetes should be given by eye doctors				
	only.				
2.4	If I am taking eye treatment, I need not				
	worry about controlling my sugar.				
2.5	Patients with diabetes often waste their				
	time and money in eye check-ups as				
	most of the time eyes are normal				
Prac	tice				 
3.1	I should go for a diabetic eye checkup				
	yearly.				
3.2	I will go for an eye check if I suddenly				
	have poor vision				
3.3	I control my blood sugar even if eye				
	complication is being treated.				
3.4	Staff in eye unit counseled me about				
	prevention and treatment for eye				
	complications				
4.1	What would you like to know about diab	etes and t	the eve?		

<sup>4.1</sup> What would you like to know about diabetes and the eye? \_\_\_\_\_

<sup>4.2</sup> What time would you like to receive messages? 8am-11pm [] 12pm-3pm [] 4pm-7pm [] Thank you for your participation. Please place your questionnaire in the envelope provided.

## **Appendix E: Initial Messages before Selection and Refining (n=115)**

4	A good way to lower the risk of diabetic eye conditions is to control your blood sugar
1	level. Diabetes is very sight threatening if not controlled
	You may have no symptoms and still have Diabetic retinopathy. Remember to check
2	your blood sugar level regularly
3	Diabetes affects blood vessels in the retina causing poor vision
	Diabetic retinopathy involves changes to eye blood vessels that can cause them to bleed
4	or leak fluid which can cause poor vision
	Controlling diabetes by taking medications as prescribed, staying physically active, and
5	maintaining a healthy diet can prevent or delay vision loss
	Try to take your medication if diabetic. If you are experiencing difficulties, please
6	inform your health care provider
	Common eye problems caused by diabetes often have no warning signs. An eye exam is
7	the only way to detect these conditions in their early stages
	At some point, nearly 1 out of 3 people with diabetes has retinopathy which damages the
8	blood vessels in the back of the eye causing poor vision
	In early stages of Diabetic retinopathy there may be no symptoms, which is why it is
9	important to have regular eye exams
10	A lot of people have diabetic retinopathy when they are first diagnosed with diabetes
11	Timely follow-up care with an eye doctor should occur after first diagnosis with diabetes
	Women with diabetes who hope to become pregnant should be screened for DR before
12	conception, during pregnancy and within the first year after childbirth
	Any person older than 15 years with type 1 diabetes should be screened for DR every
13	year, beginning five years after the onset of diabetes
	All people with type 2 diabetes should be screened for diabetic retinopathy at the time of
14	diagnosis
	Good management of diabetes includes healthy eating, staying active and taking
15	required medication
	Better control of blood sugar level slows the onset and progression of retinopathy and
16	lessens the need for surgery for severe retinopathy
	The early stages of diabetic retinopathy usually have no symptoms. The disease often
17	progresses unnoticed until it affects vision
	Bleeding due to Diabetic retinopathy from abnormal retinal blood vessels can cause the
18	appearance of "floating" spots in the eyes
	Floating spots in the eyes sometimes clear on their own but without quick treatment,
19	bleeding often recurs, increasing the risk of permanent vision loss
	Contact your doctor if you have blurred vision, see flashes of light in your field of
20	vision, sudden loss of vision, blotches or spots in vision
	Diabetes can increase the risk of Cataract and diabetes raises the risk of glaucoma which
21	damages eye nerves
	Symptoms of DR, if present, can include blurred vision, flashes of light in the field of
22	vision, sudden loss of vision, spots in vision
23	If you experience sudden vision loss in one or both eyes, see your doctor immediately
	, , ,

	Leaking blood vessels in the eyes often lead to decreased vision. At this stage, vision
	may be
24	normal or it may have started to blur or change
	Blood may leak into the eyes causing spots that appear to move in front of the eyes.
25	Please see your doctor as it can lead to severe vision loss
26	In many instances, vision loss associated with diabetic retinopathy is gradual
	The effect of retinopathy on vision in people with diabetes are different, depending on
27	the stage of the retinopathy
	A common symptom of Diabetic retinopathy includes blurred vision which is often
28	linked to blood glucose levels, and sudden loss of vision
	Diabetes can affect the vision center of the eye called the macula, the part of the eye
29	where clear vision occurs
	Diabetes changes in the eye and blurred vision can occur at any time, although it is more
30	likely to occur as the diabetes progresses
31	You may have no symptoms and still have diabetic retinopathy.
	Being overweight increases your risk of developing diabetes and other conditions like
32	hypertension, and increases the risk of eye diseases
	Diabetes increases the risk of developing cataracts, glaucoma, degeneration of the retina,
33	and other eye diseases
24	Smoking damages your blood vessels and raises your risk of developing diabetic eye
34	problems
25	Too much sugar in your blood can lead to leaking of blood and other fluids from the tiny
35	blood vessels in your eyes causing blurred vision and difficulty to see at night
36	Diabetes increases the risk of cataract. Cataract is a clouding of the lens in the eye that affects vision
37	
31	All people with diabetes both type 1 and type 2 are at risk for diabetic retinopathy  Having diabetes increases your risk of getting glaucoma, a condition that puts added
38	pressure in your eye and is also sight threatening
30	Diabetes causes glaucoma by abnormal blood vessels growing in the front part of the
39	eye. This can be very sight threatening
37	Keeping your blood sugar levels as close to normal as possible can also reduce diabetes
40	kidney and nerve diseases
	Ask your doctor of the best blood sugar level that is right for you and try to maintain that
41	level to prevent eye changes
	To prevent the onset and delay the progression of DR, people with diabetes should aim
42	to achieve optimal blood glucose control (i.e., A1C 7.0%)
	To reduce the risk of onset or to delay the progression of DR, individuals with diabetes
43	should be treated to achieve optimal control of BP (e.g. 130/80 mm Hg)
44	Maintain good blood glucose levels, blood pressure, and blood cholesterol levels
	Know your A1C (a test of your average blood glucose level over three months). Talk to
45	your healthcare team about what your target should be
	Comprehensive eye exams are needed more frequently as diabetic retinopathy becomes
46	more severe
	People with severe diabetic retinopathy may need a comprehensive eye exam as often as
47	every 2 to 4 months

	In people with no or minimal diabetes retinopathy, it is recommended you see an eye
	doctor yearly
	Because diabetic retinopathy often goes unnoticed until vision loss occurs, people with
49	diabetes should get a comprehensive eye exam at least once a year
	Early detection, timely treatment, and appropriate follow-up care of diabetic eye disease
	can protect against vision loss
	Diabetic retinopathy cannot be totally prevented but you can greatly reduce the risk if
	living with diabetes
	The interval for diabetes eye assessment follow-up care will be tailored to the severity of
	the retinopathy by your doctor
	It is important to see an eye care professional regularly and keep blood glucose (sugar)
	levels well managed
	Finding and treating the diabetic retinopathy early, before it causes vision loss is the best
	way to control diabetic eye disease
	If you have diabetes, make sure you get a comprehensive eye examination at least once a year
	Many eye diseases have no early warning signs or symptoms, but a test can detect eye
	diseases in their early stages before vision loss occurs
	While it is normal for vision to change with age, serious eye problems like diabetic
	retinopathy can be treated if detected early
	Increase your eye exams after 40 years of age to at least every year because the most eye
	changes occur during these years
	Good blood sugar control reduces the onset and progression of diabetic retinopathy
	Screening for Diabetic retinopathy in people living with type 2 diabetes should occur at
	the time of diagnosis of diabetes
	For people with type 1 diabetes diagnosed after puberty, screening for diabetic
61	retinopathy should occur 5 years after the diagnosis of diabetes
	For people diagnosed with type 1 diabetes before puberty, screening for DR should
	occur at puberty, unless your doctor suggests an earlier exam
	Can an eye test help diagnose diabetes? The answer is YES. Diabetes can show as
	changes in the eyes even before diabetes has been diagnosed
	An eye test can reveal the signs of diabetes. Over time a high blood-glucose level can
	weaken and damage the tiny blood vessels in the eye
	For people living with diabetes with no evidence of retinopathy, eye exams should occur
	every year or as suggested by your eye doctor  Finding and tracting the disease early, before it causes vision loss or blindness is the
	Finding and treating the disease early, before it causes vision loss or blindness, is the best way to control diabetic eye disease
	Visit your optometrist at least once per year. Your optometrist may recommend you visit
	more or less frequently depending on your situation
	To prevent eye disease progression, people with diabetes should manage their levels of
	blood sugar, blood pressure and blood cholesterol
	The possibility of eye complications can be greatly reduced with routine examinations.
	Many problems can be treated with greater success when caught early
	If you are living with Diabetes, you qualify for a free eye examination every year in
	Saskatchewan

	You can have a free eye examination every year if you have been diagnosed with
71	diabetes
	Diabetic retinopathy can be treated with several therapies that may be used alone or in
72	combination with others
	Your eye doctor may suggest laser surgery in which a strong light beam is aimed onto
73	the retina
	If diabetic eye changes are severe, laser surgery and appropriate follow-up care can
74	reduce the risk of blindness
	Laser surgery often cannot restore vision that has already been lost, which is why finding
75	diabetic retinopathy early is the best way to prevent vision loss
	Occasionally, urgent referral to an ophthalmologist is needed, as surgical or laser
76	intervention can save vision
77	A comprehensive eye exam measures vision, checks for the need for glasses, and
77	includes checking the eye to detect eye disease
70	There are new technologies such as digital cameras and remote digital technology to
78	improve access to screening  There are different procedures to treat dishetic retirements. The choice of avecage
79	There are different procedures to treat diabetic retinopathy. The choice of eye care
19	procedure will be decided by the eye doctor  If you have Diabetic retinopathy, ask your doctor for the possible treatments available
80	and services that can assist to pay for the treatment
- 60	Eye surgery can keep your vision better longer. It works best if done when early eye
81	changes occur such as before vessels start to bleed
01	It does not take a lot of extra work to take care of your eyes. The steps you take to
82	manage diabetes also help keep your eyes healthy
	Eye doctors can use laser therapy to seal leaking blood vessels and get rid of unwanted
83	new blood vessels
	During an eye exam, the eye care professional can see the inside of the eye and check for
84	signs of eye disease. It is short, simple, and painless
	In advanced stages of Diabetic retinopathy, it may affect your side vision, but treatments
85	can save your central vision
	Treatment works better before the eye blood vessels start to bleed, but even if bleeding
86	has started, treatment may still be possible
87	Don't stop taking your diabetes medication because you feel better.
	The good news is that there are steps you can take to catch eye complications of diabetes
88	early and prevent its progress
	Most people with diabetes do not lose their vision if they follow their treatment plan and
89	have regular eye exams
90	Early detection and timely treatment can help reduce the risk of vision loss from diabetes
91	Follow the treatment plan prepared by your eye doctor and you will have good vision
	Your health is important. Write down your blood sugar level every time you visit the
92	clinic to see if the changes you make are helping
	Diabetes cannot be cured. But a healthy lifestyle can help you manage it. Make simple
93	healthy lifestyle changes. Look out for health tips
94	Looking after yourself can help manage diabetes and also it effects on the eyes

	Lower your stress by exercising or talking about your problems. You can manage stress
95	and manage diabetes too
	Do not forget to question your caregiver about any concerns or when you need further
96	explanation
	You can lower risk of Diabetic retinopathy. Take medication, attend clinic appointments,
97	and live a healthy lifestyle. Keep up the good work
	Are carrots good for your eyes? Yes. But eating Leafy greens such as kale protects the
98	eye from damage and is important for keeping your eyes healthy too
	Taking fruit and vegetable everyday sounds like hard work, but when you include it to
99	your meal daily, you will feel great!
	Eating meals rich in fruits and vegetables, particularly dark leafy greens such as spinach
100	helps you maintain a healthy weight and reduces the effect of diabetes in the eyes
	Your daily habits and lifestyle such as exercising could seriously help your eyes without
101	you knowing it
102	Diabetes can affect the eyes and cause vision loss that may not be corrected
	Be aware of your blood sugar level and monitor it. Check it when and where you can: at
103	home, the doctor's office, or at the drug store
	High level of cholesterol can clog the arteries in the eye and may result in loss of the
104	central vision in the eye which may not be reversible
	Fruits and vegetables that contain Vitamin C such as strawberries are good for your eyes
105	because they can help lower the risk of eye diseases such as cataract
	Maintain a healthy weight to prevent the risk of developing diabetes and diabetic eye
106	disease progression
–	It is your responsibility to control your blood sugar levels and get an eye exam at least
107	once a year
100	Regular exercise will help you control your weight. Remember to reward yourself for
108	your excellent effort
100	Physical activity and consumption of alcohol are some of the factors that affect the onset
109	and progression of diabetic retinopathy
110	A person living with diabetes is more likely to have eye effects than a person without
110	diabetes
111	All forms of diabetic eye disease have the potential to cause severe vision loss, eye
111	exams can detect other health issues before there are any symptoms
112	If you have trouble understanding your doctor's answers, ask where you can go for more
112	information  Catting regular everall physicals may lead to early detection of discoses like dishetes an
112	Getting regular overall physicals may lead to early detection of diseases like diabetes or other systemic conditions that can lead to eye problems
113	• • • • • • • • • • • • • • • • • • • •
111	A blood pressure reading in the normal range is important for preventing eye
114	complications in people living with diabetes or at-risk of diabetes  If you have femily history of eye complications of diabetes and other eye diseases, you
115	If you have family history of eye complications of diabetes and other eye diseases, you
115	may need to visit your eye doctor more frequently

### **Appendix F: Sample of Messages**

Welcome! Thanks for beginning this journey with us. We hope you learn more about diabetes and your eyes along the way. You'll receive 1 message daily for 12 weeks

Greetings. You can recognize a message from the Diabetes-Eye Study, as it will start with Health Tip, Did you Know, and LiveWell with Diabetes. We will use DR as short for Diabetic Retinopathy

Let's get started. Did you Know: Diabetes is one of the leading causes of blindness in Canada! Controlling you blood sugar level helps to delay or prevent diabetic eye conditions

Did you Know: DR is when diabetes affects blood vessels in the light-sensitive part of the eye called the retina that lines the back of the eye

Did you Know: DR involves changes to eye blood vessels that can cause them to bleed or leak fluid seen as dark patches in vision in advanced stages

LiveWell with Diabetes: Making changes to your life style by eating healthy, staying active, taking your medication and living a balanced life helps prevent and control diabetes

Health Tip: See something Say something! Talking to your healthcare team e.g. nurses and dietitian is a good way to get correct and useful diabetes prevention and management information. Talk to them, today.

Hello. Did you Know: Diabetes can occur as type 1 or 2, diabetes in pregnancy and diabetes in children and young people

LiveWell with Diabetes: Visit your eye doctor and based on your eye care needs the doctor will suggest how often you should have an eye test

Health Tip: It is important to know the eye history of family members. Asking questions can empower you in knowing eye risks and take steps in preventing eye conditions

Did you Know: Visiting your eye doctor can also help diagnose other previously undetected medical conditions e.g. High blood pressure, diabetes

Did you Know: Poor blood sugar control can cause changes in the way you see far and near objects and the ability to focus on close objects when reading

Health Tip: All persons diagnosed with diabetes with a Saskatchewan Health Card can have free yearly eye exam. Visit optometrists.sk.ca to find an eye doctor near you

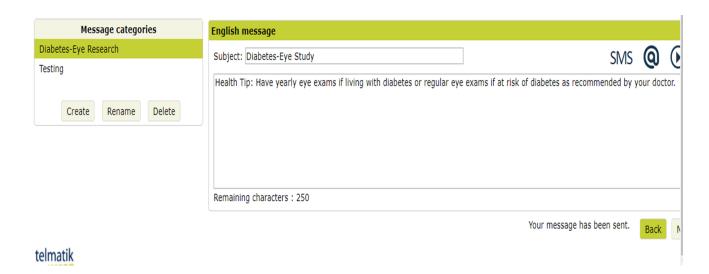
Health Tip: Start a walk group with family and friends. Getting regular physical activity can go a long way in improving your general health including your eyes

Hello. Health Tip: Remember, no symptoms, does not mean that you do not have DR. Do not skip visits to the eye doctor if living with diabetes

Health Tip: Many eye diseases have no early warning signs or symptoms, but an eye exam can detect eye diseases in their early stages before vision loss occurs

Health Tip: Continue talking to family and friends if you need help. And inquire from your doctor or healthcare worker on how you can stay healthy

# **Appendix G: Bulk Messaging Platform**



### **Appendix H: Sharing circle 2 Discussion Guide (Post-intervention)**

This sharing circle discussion guide shows the main areas for discussion. The questions will evolve and undergo refinement before it is administered. The sharing circle will occur at the different LiveWell Diabetes program sites were participants will be recruited.

### Sharing Circle Procedure:

- ➤ Participants will be seated in a circle and the sharing circle discussion will begin with a prayer and smudging led by the Elder.
- ➤ Warm up: I would like everyone to introduce themselves. Can you tell us your name and indicate if you received SMS messages providing some information on diabetes and the eyes the past three months?
- ➤ Introduction and rationale for the sharing circle:
  - Thank you for giving me your time and participating in our study. I hope we will have an interesting conversation this afternoon. The aim of this discussion is to explore your perception on the mHealth (Texting) program that was administered for the past three months to you and determine your feelings on the information you received via mHealth (Texting) and your opinion on if it had any impact on your eye care and health in general? This will assist in the design and implementation of subsequent mHealth (Texting) interventions in the future. Thus, for that purpose we want to learn from your experience.
- ➤ Question 1: This will be a narrative;

I would like you to share your story of your experience with receiving diabetes health messages via text messages. As you think of your experience, I would like you to think about what worked and what did not work with the messages you received.

- > Since you have already filled the consent form, I know that you agree to participate, but I just want to go through some points with you, is that okay with you?
  - 1. Participation in this study is completely voluntary.
  - 2. You can decide not to answer a particular question if you feel uncomfortable.
  - 3. You can speak if you are holding the sacred object.
  - 4. Please don't interrupt anyone holding the sacred object. The group should listen silently until the speaker has finished.
  - 5. Do you have any question before we start the discussion?

- ➤ Repeat Question 1 and proceed with discussion by passing the sacred object to participants.

  The sacred object will be passed around twice, in order for participants to be able to have another opportunity to make their input.
- ➤ Question 2: How do you feel about receiving health information via mobile phones?

### Conclusion

That concludes our sharing circle discussion. Thank you so much for coming and sharing your thoughts and opinions with us. We hope you have found the discussion interesting. Your opinions will be valuable to the study. We have a short questionnaire that we would like you to fill out. If you have additional information that you did not get to say during the discussions, please feel free to write it on this form. Before you leave, please hand in your completed questionnaire. If you have questions about the study in the future, please feel free to contact us. The names and phone numbers of the investigators are included in the consent form.

- ➤ The Elder closes the discussion with a prayer.
- > Share a meal with the participants.

## Appendix I: DR Knowledge, Attitude, and Practice Survey (Post-intervention)vii

This questionnaire will help us understand your knowledge, attitude and practices in respect to DR. Please fill out the questionnaire to the best of your ability. Please note that you can decide not to answer certain questions.

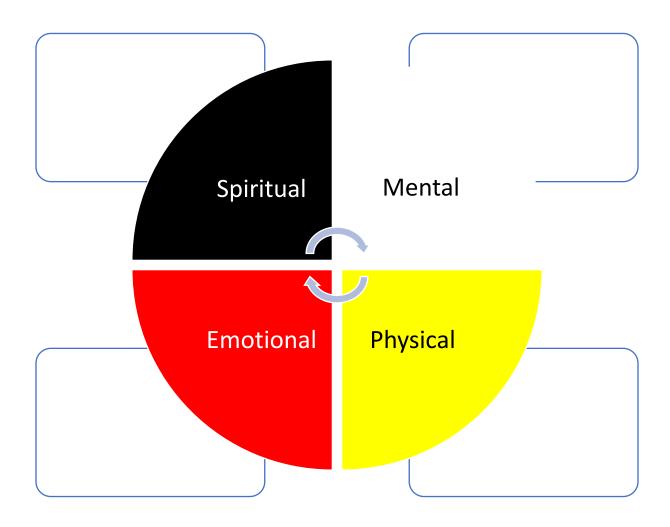
Question Responses

		Fully Agree	Agree	Can't Decide	Disagree	Fully Disagree
Knov	vledge	1	ı		l	
1	Diabetes can damage eyesight					
2	Retina (at the back of the eye) is the main part of eyes that gets damaged in diabetes					
3	Eye doctor will examine eyes using special equipment to find effects of diabetes					

vii Adapted from: Khandekar, R., Harby, S. Al, Harthy, H. Al, & Lawatti, J. Al. (2010). Knowledge, attitude and practice regarding eye complications and care among Omani persons with diabetes - a cross sectional study. Oman Journal of Ophthalmology, 3(2), 60–65. https://doi.org/10.4103/0974-620X.64228

4	Timely treatment can prevent/ delay				
7	damage due to diabetes in eyes				
5	Control of Blood sugar makes eye				
3	treatment effective				
6	Poor control of diabetes increases				
U	the risk of eye complications				
7	In diabetes, one eye may be affected				
,	first followed by the other eye				
8	Children with diabetes also have risk				
O	of eye complications				
9	An eye with DR if successfully				
	treated will not need treatment again				
10	Treatment of diabetes is painful				
11	If vision is damaged due to diabetes,				
11	use of 'low vision' aids helps in				
	daily work				
Attitu	, and the second				
2.1	If my vision is good, my eyes are				
2.1	not affected. So, I do not need				
	annual eye testing.				
2.2	If my blood sugar level is controlled,				
2.2	I do not need annual eye tests				
2.3	The information on eye problems				
2.3	due to diabetes should be given by				
	eye doctors only.				
2.4	If I am taking eye treatment, I need				
_,,	not worry about controlling my				
	sugar.				
2.5	Patients with diabetes often waste				
	their time and money in eye check-				
	ups as most of the time eyes are				
	normal				
Pract	ice		•	<b>.</b>	
3.1	I will go for a diabetic eye checkup				
	yearly.				
3.2	I will go for an eye check if I				
	suddenly have poor vision				
3.3	I will control my blood sugar even if				
	eye complication is being treated.				
3.4	Staff in eye unit counseled me about				
	prevention and treatment for eye				
	complications				
				-	

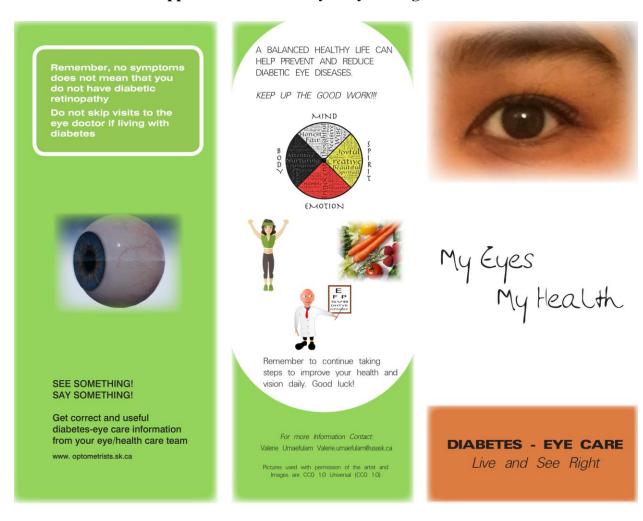
4.1 Please write or draw something about how the messages you received have impacted your Physical, Mental, Emotional, and Spiritual health in each of the four quadrants.



Thank you for completing the questionnaire and for your input in this study.

Please place your questionnaire in the envelope provided.

## Appendix J: Diabetes-Eye Key Message Brochure



### **Key Messages**

- Control blood sugar, eat right, and keep active
- Know family eye history
- Sight threatening eye problems often have no warning signs
- Detect eye diseases in early stages
- Get yearly eye exams if living with diabetes or regular eye exams as recommended by the eye doctor
- If you live with diabetes
   & have a Saskatchewan
   health card you can get
   free yearly eye exam
- Early stages of diabetic retinopathy may have no symptoms

Blurred vision, Flashes of light, Sudden vision loss, Blotches in vision?

Contact your eye doctor immediately

### Early Stages of Diabetic Retinopathy



Normal view



Blurred view

### Advanced DR Stage



Normal view



Diabetic Retinopathy View

Appendix K: DR Attitude Post-Score adjusted by variables and pre-score (Multivariate GLM regression) in a population of Indigenous Women with or at risk of Diabetes, Saskatoon.

		95% Confide		
	В	Lower	Upper	<i>p</i> -value*
Age				
26-45	-5.78	-30.06	18.49	.641
46-69	-29.34	-57.09	-1.59	.038*
18-25 (Reference group)	$O^a$	•		
Indigenous Ancestry				
First Nations	6.16	-17.673	29.99	.613
Métis (Reference group)	$O^a$			
Education Level				
Completed high school	-22.70	-52.70	7.30	.138
Some college or university but did not finish	-13.46	-41.59	14.67	.348
College or university degree	-10.03	-37.63	17.58	.476
Some high school but did not finish/ No formal Education	$O^a$	•		
(Reference group)				
Diabetes Status				
Diabetes	26.68	1.29	52.07	.039*
At risk of Diabetes (Reference group)	$O^a$			
Work Status				
Working	-7.39	-40.40	25.64	.661
Not working	10.10	-28.80	48.99	.611
Student	5.52	-32.10	43.14	.774
Other (Reference group)	$O^a$			
Attitude Pre-Score	.78	.52	1.04	.000

<sup>\*</sup>*p*<= 0.05

Dependent Variable: Attitude Post-Score: Median

Model: (Intercept), Age categories, Indigenous Ancestry, Education Level, Work Status, Diabetes Y/N

a. Reference category. Set to zero because this parameter is redundant

Appendix L: DR Practice Post-Score adjusted by variables and pre-score (Multivariate GLM regression) in a population of Indigenous Women with or at risk of Diabetes, Saskatoon.

		95% Confidence	_	
	В	Lower	Upper	<i>p</i> -value*
Age				
26-45	-1.378	-27.09	24.33	.916
46-69	-34.59	-64.00	-5.17	.021*
18-25 (Reference group)	$0^{a}$			
Indigenous Ancestry				
First Nations	24.56	61	49.74	.056
Métis (Reference group)	$O^a$			
Education Level				
Completed high school	27.85	-4.33	60.02	.090
Some college or university but did not finish	17.89	-12.73	48.51	.252
College or university degree	38.55	9.43	67.68	.009*
Some high school but did not finish/ No formal Education	$0^{a}$	•	•	
(Reference group) Diabetes Status				
Diabetes Status	33.59	6.90	60.29	.014*
At risk of Diabetes (Reference group)	$0^{a}$			
Work Status				
Working	2.45	-32.62	37.52	.891
Not working	34.22	-6.64	75.08	.101
Student	20.636	-18.935	60.206	.307
Other (Reference group)	$O^a$			
Attitude Pre-Score	.467	.202	.732	.001

<sup>\*</sup> *p*<= 0.05

Dependent Variable: Practice Post-Score: Median

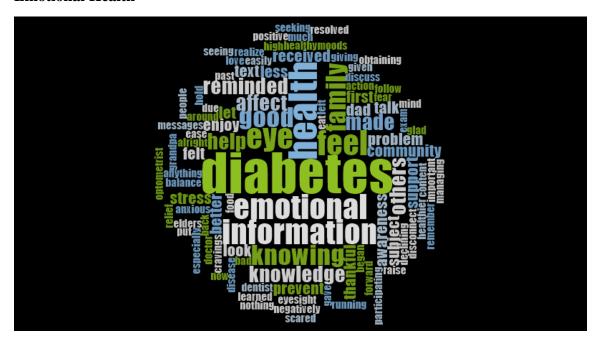
Model: (Intercept), Age categories, Indigenous Ancestry, Education Level, Work Status, Diabetes Y/N

a. Reference category. Set to zero because this parameter is redundant

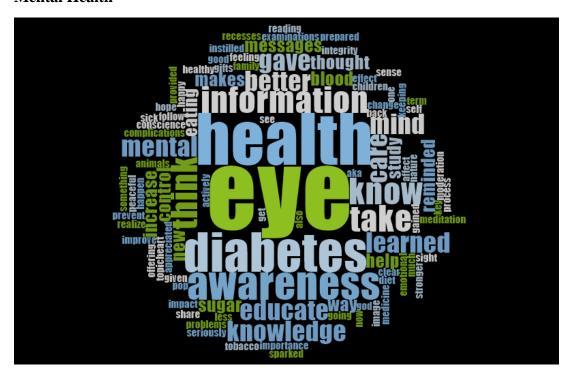
Appendix M: Word Cloud of Recurrent Words in Post-Intervention Survey Physical Health



### **Emotional Health**



## **Mental Health**



## **Spiritual Health**



This is a visual representation of the commonly used words and not intended to quantify the qualitative data. The font size of words proportionately reflects the frequency of usage of these words by participants. The words seen are those used by participants in describing the impact of the mHealth intervention on their physical, emotional, mental, and spiritual health.

Appendix N: Comments on the impact of the text messages on physical, emotional, mental, and spiritual health

Spiritual	Mental	Emotional	Physical	Other comments
Elders, smudge, pow-wow.	Offering tobacco, meditation, been with nature, Gifts are there, Animals, Medicine.	Talking to someone when I have problem, seeking family for support, Elders support, giving back to the community.	Exercise, good healthy food, taking medication as prescribed, regular checkup.	
Uplifted me, felt I had an angel working with me.	Gave me much to think about and share with my family. Will use information to help change my way of thinking/eating for better eye health. Good thoughts.	At first, I felt nothing then I began to enjoy it and look forward to texts. I would discuss and use information with others. I feel content and less anxious about my eye health.	I was able to expect a text reminder, that reminder turned into action, action became routine, hope not to lose it and keep a new routine.	Overall, I have a better understanding regarding my eye health and can share my new knowledge. It is empowering.
	Diet can improve my eye health but also mental health	Managing my cravings won't negatively affect my moods.	My metabolism will thank me for eating better.	
Lifted, New.	Healthy, Learn.	Good	Health	
Taking care of my body that houses my spirit.	Actively thinking about the health of my eyes.	Let me know that Diabetes and eye problems can be easily treated and prevented.	Gave lots of ideas on exercise and how it manages diabetes.	
	Oh GodI have to take better care of myself.	I felt reminded to take action of my health. I want to help raise community awareness.	Must eat carrots! Must work out to be healthy and get average body.	

are looking into eyes/diabetes more.

Enjoyed receiving.

Gave knowledge to

share with others.

Made me realize

to follow through with

**Knowing** 

Balance

Helpful

Helpful

More Balance

I will see my

Fit, feeling better

about oneself.

Educated me

Education

Awareness

Peaceful

I have the importance

Got in touch with my inner

I know I will feel better

Just use common sense.

soul.

Heartfelt

Reawaken

Take care of whole self, not just aspects.	By reading the messages, this instilled awareness of the impact of diabetes on eyehealth.	My dad has diabetes, so this reminded of diabetes health.  Given that my grandpa is diabetic and has		
		declining eyesight, it affected me emotionally.		
Spiritually, the messages didn't really contribute anything but were a great reminder to take care of myself.	Reminded me to take eye examinations more.	The messages left a feeling of relief because they were good reminders	The messages made me more aware of how it's important to lead a healthy lifestyle.	
		Dad is diabetic and now I have more information to help him		
My eyes are from creator, to send my visions to him. Great	Know that my eye sight has an effect on my mental health. They help me take self-care more seriously.	That it's alright to be emotional and not hold on to the past. Let my emotions be.	Take care of my body. Walking, eating healthy, call can prevent diabetes.	
	Knowledge is key. Educate yourself.		Physical activity can help prevent/control diabetes.	
I know I should get annual checkups yearly.	I am more aware of what can happen when you have diabetes and eye problems.	Eat healthier to prevent anything serious.	I will make appointment.	

	Taking care of		Eat healthy, be	I didn't receive any
	yourself. See you		active and make	messages.
	don't get sick.		good decisions.	
	I have gained valuable	I have positive	I am more aware of	
	information about my	emotions about further	how diabetes could	
	health that I did not	understanding diabetes.	affect my body.	
	know before this	Less stigma around the		
	study.	subject.		
Throughout the study, I now			I booked an eye	
have the knowledge of how			exam. I haven't had	
truly interconnected all			an eye test since I	
aspects of my body are. I			was 6 years old.	
know that what I put into my				
body can have detrimental				
impact on all aspects of my				
health including eye health. It				
is extremely important for me				
to now watch what I eat more				
carefully and control my				
blood sugar. I will also now				
go for an eye exam yearly.				
	More knowledge on	Sense of fear to bad	Watching closer to	
	the term Diabetes.	health has resolved,	health problems.	
		knowing the	1	
		information I received		
		through text.		
Prayers for those with	Awareness sparked		Empathy for those	Encouraged me to
diabetes.	my thought process		I know with	increase exercise for
	about diabetes.		diabetes.	myself and my son. More
				aware of my position to
				help care for grandpa
				with diabetes.

### **Appendix O: Published Article**

Development of Text Messages for Mobile Health Education to Promote Diabetic Retinopathy Awareness and Eye Care Behavior Among Indigenous Women

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Abstract. Background: Diabetes is increasingly prevalent in Indigenous people along with associated ocular complications such as diabetic retinopathy, which is the most common cause of blindness in Canadian adults. Though the risk of diabetic retinopathy is higher particularly among Indigenous women, there is limited utilization of diabetic eye care services. Hence there is the need for studies and interventions that pursue an innovative and culturally appropriate way of providing relevant information to promote diabetes-eye knowledge and prompt eye care behavior among Indigenous women living with and at-risk of diabetes. Aim: To develop diabetes-eye messages for a mobile health (mHealth) intervention to promote diabetic retinopathy awareness and eye care behavior among Indigenous women living with diabetes and at-risk of diabetes in Saskatoon.

Methods: In this study, we used a multi-stage content development approach to

Methods: In this study, we used a multi-stage content development approach to crafting text messages, informed by Self-determination theory. The authors carried out content development in four major phases: content selection, user input, review and refining of messages, and pre-testing of messages.

Result: Messages were selected via content analysis and literature search. The messages were informative/educational, reminders, motivational, and supportive. Important considerations in message development included: message prioritization, text message formatting, delivery, and dissemination plan.

Discussion and Conclusions: A collaborative approach with a multidisciplinary team was essential to develop a comprehensive, culturally pertinent and appropriate mHealth messaging. The study provided some key steps and considerations for the development of a mHealth text messaging initiative in an Indigenous population and may serve as a guide for similar health promotion interventions.

Keywords: Mobile health · Diabetic retinopathy · Indigenous

### 1 Introduction

### 1.1 Diabetes and Diabetic Retinopathy

Diabetes epidemic is acute among Canadian Indigenous populations and can be attributed to the social, cultural, and environmental changes Indigenous people have

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undergone due to colonization. The First Nations, Metis and Inuit peoples make up the Canadian Indigenous people and the prevalence of diabetes is slightly higher in females within the 30–34 years age group [1]. Indigenous women (First Nations and Métis) are particularly prone to developing diabetes with more than four times the rate of non- Indigenous women, due to higher rates of obesity and gestational diabetes [2]. In addition, Indigenous women in Saskatchewan living with diabetes have higher rates of fetal macrosomia (children with birth weight >4,000 g), than non-Indigenous peoples [3].

Diabetic Retinopathy (DR) is a chronic eye complication of diabetes and the most common cause of blindness in developed countries including Canada, particularly among the working population (25–75 years of age) [4]. Few studies have assessed the prevalence of DR in Canada, particularly among Indigenous Canadians. However, Canadian Indigenous people have shown to have a higher rate of advanced DR changes compared to non-Indigenous populations which may be as a result of the early onset of diabetes, predisposing them to higher rates of DR complications [5]. A study that examined Indigenous peoples from Sandy Lake, in Northern Ontario, revealed a prevalence rate of 24% for non-proliferative DR, 5% for macular edema and 2% for proliferative DR [6].

It is theorized that women with myocardial ischemia and arteriosclerosis may be at greater risk of developing microvascular diseases such as retinopathy [7]. Also, DR tends to accelerate during hormonal changes such as pregnancy and puberty [8]. Accordingly, diabetes will lead to a significant burden of preventable vision loss in Indigenous communities, particularly in women if not addressed [9]. In addition, Indigenous women at risk of diabetes i.e. with family history of diabetes, gestational diabetes, pre-diabetes have greater risk of developing type 2 diabetes at an early age and increased risk of vision loss and associated ramifications that occur as a result of diabetic retinopathy blindness including; mental health conditions and poor quality of life. Hence, the authors focused on Indigenous women with diabetes and at-risk of diabetes in the study.

### 1.1 Mobile Health

mHealth is a term used to cover all mobile digital health technologies and health informatics such as personal digital assistants and mobile phones to improve health knowledge, behaviors and outcomes. mHealth has been widely applied to address health inequities in Indigenous communities which occurs due to economic, political and sociocultural factors and to mitigate some of these barriers [10]. Due to the ubiquity, affordability and ownership of digital technologies, mHealth has the potential to deliver preventative health services, and address disparities in diabetes complications between Indigenous and non-Indigenous communities [11].

### 1.2 Rationale

Diabetic retinopathy is a chronic eye complication of diabetes and the primary cause of blindness in Canada especially among adults. Almost all persons with diagnosed diabetes develop some stage of diabetic retinopathy over time and if poorly managed at

critical periods, it can result in vision loss that subsequently impacts functional independence and productivity as well as increases the risk of physical and mental comorbidities including falls, social isolation, and depression, thus making diabetic retinopathy a serious eye population health concern [12]. People living with diabetes can manage the onset and progression of diabetic retinopathy by adherence to diabetes medication, annual eye examination, and prompt retinopathy treatment where necessary. However, many people living with diabetes have inadequate understanding of diabetic eye complications, the importance of tight control of blood sugar, strict treatment adherence, and swift management of retinopathy signs/symptoms [4], resulting in low compliance with recommended annual screening [5].

Limited eye health literacy among other social determinants of health experienced by Indigenous people influence diabetic retinopathy awareness and eye care behavior leading to late diagnosis, poor management, poor prognosis, and vision loss. This is because, although Indigenous people are at high risk of diabetic eye complications, there are significant gaps in care, thus buttressing that interventions aimed at improving diabetes outcomes are essential [13]. Such interventions may empower Indigenous people with relevant knowledge that will influence their uptake of eye care services for early diabetic retinopathy identification, management, and the prevention of vision loss.

Indigenous women health risks, needs and preferences differ from men and non-Indigenous people, hence the gendered perspective in order to close the health/wellness gap [14]. Thus, with the increasing population of Indigenous people in cities such as Saskatoon and the population health impact of diabetic retinopathy in Indigenous women, it is vital to pursue an innovative, culturally relevant, and appropriate way of providing targeted diabetic eye care information to Indigenous women with diabetes and at-risk of diabetes in Saskatoon. To the best of our knowledge, there is no published report on the use of mHealth for diabetes-eye care among Indigenous women. Hence, this research process was part of a larger study that sought to evaluate the impact of the mHealth intervention in diabetic retinopathy awareness and eye care behavior among Indigenous women living with diabetes and at-risk of diabetes in the city of Saskatoon in Saskatchewan, Canada.

### 1.1 Purpose

To develop a relevant and culturally appropriate diabetes-eye content suitable for a mHealth intervention for Indigenous women living with diabetes and at- risk of diabetes in Saskatoon.

### 2 Literature Review

### 2.1 Diabetic Retinopathy

People living with diabetes have an increased risk of developing various eye complications at a younger age but, the main threat to vision due to diabetes is diabetic retinopathy (DR) which is a chronic eye condition. DR prevalence rate increases sharply after 5 years duration of type 1 diabetes in post pubertal individuals while in

### 110 V. O. Umaefulam and K. Premkumar

persons with type 2 diabetes, retinopathy may be present in about 21% soon after clinical diagnosis [15]. DR is often asymptomatic in its early stages but as it progresses, may cause irreversible vision loss.

### 1.1 Canadian Indigenous People

Canadian Indigenous people are the original inhabitants of Canada and constitute of First Nations, Inuit, and Métis people with unique languages, history, and cultures; and Saskatchewan has the second highest number of Indigenous people in Canada [16]. Generally, each of these Aboriginal groups have their own unique culture, way of life, language, food, beliefs, and are largely influenced by their natural environments. Large communities of Indigenous people live in Saskatoon and are the focus of this study.

### 1.2 Mobile Health

Initiatives to support the care and treatment of patients via mobile technology are emerging globally and mobile phone use is increasing rapidly with more than two thirds of the world's population now owning a mobile phone [17]. Hence, given the popularity of mobile phones, health professionals are increasingly using mobile phones to link people to health information and services across various settings. Research in high-income countries have shown that mHealth addresses numerous barriers in health care such as; access to medical services for vulnerable populations, enhanced com- munication among health care workers and patients, and improved health care delivery [18].

mHealth initiatives have thrived in both low and high-income contexts and mHealth technologies are contributing to a burgeoning number of novel health pro- motion, public, and population health interventions for numerous chronic disease management initiatives [19]. mHealth can support people in the management of chronic diseases during the interval between appointments and help reduce the risk of them developing complications that could have serious health consequences.

Text messaging (short message service or SMS) is now the most universal form of mobile communication and utilized to provide automated and tailored messaging [20]. Also, texts can be individually tailored for content and timing as well as for a range of variables, including language, age, gender etc. The development of health-related text messaging is on the other hand challenging in respect to the style, language, length of the messages, and quality of content in order to have maximal impact on recipients.

### 2 Methods

In this study, we used a multi-stage content development approach [21] to crafting text messages, informed by Self-determination theory. The authors carried out content development in four major phases: content selection, user input, review and refining of messages, and pre-testing of messages. Ethical approval was obtained from Research Ethics Board of the University of Saskatchewan.

### 3.1 Intervention Theory

Prior to developing the text message program, it was essential to have a prespecified framework for the focus of each information delivered. Health behavior theories can help guide the process of understanding underlying behavior change [22] and a theory driven mHealth intervention assists in providing certainty about its effectiveness. The authors used Self Determination Theory (SDT), which describes how behavior can be self-determined as a result of self-efficacy, intrinsic motivation, self-identity, needs fulfillment, and autonomy [23]. Theories of human behavior often account for the direction of behavior, but fail to account for what stimulates that behavior [24] thus, SDT posits that motivation for behavior can be self-determined when three needs are met; autonomy, competence, and relatedness.

SDT is particularly relevant to self-management of diabetes and its complications particularly as it relates to behavior change. Thus, the information on diabetes care should support the need for competence and relatedness which will prompt the feeling of autonomous integration and self-efficacy around this recommended health behavior change and may result in action planning, problem solving, and decision making.

This theory is an ideal guide for this study because it emphasizes the ways in which people actively cope with information about their health and make decisions regarding health behaviors. Also, engagement with Indigenous peoples should be respectful, supportive, and enhance self-efficacy to prompt behavior change. In addition, Schnall et al. [25] utilized self-determination theory to show how mHealth technology can be used as a social change agent to improve health via reminders and text alerts.

Focusing on beliefs and attitudes towards adherence and providing social support or social norms can strengthen motivation for engaging in behavior change [22]. Thus, we intend that the content should enhance competence (the knowledge of diabetes and its eye complications) and this will motivate and influence the ability of recipients to make autonomous and informed decisions regarding their eye care. This would be supported by relatedness which occurs via communication among family, friends, and health professionals who influence feelings about diabetes-eye risk and their eye care behavior.

### 3.2 Development Process

It is vital that mHealth applications align with health systems and services in the region, hence the need to involve stakeholders such as health care providers, patients, other groups addressing diabetes health care. The content development process brought together a multidisciplinary team of researchers, Indigenous people, information, communication and technology professionals; academics, health care workers and program coordinators to develop the mHealth diabetes-eye content for Indigenous women living with diabetes and at-risk of diabetes in Saskatoon. Five intended users of the mHealth initiative were also involved in the message development so as to enhance intrinsic value for the user [11] and incorporate their values and perceptions.

Content development occurred in four phases: content selection, User input, review and refining of messages, and pre-test of messages with a sample of the target audience.

#### 112 V. O. Umaefulam and K. Premkumar

Content Selection. During the first phase, the authors reviewed guidelines from Canadian Optometry and Diabetes organizations and conducted content analysis of patient directed diabetes-eye health educational materials via online searches from 2010–2017, using search terms: diabetic retinopathy and patient education. Major websites accessed included the Canadian Association of Optometrists, Canadian Diabetes Association, World Health Organization, National Eye Institute and secondary searches in diabetes organizations, support services such as Canadian National Institute for the Blind and provincial health organizations including, LiveWell Diabetes- Aim4Health program and Saskatchewan Optometric Association. The authors con- ducted searches until no new material was found and similar messages were deleted. Identified relevant materials were considered and adapted to text messages.

Materials such as complexity of treatments, graphics and photos were excluded since they were irrelevant or could not be used as text messages and would not be received by all phone types. The author (VU) who is an Optometrist prepared a library of 115 messages that aligned with the SDT constructs and incorporated various aspects, such as behavior change goals, clinical evidence and facts, and information from clinical guidelines. The messages were adapted for SMS to meet the 160 characters count limit. Field notes were maintained to document the process of content development.

User Input. In a preliminary study, the authors carried out four sharing circles [26] in the primary research which explored the information users would want to know about diabetes and eye care. The authors analyzed the transcripts of sharing circles and field notes to determine the type of information users would like to know or receive and what could motivate them to utilize eyecare services.

Four major themes emerged from the data: a. information on diabetes-eye care, b. etiology of diabetes, c. prevention and management, and d. Learning via images. Based on the themes, messages developed addressed: diabetic retinopathy related symptoms, the frequency of eye check, how to book an eye appointment, holistic information about diabetes. Users also requested for pictures of the eye, showing changes as the disease progresses, indicating that information communicated using images was helpful.

Review and Refining of Messages. A systematic approach with the engagement of endusers is important in developing mHealth content via involving input from a range of experts and users, evaluation and refinement, and pilot testing [27]. A multidisciplinary team of dieticians (n = 2), diabetes experts (n = 2), optometrists (n = 2), Indigenous community members (n = 3), peer leaders from the community groups (n = 2), Indigenous Elders (n = 2), researchers (n = 2), and potential participants (n = 5) (hereafter referred to as team) examined the library of messages via a community engaged workshop wherein team members reviewed each message and shared feedback during discussions on each of the messages ranging from "like it", "don't understand" and "not appropriate". The authors asked follow-up or clarifying questions as needed during the discussions and compiled notes on the feedback. The content was modified based on the feedback and recommendations, used plain language to ensure that the mHealth intervention was suitable for the targeted women.

Pre-testing of Messages. The content underwent pre-testing with five recipients for three days to ensure the delivery of the text messages to recipients on different mobile networks and sought feedback on real-time experiences in respect to message timing. Following the pre-testing, further minor modifications were incorporated. The authors developed the diabetic-eye content for mobile text messaging by ensuring that the messages aligned with the 160-character limit for a text message. Figure 1 shows an outline of the content development process.

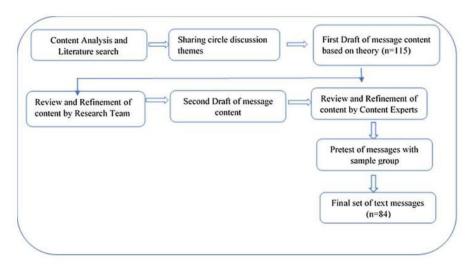


Fig. 1. Process of developing and refining text message content

### 4 Results

Key considerations in message development for the diabetes-eye mHealthintervention included: message prioritization, text message formatting, message delivery, and dissemination plan.

### 4.1 Message Prioritization

The authors prioritized selected message content based on the information provided by the intended recipients from prior formative study, key messages considered important by team members from feedbacks, and messages addressed the three constructs of the underlining theory. Based on these recommendations we included content on diabeteseye care, information on diabetes, and prevention and management. Such as: "Health Tip: Do you know what you weigh? Maintaining a healthy body weight helps with your general health and reduces your risk of eye diseases. Check your weight today!"

Several themes emerged from the feedback from the review team, including language, positivity, and simplicity of messages. The team reported that the content of the motivational messages was acceptable due to the gentle, suggestive nature and

#### 114 V. O. Umaefulam and K. Premkumar

suggested practical tips for adding necessary vegetables to traditional foods found in the city and some messages addressed this. The team shared that; a message that says, "Poor sugar control" was not positive and suggested it altered to "Unhealthy blood sugars". Again, "common sight threatening eye problems often have no warning signs. An eye exam is the only way to detect these conditions in their early stages" was too complex and team suggested it changed to, "An eye exam is the best way to find eye problems in the early stages. You can't always tell when your eyes are getting sick".

The authors included messages based on the theory that can increase knowledge of diabetes-eye care, messages that can prompt autonomous informed health decisions and messages that connect recipients to family and community services in Saskatoon. Messages were activity-based by not solely focusing on providing education content, and since mobile phone initiatives may be most effective when designed to link users to health care services and programs through communication of available services; hence messages provided information on diabetes and eye care services available in Saskatoon as well as provided information on how to book appointments with optometrists.

Messages consisted of the following: informational/educational, reminder, motivational/supporting. Information/educational text provided information about the health-related consequences of diabetic retinopathy and general diabetes-eye health information and related conditions. For example: "Did you Know: Poor blood sugar control can cause changes in the way you see far and near objects and the ability to focus on close objects when reading".

Reminder messages provided information, cues, and prompts for recipients to take critical actions, seek eye care and to self-monitor diet and blood sugar levels. For instance: "Hello. Health Tip: Remember to add physical activity to your long weekend activities so as to improve circulation and your general health" and "Hello. Health Tip: When was the last time you had an eye exam? If more than 1 year ago, and you are living with diabetes, you are due for an eye checkup".

Motivational/supporting text shared information that elicits engaging in activities that will enable recipients manage or prevent diabetes-eye conditions. For example: "Health Tip: Your daily habits and lifestyle such as exercising could seriously help your eyes without you knowing it. Keep up the good work".

### 4.2 Text Formatting

Messages were careful worded to ensure clarity and avoid misunderstandings. The author (VU) has experience in digital content development as such was responsible for shortening the messages to 160scharacters while maintaining their meaning. In addition, we utilized a flexible approach thus, the content could be tweaked based on present conditions at the period of delivery.

### 4.3 Delivery

The authors considered cost, ease of messaging platform, ease of dissemination, applicability to devices and tracking of delivery when looking for messaging vendors.

The authors plan to deliver daily text messages to the target population's mobile devices (77 recipients) between 8.30am and 9am daily (as suggested by the intended recipients during review) by Telmatik a communications management and bulk messaging platform that supports personalized user outputs and inputs via text messaging and provides technological solutions [28].

#### 4.4 Dissemination Plan

The authors designed a messaging sequence such that every week, messages provided information relating to: general eye care, information targeting those with diabetes, at risk of diabetes, action-based, and connecting with health/community services.

### 5 Discussion

The mHealth messages utilized evidence-based information and approaches for diabetes-eye prevention and management and it was informed by behavioral theory. Content analysis of diabetes educational material across various health organizations provided the team with an extensive list of message options. The theory helped organize messages and guided the choice of messages selected which was ideal in making message content development systematic and comprehensive [22]. The messages came from trusted sources, were informative, encouraging, reassuring, non-judgmental, and provided "cues to action". In addition, the content gave information on availability of heath care services, not only focusing on the condition [29], and included information on co-morbidities associated with diabetes and the eyes, such as holistic information on diabetes and general eye care.

The community engaged feedback process enabled community members and intended users identify and address concerns such as the cultural appropriateness of the content. This aligns with a family-focused diabetes self-Care support mHealth intervention for diverse, low-income adults with type 2 diabetes that utilized community engagement in the development of the content and mHealth protocol [30]. In addition, it balanced bottom-up and top-bottom approaches in community health that often results in an acceptable and equitable intervention [11].

The messages did not focus on the negative health consequences of diabetes since it was not motivational and doesn't enhance self-confidence, rather the focus was on the benefits and opportunities for eye health. Morton and colleagues similarly indicated that messages on the benefits of physical activity rather than the impact of overweight in type 2 diabetes management was preferable [31]. In addition, a text message would prompt users to seek eye care if they are light-hearted, positive, supportive, and encouraging [31]. The authors added a personal greeting and encouragement in messages and this has shown to be useful in the design of text messaging content, as this may facilitate women's self-confidence and perceived self-efficacy [21], and may prompt them to utilize eye care services and manage their health.

### 6 Conclusion

116

This study supports the use of a collaborative approach in the development of mobile health messages. The approach involving multidisciplinary experts and community members resulted in a mHealth content that responded to participants needs, culturally appropriate and relevant. Messages were developed as a team, using an iterative process of writing, review, pre-testing and further modification until a final version was agreed upon. The diabetes-eye mHealth content was evidence based, flexible and aligned with the community needs, and the developed messages consisted of informational and educational, reminder, and motivating/supporting content as well as provided cues to making informed diabetes- eye care decisions. The mHealth intervention will provide evidence-based information about diabetes and eye care and ways that women can control and reduce their risk of the condition and improve diabetes-eye outcomes.

Mobile health applications are promising in addressing health disparities, particularly in Indigenous populations who disproportionately face barriers to self-management due to limited heath communication, cultural competency of health care workers, social support, and access to health care. This study provides some key steps and considerations for the development of a mHealth text messaging initiative that responds to community need in an Indigenous population. Future directions include testing the efficacy of the mHealth intervention in increasing diabetes knowledge and eye care behavior. Thus, the content is being evaluated among the targeted population to access the quality and reliability of this proposed approach and its impact is under analysis.

Strengths and Limitations. The authors developed the content specifically for Indigenous women living in Saskatoon as such reflects the needs of the population. Importantly, since a theory guided our process of crafting these messages, it can explain how the messages can potentially result in behavior change. Thus, the mHealth content and intervention may be adapted for use in other regions and in different contexts. Limitation includes the inability to provide pictorial content as requested by participants due to the text messaging platform chosen for content dissemination.

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Conflicts of Interest. The authors have no conflicts of interest to declare.

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### 118 V. O. Umaefulam and K. Premkumar

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