

Engaging with mHealth to Improve Self-regulation: A Grounded Theory for Breast  
Cancer Survivors

Dissertation

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By

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## Abstract

Breast cancer survivors are at risk of cancer recurrence and other cancer-related chronic diseases. Lifestyle modification reduces these risks; however, traditional approaches are costly and often lack efficacy. Mobile health (mHealth) interventions may offer advantages over traditional risk-reduction approaches, but limited knowledge about survivors' use of mHealth interventions restricts scientific advancement. The goal of this dissertation research was to develop a substantive theory to understand the process associated with the use of mHealth interventions by breast cancer survivors for lifestyle behavior improvement. Using a grounded theory approach, 16 female breast cancer survivors from central Ohio were enrolled. Each participated in an interview and an interaction with a prototype mHealth intervention. Data were analyzed using constant comparative analysis. The resultant substantive theory describes the synergy between *mHealth Engagement* and *Self-regulation* of lifestyle behaviors. The basic process enabling this synergy consists of 5 non-linear phases: *adopting*, *sustaining*, *habituating*, *disengaging*, and *re-adopting*. Four main concepts form the basis of this theory and include *mHealth Engagement*, *Self-regulation*, *Relationships*, and *Functionality and Features*. These findings may inform future mHealth intervention research and development. However, more research is needed to validate and test this new substantive theory.

## **Dedication**

To my family and friends.

## **Acknowledgments**

I wish to express my sincere appreciation to my mentors and advisors. Their continued guidance and instruction throughout this academic journey have been invaluable. I am also grateful for the love and support of my family and friends, as this dissertation would not have been possible without their unconditional devotion and encouragement.

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2.     Yen PY, **Kelley M**, Lopetegui M, Rosado A, Migliore E, Chipps E, Buck J. Understanding and Visualizing Multitasking and Task Switching Activities: A Time Motion Study to Capture Nursing Workflow. *AMIA Annu Symp Proc.* 2017 Feb; 10;2016:1264-1273. eCollection. PMCID: [PMC5333222](#).
3.     Roth C, Payne PR, Weier RC, Shoben AB, Fletcher EN, Lai AM, **Kelley M**, Plascak JJ, Foraker RE. The Geographic Distribution of Cardiovascular Health in the Stroke Prevention in Healthcare Delivery Environments (SPHERE) Study. *J Biomed Inform.* 2016 Apr; 60:95-103. doi: 10.1016/j.jbi.2016.01.013. PMCID: [PMC4836963](#).
4.     Foraker RE, Shoben AB, **Kelley MM**, Lai AM, Lopetegui M, Jackson RD, Langan MA, Payne PR. Electronic Health Record-Based Assessment of Cardiovascular Health: The Stroke Prevention in Healthcare Delivery Environments (SPHERE) Study. *Prev Med Rep.* 2016 Jul; 13;4:303-8. doi: 10.1016/j.pmedr.2016.07.006. PMCID: [PMC4959947](#).
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6. Foraker RE, Shoben AB, Lopetegui MA, Lai AM, Payne PRO, **Kelley M**, Roth C, Schreiner A, Jackson RD. Assessment of Life's Simple 7<sup>TM</sup> in the primary care setting: The Stroke Prevention in Healthcare Delivery EnviRonmEnts (SPHERE) study. Contem Clin Trials. 2014 Jul; 38(2):182-189. [doi: 10.1016/j.cct.2014.03.007](https://doi.org/10.1016/j.cct.2014.03.007)
7. **Kelley M**, Demiris G, Nguyen H, Oliver DP, Wittenberg-Lyles. Informal Hospice Caregiver Pain Management Concerns: A Qualitative Study. Palliat Med. 2013 Jul;27(7):673-682. doi: [10.1177/0269216313483660](https://doi.org/10.1177/0269216313483660). PMCID: [PMC3950803](https://pubmed.ncbi.nlm.nih.gov/PMC3950803/).

### Fields of Study

Major Field: Nursing



## Table of Contents

Abstract .....	ii
Dedication .....	iii
Acknowledgments .....	iv
Vita .....	v
Education .....	v
Work Experiences .....	v
Peer-Reviewed Publications .....	vi
Table of Contents .....	viii
List of Tables .....	xii
List of Figures .....	xiii
Chapter 1. Introduction .....	1
Purpose of the Study .....	4
Rationale for a Grounded Theory Approach .....	4
Relativist World View .....	5
Ontology .....	6
Epistemology .....	6
Axiology .....	7
Other Assumptions.....	7
Relevance to Nursing.....	9
Relevance for Research.....	11
Summary .....	15
Chapter 2. Literature Review .....	16
Background of the Problem .....	16
Stress .....	17
Tobacco .....	18

Weight, Exercise, and Diet .....	19
Alcohol.....	20
Drugs.....	21
Cancer Survivors and Increased CV Disease Risk .....	21
Traditional Approaches to Lifestyle Behavior Change .....	22
Mobile Health .....	24
mHealth and Smartphone Use .....	25
Potential for mHealth Apps as Interventions .....	26
Challenges of mHealth Interventions.....	27
Lack of Rigor .....	27
Siloed Disciplines .....	27
Lack of Theory.....	29
General mHealth Interventions for Behavior Change .....	30
Cancer Survivors, mHealth, and Non-Lifestyle Focused Interventions .....	33
Summary .....	36
Chapter 3. Methods .....	37
Introduction.....	37
Design Overview and Rationale .....	38
Setting .....	40
Sample.....	40
Purposive Sampling .....	41
Theoretical Sampling.....	42
Data Collection .....	43
Prototype Description .....	47
Data Collection Details.....	48
Data Analysis .....	49
Overall Analysis Process .....	49
Phase 1 Analysis — Initial (in vivo) Coding.....	52
Phase 2 Analysis — Focused Coding.....	53
Phase 3 Analysis — Theoretical Coding .....	55
Trustworthiness and Rigor.....	56
Adapted from criteria by Lincoln and Guba <sup>211, 213, 217</sup> .....	60
Chapter 4. Results .....	61

Demographics .....	61
Substantive Theory Overview.....	65
mHealth Engagement and Self-regulation using Intervention Applications Theory....	67
Processes Overview .....	70
Theoretical Assumptions and Propositions.....	70
Five Phases of the Sociotechnical Process.....	70
The Adopting Phase.....	71
The Sustaining Phase .....	74
The Habituating Phase .....	81
The Disengaging Phase.....	83
The Re-adopting Phase .....	86
Concept 1 - mHealth Engagement .....	88
Concept 2 - Self-regulation.....	89
Concept 3 - Relationships .....	94
Relationships with Healthcare Providers .....	95
Relationships with Family and Friends.....	98
Relationships with Technology.....	99
Relationship with Self.....	100
Variation in Patterns within the Relationships Concept .....	100
Concept 4 - Functionality and Features .....	102
Content.....	103
Personalization.....	104
Usability.....	104
Goals .....	105
Feedback .....	106
Integration .....	108
Data Security and Trust .....	110
Subject Matter Experts and Participant Follow-up .....	110
Chapter 5. Discussion .....	112
Comparisons to Existing Research Findings .....	114
Literature on mHealth Engagement .....	114
Theoretical “Fit” .....	116
Process Models of Health Behavior.....	116

Compensatory Carry-over Action Model .....	119
The Common-Sense Model of Self-regulation .....	123
Self-regulation in the Literature .....	124
The Social Cognitive Theory .....	125
The Fogg Behavior Model .....	127
Further Support of the <i>Relationships</i> Concept.....	129
Information Systems Theories .....	131
The Digital Behavior Change Interventions framework.....	133
Study Limitations.....	135
Future Directions for the mHESIA Theory .....	138
Conclusion .....	143
References .....	144
Appendix A. Demographics Questionnaire .....	171
Appendix B. Health Behaviors and Factors Questionnaire .....	175
Appendix C. Trustworthiness Criteria, Definitions, and Applications (extended)* .....	178
Appendix D. Theoretical Assumptions and Propositions .....	182

## List of Tables

Table 1. Initial Interview Guide.....	45
Table 2. Terms, Definitions, and Coding Phases.....	50
Table 3. Partial Audit Trail for the Concept Relationships .....	51
Table 4. Trustworthiness Criteria, Definitions, and Applications .....	60
Table 5. Sample Characteristics ( $n = 16$ ).....	63
Table 6. Theory Concepts, Dimensions, and Attributes .....	66
Table 7. Health Factor of Concern versus Health Factors Undergoing Active Improvement by User Type per Participant.....	69
Table 8. mHESIA Theory Mapped to Existing Theories .....	113

## **List of Figures**

Figure 1. Grounded Theory Analysis Model .....	38
Figure 2. The mHESIA Theoretical Model .....	67

## **Chapter 1. Introduction**

Cancer is the second leading cause of death globally, with the number of new cancer cases expected to increase by 70% in the next two decades.<sup>1</sup> As of January 2019, there were more than 3.1 million breast cancer survivors in the United States (U.S.)<sup>2</sup> with prevalence expected to increase to nearly 4.6 million by 2026.<sup>3</sup> Modifying lifestyle behaviors (diet, physical activity, smoking, stress, and alcohol/drug misuse) to healthier levels attenuates the risk of cancer recurrence in cancer survivors.<sup>4-7</sup> Additionally, lifestyle modification lowers the risk of cancer-related chronic health issues such as cardiovascular (CV) disease - one of several significant concerns for breast cancer survivors.<sup>8-11</sup> A cancer survivor, as defined by the National Cancer Institute (NCI)<sup>12</sup> and the American Cancer Society (ACS),<sup>13</sup> is any person with a cancer diagnosis, from the time of diagnosis until his or her death.

Traditional approaches to lifestyle modification, such as face-to-face counseling or group educational programs, are expensive,<sup>14</sup> require significant human resources,<sup>14</sup> are time-consuming for clinicians and patients,<sup>15</sup> and are difficult to sustain.<sup>16</sup> Efficacy is also of concern in these traditional programs.<sup>17</sup> Mobile health (mHealth) interventions, delivered through mHealth applications (apps), offer a novel alternative to traditional approaches and have the potential to address some of the shortcomings of such programs.

mHealth interventions can ameliorate burdens associated with time, workflow, and lack of resources. Also, mHealth interventions have the inherent capability of increasing the reach of lifestyle interventions, transcending geography and time. They can be delivered asynchronously at a time most convenient and appropriate for the patient. Moreover, they can be explicitly tailored to the individual patient's needs. Although mHealth interventions are a relatively new phenomenon, having been available only since about 2009, their presence and use have increased substantially in the last few years.<sup>18</sup>

mHealth interventions have demonstrated mixed success in improving lifestyle behaviors in non-cancer settings and populations,<sup>19-21</sup> with scant research conducted among cancer survivors. An integrative literature review was conducted preliminary to this dissertation work that identified 19 articles focused on cancer, mHealth interventions, and lifestyle behavior change.<sup>22-40</sup> Overall study quality was poor and there was a lack of scientific rigor. Only 1 pilot study reported the use of theory in the development of the mHealth intervention.<sup>22</sup> The lack of rigorous research limits the scientific knowledge base and thus scientific advancement in the use of mHealth interventions for lifestyle improvement in cancer survivors. Moreover, a lack of theoretical underpinnings in the design and evaluation of mHealth interventions limits mHealth intervention success.<sup>41-44</sup> Compelling evidence indicates that theory-driven interventions are more effective in changing behavior<sup>45</sup> with specific evidence indicating that extensiveness of theory use enhances intervention effectiveness among breast cancer survivors.<sup>46</sup> Taken together, lack of rigor and lack of theory-driven interventions impair scientific advancement.



Rigorous intervention studies are needed, but the appropriate selection of theories for use in this new context remains poorly understood. For example, understanding which behavior to address (lifestyle behavior or mHealth use behavior) complicates theory selection. Both behaviors are essential when using attempting to improve health outcomes through technology use.

Another limitation to mHealth intervention success involves siloed research domains. Researchers investigating human-computer interaction (HCI), system informatics, nursing, and clinical informatics, as well as researchers in the behavioral science fields (e.g., cognitive science, psychology) currently guide this evolving line of mHealth intervention research. Their respective theories often contain conflicting or missing concepts important to the other domains.<sup>43, 44, 47-51</sup> A dearth of theories, from an integrated perspective of the aforementioned scientific domains, limits the advancement of mHealth intervention science, particularly given the rapidly evolving nature of this technology.<sup>52</sup> The lack of theories represents a significant gap in the scientific knowledge base of mHealth interventions used to affect lifestyle behavior change. This knowledge gap limits researchers' ability to design and rigorously test mHealth interventions focused on lifestyle behavior change, particularly in cancer survivors. This dissertation study addressed this problem using a qualitative Grounded Theory approach to identify and explain survivors' experiences with mHealth interventions and the sociotechnical processes around the use of mHealth interventions for lifestyle behavior change. Sociotechnical processes are processes and interactions between people (survivors) and technology (mHealth interventions) within a complex environment (healthcare).<sup>53</sup>

Additionally, using Grounded Theory Methods (GTM) facilitated the development of a substantive theory to explain how mHealth works for or is employed by cancer survivors to affect behavior change and lifestyle modification.

### ***Purpose of the Study***

The purpose of this dissertation research was to develop a substantive theory using a grounded theory approach to identify and understand the sociotechnical processes associated with mHealth interventions use by breast cancer survivors for lifestyle behavior change. The following research question was answered: What are the processes explaining breast cancer survivors' use of mHealth interventions for lifestyle behavior change?

### ***Rationale for a Grounded Theory Approach***

Grounded theory methodology and methods are useful when exploring processes and phenomena where little is known,<sup>54</sup> such as the relatively new and unexplored phenomena of using mHealth interventions to modify lifestyle behavior in cancer survivors. Almost since the inception of mHealth interventions, researchers have called for adequate theories to inform the science.<sup>43, 44, 55</sup> This lack of theory-based research is particularly evident in the context of cancer survivorship and mHealth as outlined above.

GTM are also useful when there are perceived biases or omissions in what is known<sup>56</sup> as is also the case within the developing field of mHealth intervention research. For example, researchers frequently call for the use of behavior change theories in the development of mHealth interventions.<sup>43, 44</sup> However, this logic omits underlying HCI processes essential to understanding the behavior of mHealth intervention use. GTM may

help overcome these omissions. Specifically, constructivist grounded theory may be useful as it emphasizes examination of processes (e.g., use of mHealth interventions) and an understanding of transactional experiences (e.g., HCI, researcher-participant). Additionally, meaning is individually and socially constructed; both the researcher and the participant explore the phenomenon to develop greater understanding. However, disentangling the rhetoric of the various GTM philosophies, epistemologies, ontologies, and methods and identifying my world view a priori was essential yet nontrivial work. Identifying and understanding my world view involved significant personal reflection. Understanding how my world view might best be reflected through the assumptions of a specific grounded theory methodology was also critical before proceeding with dissertation work. The results of my reflections, outlined below, informed all aspects of this dissertation work including the epistemological, ontological, and methodological assumptions.

### ***Relativist World View***

My research question determined the selection of a qualitative GTM approach, but my relativist world view informed selection of a constructivist grounded theory methodology. Relativism assumes multiple realities arising from both the perspective of the researcher and the perspectives of the study participants. This relativist stance assumes that a researcher's background (i.e., work in informatics, cancer, and research) and personal experiences (i.e., caring for loved ones dying of breast cancer) serve to inform values, actions, perspectives, and relationships with the survivors and their data.

Through a relativist lens, meaning and understanding of the world (i.e., survivors' processes for using mHealth interventions for lifestyle modification) are assumed to occur through the transactional co-construction of knowledge (i.e., knowledge generated from words and explanations of survivors and my interpretation of the meaning of the data). In alignment with the relativist tradition, using the constructivist GTM approach helped evoke meaning from language, actions, experiences, values, and preconceptions of both survivors and the researcher. Similarly, ontological, epistemological, axiological, and methodological assumptions associated with the constructivist paradigm aligned closely with my relativist world view.

### ***Ontology***

Ontology refers to the nature of reality and how human beings exist in the world. A constructivism paradigm focuses on relativism as an ontological stance or an understanding that realities are relative, subjective, and constructed by individuals. Constructivist theorists assume that "reality is multiple, processual, and constructed and the researchers' position, privileges, perspectives, and interactions are an inherent part of the research reality."<sup>57(p13)</sup> The underlying assumption that reality is local and co-constructed, meaning both the researcher and participant are involved in the creation of the subjective reality experience, resonated with my world view.

### ***Epistemology***

Epistemology concerns the study of knowledge. In alignment with constructivist GTM traditions, I assumed that truth and knowledge were created through personal transactions and interactions. A constructivist GTM aligned with this epistemic claim as

the methodology focused on understanding through the reconstruction of meanings (e.g., researcher interacting with data derived from participant's words). I assumed that as I interacted with participants through interviews and observations the resultant theory would be a creation reflecting meaning from the participant-researcher interactions as well as transactions with the data and the technology.

### ***Axiology***

Axiological assumptions are described as the role of values in the inquiry process.<sup>58</sup> The constructivist paradigm asserts that subjectivity and values are inevitable and desirable.<sup>58</sup> Values are part of all individuals' experiences and as such, lend meaning and understanding to the participant-researchers interaction and the reality they co-create. Identifying participants' and researchers' values in creating reality helps the researcher minimize the distance between herself and her study participants. I assumed that minimizing this distance would help me understand the phenomenon under investigation. The constructivist paradigm assumes that knowledge is maximized when this distance is minimized.<sup>58</sup> Methods such as keeping a reflexive journal, memoing, and identifying my own assumptions and world view helped minimize the distance.

### ***Other Assumptions***

Several other assumptions underpinned this research. Constructivist grounded theorists assume that inductive processes will lead to a substantive grounded theory and ultimately hypothesis generation. For example, the grounded theorists Bryant and Charmaz posit that a set of specific methods must be used for the final product to be considered a substantive grounded theory and that the resultant theory will reflect a

combination of the participants' and researchers' experiences and a co-constructed understanding of the world.<sup>59</sup> This assumption resonated with me as did the assumption that such methods focus on the whole subjective phenomena.

I assumed that using constructivist grounded theory methods to focus on the phenomena of interest would result in emerging insights grounded in the participants' experiences. The research process was flexible and emergent in design (e.g., theoretical sampling, constant comparison analysis) with consideration of context (e.g., breast cancer survivors in central Ohio). The methods outlined in Chapter 4 included a small, informative sample of participants and use narrative information to seek a deep understanding of processes involved in the use of mHealth interventions for behavior change among breast cancer survivors.

Constructivist grounded theorists have interpreted Blumer's seminal work in symbolic interactionism<sup>60</sup> and understand that "the world is made real in the mind and through the words and actions of its members."<sup>61(p523)</sup> Such interpretations embodied my viewpoint that breast cancer survivors interact with their physical environment (e.g., mHealth apps) and with their social environment (e.g., family, friends, researcher) to create meaning based on their interpretations and experiences. I supported these positions and also assumed that "reality is constantly reformulating as a fluid construction of individuals and in turn their social reference groups."<sup>62(p51)</sup> For example, sociotechnical processes in healthcare systems are the interaction between people and technology within the complex and dynamic healthcare system.<sup>53</sup> I assumed that breast cancer survivors interact with mHealth interventions in specific ways and in particular contexts, based on

the meaning that the mHealth intervention has for them and that these meanings are informed by interactions with others and sociotechnical processes. I also assumed that these meanings are fluid and evolving within different contexts and with time and that these sociotechnical processes are discoverable through discussion and observation.

Finally, I assumed that my personal experiences with family members diagnosed with breast cancer and caring for those loved ones through treatment and death were relevant experiences that informed meaning and influenced data analysis and theory development. Feelings about those prior experiences were triggered by interviews and data analysis and may have unduly influenced the process. Using reflexive techniques (i.e., reflexive journal, memoing reflexive thoughts) helped identify and capture some such biases, but perhaps not all. Similarly, I assumed that my work in the breast cancer clinic, relationships with breast cancer care providers, and volunteer work for community breast cancer organizations informed and influenced this dissertation work.

### ***Relevance to Nursing***

This dissertation research fits within the meta-paradigm of nursing and includes the concepts of human beings, environment, health, and nursing.<sup>63, 64</sup> The concept of human beings refers to breast cancer survivors within their family, culture, and community. Next, the concept of environment refers to the physical surrounding and the healthcare environment as well as the mobile healthcare environment. Interacting with mHealth applications includes the real-time environment in which the patient is interacting with the technology and the online environment thus extending the idea of the environment in which nursing occurs.<sup>64</sup> Health is the third concept in the nursing meta-

paradigm and is represented in this dissertation study by the focus on improving lifestyle behaviors to improve health outcomes for cancer survivors. Finally, nursing informatics encapsulates the concept of nursing and the potential of delivering nursing care through mHealth interventions. The nursing informatics specialty “integrates nursing science with multiple information and analytical sciences to identify, define, manage, and communicate data, information, knowledge, and wisdom in nursing practice.”<sup>65(p1-2)</sup> Nurse informaticians use and develop information and communication technologies in conjunction with patients, other healthcare stakeholders, and informatics stakeholders to improve the health outcomes of patients.

The importance of this dissertation work for clinical nursing rests in the ability of the resultant theory to inform the practice of nursing in the care of breast cancer survivors and in moving healthcare closer to realizing the potential of mHealth for lifestyle behavior change. This dissertation work resulted in the development of a mid-range theory for use in development and testing of mHealth interventions for lifestyle behavior change with important survivor-generated interest in a larger technology platform to deliver the survivorship lifestyle improvement care.

In sum, a gap exists in the scientific knowledge base for the design of effective mHealth interventions to modify lifestyles in this growing population of cancer survivors. Lack of theory to inform the design and testing of mHealth interventions limits efficacy and effectiveness. Despite a decade of calls for such theories, none have been developed.<sup>43, 44, 47, 48, 51, 66</sup> This dissertation work begins to build the science toward addressing this critical need.



### ***Relevance for Research***

Behavior change theories and behavior change techniques are essential for lifestyle behavior modification, but in the field of mHealth, understanding the behavior of app use, in this case, mHealth intervention apps, is also crucial. To understand the behaviors of mHealth app use as a lifestyle intervention, researchers need to investigate the relationship between both. The emerging discipline of Health Behavior Change Support Systems (HBCSS) holds promise toward that end.<sup>48</sup> HBCSS researchers working in this new field argue that the first step for this emerging research domain is to create an integrated theoretical background, from diverse disciplines to inform research and design.<sup>48</sup> They recommend significant extension or adaptation of existing theories from multiple disciplines or the creation of new theories.<sup>48</sup> However, adapting or extending existing theories from one research domain (e.g., engineering) may overlook critical concepts from the other scientific areas (e.g., health behavior). Additionally, theory adaptation may disregard or create other concerns, such as 1) the broader context of technology use (e.g., differences in technology literacy); 2) selecting singular concepts of interest from existing theories and losing the potency of a complete theory; 3) treating design guidelines (assembled from concepts in various theories – the supermarket approach) as design requirements before theoretical knowledge supports such guidelines; and 4) using selective concepts from a theory while stating the full theory informed the study.<sup>47</sup>

Using GTM to develop a substantive theory grounded from the perspectives of breast cancer survivors will circumvent these theory adaptation concerns. Moreover,

developing a substantive theory helps identify variables and relationships that can improve causal inference in rigorous, randomized study designs. While this dissertation work addressed the research needs of scientific domains working on mHealth intervention, it also aligned with current national research agendas in nursing.

This dissertation work, which has a focus on leveraging technology to support healthy behaviors in cancer survivors, aligns with national research agendas advanced by the Oncology Nurses Society (ONS) and the National Institute of Nursing Research (NINR).<sup>67</sup> Both organizations place specific emphasis on promoting innovation through technology use to improve and personalize healthcare.

A primary focus of the ONS research strategy concerns the long-term and late effects and risks associated with comorbid illness in cancer survivors. In this dissertation study, we investigated the use of mHealth lifestyle behavior interventions as a strategy to address risks and comorbidities in cancer survivors. Priority areas of the ONS strategic research plan focus on healthy weight, physical outcomes, psychological outcomes, and functional outcomes to reduce the risk of cancer recurrence, reduce the risk of comorbid disease, and improve long-term survival.<sup>67</sup> Moreover, ONS explicitly calls for the use of health informatics solutions to enhance cancer survivorship care delivery and improve health outcomes.<sup>67</sup> This dissertation study directly addresses this need. The ONS strategy also includes support of the Institute of Medicine's (IOM) recommendation for health promotion in the survivorship period. This dissertation research study also parallels this ONS research strategy.

This dissertation research study also supports the national research agenda of the NINR.<sup>68</sup> Two of the NINR research focal areas, Wellness – Promoting Health and Preventing Illness, and the cross-cutting theme of Promoting Innovation Through the Use of Technology,<sup>68</sup> aligned directly with the research of building theory to support the development and testing of mHealth interventions for lifestyle behavior change.

Under the Wellness theme, the NINR commits to supporting research to improve health across the lifespan, to prevent chronic illness, improve quality of life (QoL), and reduce the burden of disease for patients.<sup>69</sup> This dissertation work focused on the scientific development of theory to support interventions to prevent cancer recurrence and lessen the risk of cancer-related, chronic illness over survivors' lifespans. The NINR also emphasizes the importance of working in close research partnerships with communities to develop culturally congruent, feasible, and sustainable interventions.<sup>68</sup> The NINR recognizes the complex relationships between physical activity, nutrition, environment, mental health, and lifestyle behavior, thus underscoring the need for community-based participatory research.<sup>69</sup> Research participants for this dissertation work were recruited from community survivorship organizations as well as from urban and rural areas in central Ohio to garner a diverse set of survivors (theoretical sampling) and to establish research partnerships with community organizations.

The NINR makes a further commitment to technologies that play a role in improving health. The strategic plan focal area of Promoting Innovation supports programs of research in developing and refining “technologies... to promote health, prevent illness, and improve health-related quality of life across the lifespan.”<sup>68</sup> This

dissertation work aligns with aspects of the NINR Innovative Questions under Promoting Technology to Improve Health<sup>69</sup> as theories are needed to inform research questions, intervention study design, and technology development before the science can advance.

While national organizations are delimiting mHealth as an area of research need, reporting consortiums such as the Consolidated Standards of Reporting Trials (CONSORT) organization are beginning to understand the limitations of mHealth research without theory. The recently developed CONSORT-eHealth statement supports the use of theory in the design and testing of mHealth interventions.<sup>70</sup> Recently, the application of theory to inform mHealth intervention research became part of the CONSORT-eHealth checklist. In addition, recommendations from the international academic and business communities support the use of theory in the design, development, and testing of mHealth interventions.<sup>49</sup> Because of the complexity involved in these interventions and the newness of the technology, theories have failed to keep pace with mHealth intervention development. This dissertation research addressed these research needs.

mHealth interventions have had mixed success in changing lifestyle behavior in other chronic illnesses, but research suggests efficacy is limited due to a lack of theoretical underpinnings.<sup>41</sup> This dissertation research enhances the overall understanding of how behavior modification can be influenced using mHealth interventions such that the potential for mHealth interventions can be fully realized.

## *Summary*

Improved lifestyle behavior is paramount for most cancer survivors' overall health. New and novel mHealth interventions hold promise in improving health outcomes. Yet rigorous research with theoretical underpinnings is lacking, thus limiting scientific study and the advancement of mHealth intervention science. Use of a qualitative approach, using constructivist GTM resulted in a substantive theory which clarified the concepts and processes critical to breast cancer survivors in using mHealth interventions for lifestyle behavior change. This new theory begins to address the gaps in the current scientific knowledge base, specifically the theoretical underpinnings necessary for mHealth intervention research.

## **Chapter 2. Literature Review**

### ***Background of the Problem***

Currently, there are approximately 3.1 million breast cancer survivors in the U.S.<sup>2</sup> with prevalence increasing to about 4.6 million by 2026.<sup>3</sup> Better treatment and earlier detection contribute to the increasing number of survivors.<sup>71</sup> Yet survivors' quality of life (QoL)<sup>72</sup> and life trajectories are limited by the risk of cancer recurrence and the prevalence of cancer-related chronic health issues such as CV disease - a significant concern for breast cancer survivors.<sup>8-11</sup> These chronic diseases have been attributed to the secondary effects of cancer treatments.<sup>73-75</sup> Improving the lifestyle behaviors and factors of diet, physical activity, smoking, stress, and alcohol/drug misuse attenuates the risk of cancer recurrence,<sup>4, 7</sup> and lowers the risk of chronic, cancer-related health issues such as CV disease.<sup>8, 9</sup>

Despite internationally-consistent guidelines promoting lifestyle improvement<sup>76</sup> and calls from the ACS,<sup>77</sup> the IOM,<sup>78</sup> and the NCI<sup>79</sup> for survivorship care to address lifestyle behavior change, the majority of survivors are not meeting goals for healthy diet, weight management, and exercise.<sup>80</sup> Thus lifestyle modification remains a health priority for cancer survivors, healthcare organization, and policymakers.

Lifestyle modification decreases cancer risk,<sup>14, 81, 82</sup> cancer recurrence,<sup>6, 82-84</sup> and chronic diseases secondary to cancer treatment.<sup>85-88</sup> As outlined below, reducing stress,

quitting smoking, eating a healthy diet, exercising, losing weight, and recovering from drug/alcohol misuse are lifestyle behaviors important for all individuals, but especially cancer survivors to attenuate the risks of cancer recurrence and chronic disease. Of note, the majority of U.S. adults meet criteria for 2 or more of the following high-cost, high-risk factors: stress, tobacco use, poor diet, lack of exercise, and misuse of alcohol/drugs.<sup>89, 90</sup> When such behaviors co-occur, negative health outcomes increase significantly.<sup>90</sup>

### Stress

Cancer survivors are at increased risk of emotional and psychological stress (i.e., distress, anxiety, depression). For early-stage breast cancer survivors, 4% meet the criteria for a Post-traumatic Stress Syndrome (PTSD) diagnosis, with 41% meeting subsyndromal criteria for PTSD.<sup>91</sup> These subsyndromal criteria are also predictive of elevated distress, major depressive disorder, global anxiety disorder, and past major depressive disorder.<sup>91</sup> Breast cancer survivors report a higher prevalence of moderate depression with rates as high as 15% five years after diagnosis compared to 4.5% - 9.3% in non-cancer peers.<sup>92</sup> In a large multi-center study involving 460 breast cancer survivors across a 12 month period, 16.6% of women met the criteria for a major depressive episode,<sup>93</sup> nearly double that of women in the general U.S. population.<sup>94</sup> Additionally, 56.6% met the Center for Epidemiologic Studies Depression scale (CES-D) cutoff of 16 or greater, indicating moderate or severe depressive symptomatology, compared to 15% of people meeting the cutoff in a sample of older adults in the community.<sup>95</sup> Thus, breast cancer affects women long after the initial diagnosis and treatment with long-term

symptoms affecting psychosocial, emotional and cognitive well-being.<sup>96</sup> Other recent research suggests breast cancer survivors suffer from combined anxiety and depressive symptoms at percentages over 44% with resultant poorer quality of life.<sup>97</sup> Even for breast cancer survivors without depressive symptoms, fear of recurrence, hopelessness, uncertainty, loss of control, and poorer life satisfaction produce high levels of anxiety.<sup>97</sup>

### Tobacco

Cancer survivors diagnosed with high survival rate cancers (5-year survival greater than 80%, including breast, prostate, colorectal, and gynecologic cancers) often die of CV disease rather than cancer progression or recurrence. Smoking is a risk factor for CV disease. For example, among long-term survivors, poor diet, physical inactivity, and smoking were among the modifiable risk behaviors associated with an increase in CV disease risk.<sup>52</sup>

The associations between smoking and the risk of all-cause and breast cancer associated mortality are well documented in the literature. Smoking negatively affects long-term breast cancer survival by increasing all-cause mortality above non-cancer peers.<sup>98</sup> Quitting after diagnosis partially attenuates this increased risk.<sup>98</sup> Several large population-based cohort studies have reported an increase in breast cancer mortality with persistent smoking,<sup>99-101</sup> with some researchers associating smoking with a greater than 30% increase in breast cancer mortality.<sup>102</sup> A recent systematic review and meta-analysis of 400,944 breast cancer survivors identified a 28% increase in breast-cancer mortality in smokers compared to never smokers.<sup>103</sup> Researchers identified the importance of quitting smoking at diagnosis as mortality from breast cancer in former smokers approached that



of never smokers.<sup>103</sup> A recent meta-analysis of cohort studies examining smoking and breast cancer survival identified the deleterious effects of smoking on breast-cancer-specific mortality.<sup>104</sup> Compared to non-smoking peers, current smokers had higher breast cancer-specific mortality and all-cause mortality.<sup>104</sup> In other words, breast cancer survivors who smoke have a 30% higher risk of dying of breast cancer compared to non-smoking peers and a 59% higher risk of dying from all causes compared to non-smokers. A dose-response relationship between former smoking and breast cancer-related mortality was also noted.<sup>104</sup>

### Weight, Exercise, and Diet

Following a diagnosis of breast cancer, women often gain weight which increases the risk of fatigue,<sup>105, 106</sup> functional decline,<sup>105, 106</sup> lymphedema,<sup>107</sup> CV disease,<sup>52, 108</sup> diabetes,<sup>52, 109</sup> and poorer QoL.<sup>105, 106</sup> Survival outcomes are poorer for breast cancer survivors who gain just 5-10% above pre-diagnosis weight, while those survivors maintaining their weight for 2-3 years after diagnosis have improved survival outcomes.<sup>110, 111</sup> Exercise significantly reduces fasting insulin levels and improves insulin resistance in breast cancer patients and may be one mechanism by which weight reduction influences improved prognosis.<sup>112</sup> However, up to 70% of all cancer survivors fail to meet the recommendations for exercise,<sup>80</sup> with estimates of breast cancer survivors at 66%.<sup>113</sup> Importantly, cancer survivors are less likely to engage in exercise compared to non-cancer peers,<sup>114</sup> even when comparing low levels of physical activity.<sup>115</sup>

Recent survivorship nutrition and weight management clinical practice guidelines from the National Comprehensive Cancer Network underscore the importance of diet,

exercise, and weight management in cancer survivors.<sup>116</sup> A recent systematic review of randomized controlled trials (RCTs) of interventions in breast cancer survivors also supports the importance of weight reduction through diet and exercise on mortality and cancer recurrence for obese and non-obese women.<sup>7</sup> Breast cancer survivors who exercised moderately had approximately 40-50% lower risk of cancer recurrence, death from cancer, and death from all causes.<sup>117</sup> Weight reduction through the adoption of a healthy diet and exercise is an essential consideration for maintaining health as a cancer survivor.

### Alcohol

Alcohol use/abuse behavior also increases the risk of cancer progression. The International Agency for Research on Cancer (IARC) classifies alcoholic beverages as causal for breast, colorectal, laryngeal, liver, esophageal, and oropharyngeal cancers and probably causal for pancreatic cancer.<sup>118, 119</sup> Epidemiological research underscores the importance of alcohol as a significant contributor to cancer mortality and years of potential life lost with no safe threshold for alcohol use and cancer risk: higher consumption equates to higher risk.<sup>120</sup> Currently, investigators are delineating the cellular mechanisms of how alcohol use promotes breast cancer development and progression.<sup>119, 121</sup> Research suggests that alcohol not only increases the risk of breast cancer but also increases the progression and aggressiveness of breast cancer via several different genetic and cellular pathways.<sup>122</sup>

## Drugs

Cancer survivors are at increased risk of opioid-use disorder,<sup>123</sup> particularly given the prevalence of chronic, uncontrolled pain in cancer survivors. Moreover, high survival rate cancer survivors (i.e., breast cancer) are living longer with such chronic pain, experiencing chronic pain syndromes associated with drug-induced neuropathies, and experiencing different types of pain from varied locations secondary to treatments.<sup>124</sup> Up to 50% of patients in cancer treatment and 70-90% of patients with advanced disease report pain, with the burden of unrelieved cancer pain falling disproportionately on medically underserved survivors.<sup>125</sup> Thus, paradoxically, 20% of patients with cancer have an opioid-use disorder.<sup>123</sup> Patients diagnosed with an opioid-use disorder have more hospitalizations, more emergency room visits, and higher mortality.<sup>126</sup> The opioid abuse problem among cancer survivors is complex and more extensive than the greater crisis prevalent in the U.S. today.

Stress, tobacco use, weight gain, lack of exercise, poor diet, and alcohol/drug abuse contribute to poor health outcomes and inferior QoL for cancer survivors. Poor health outcomes are particularly troubling for breast cancer survivors of racial minorities, and breast cancer survivors of lower socioeconomic status.<sup>127-129</sup> Addressing this growing public health and healthcare issue has the potential to improve cancer survivors' health, morbidity, mortality, and QoL; not to mention conserve valuable human and financial resources over time.

## Cancer Survivors and Increased CV Disease Risk

A primary concern for breast cancer survivors is CV disease. Causes of increased CV disease risk include the effects of chemotherapy and other anticancer agents as well

as the CV side effects of radiation.<sup>130, 131</sup> Increased insulin resistance associated with certain treatments<sup>132, 133</sup> and increased C-reactive protein levels<sup>134</sup> complicate the CV health of survivors. The increased prevalence of obesity and physical inactivity during the cancer survivorship period adds to the risk of developing CV disease.<sup>135</sup> For all cancer survivors, and particularly those with specific cancer types, CV disease is the second-leading cause of mortality after recurring malignancies,<sup>52, 136-138</sup> and in some cases CV disease mortality eclipses recurring cancer mortality in as little as 5 years after a cancer diagnosis.<sup>139</sup>

Breast cancer survivors have increased morbidity and mortality from CV disease.<sup>111, 140</sup> After 7 years, breast cancer survivors have CV disease death rates 1.5 times the rates of their non-cancer peers.<sup>111</sup> As with cancer recurrence, lifestyle modification improves CV disease risk in cancer survivors. Current healthy lifestyle behavior guidelines from the American Heart Association (AHA) and lifestyle behavior guidelines from the ACS align, yet few cancer survivors meet the recommended guidelines.<sup>80</sup> A need exists for scalable, cost-effective, lifestyle behavior interventions to address CV disease and cancer recurrence in the growing population of cancer survivors.

### ***Traditional Approaches to Lifestyle Behavior Change***

Traditional lifestyle interventions (i.e., counseling, educational programs, coaching) have demonstrated mixed efficacy,<sup>17, 141</sup> inadequate sustainability,<sup>142</sup> and limited generalizability (scalability) in cancer survivors. These interventions can be costly in both fiscal and human resources.<sup>14</sup> Additionally, the optimum type, dose, and duration of these interventions remain mostly unknown.<sup>8, 14, 141</sup> And as outlined

previously cancer survivors fail to meet goals for diet, weight management, and physical activity.<sup>80</sup> Current approaches to lifestyle behavior change remain inadequate in addressing the needs of this growing population of cancer survivors. Importantly, traditional interventions may fail to meet the needs of those most vulnerable to cancer, as well as those most negatively affected by the disease.

African American (AA) breast cancer survivors continue to have a higher risk for cancer-related comorbidities<sup>143</sup> and mortality<sup>144</sup> compared to whites. AA breast cancer survivors also have a lower 5-year survival rate at every stage of diagnosis.<sup>127</sup> However, few traditional interventions aimed at lifestyle behavioral risk have demonstrated efficacy in AA breast cancer survivors.<sup>16</sup> Rigorous intervention research is scant with only 6 RCTs conducted between 2012 and 2016, evaluating lifestyle interventions for AA breast cancer survivors.<sup>16</sup> In addition, a high risk of bias (unclear randomization and blinding techniques, lack of a priori power analysis, missing effect sizes and precision estimates, and unclear approaches to missing data) limited the ability to draw conclusions about the interventions for AA breast cancer survivors. Heterogeneity of participants and interventions prevented meta-analysis.<sup>16</sup> Moreover, the inclusion of ongoing and feasibility studies may have confounded study results. In sum, little is known about lifestyle interventions for AA breast cancer survivors.

Significant fiscal and human resources are necessary for the delivery of lifestyle interventions in clinical settings.<sup>145</sup> Patients require time and money to travel to in-clinic intervention programs, often requiring repeated visits.<sup>146, 147</sup> These time demands and additional costs are particularly burdensome to populations most at risk and most in need.

Additionally, traditional programs can be burdensome for healthcare providers, who are already in limited supply within oncology. These traditional programs demand additional time, effort, and staff to address behavior change and wellness while concurrently delivering oncology care.<sup>148</sup> Oncology providers report a lack of time and skill to address lifestyle behavior change.<sup>148</sup> In a recent systematic review and meta-analysis, researchers suggested less resource-heavy interventions, using phone or email, may be as effective as traditional clinic-based interventions for increasing physical activity in breast cancer survivors.<sup>149</sup> As technology advances, mHealth interventions have the potential to ameliorate burdens associated with time, workflow, and lack of resources in clinical settings. Also, mHealth apps have the potential to increase the reach of lifestyle interventions. While mHealth apps offers much potential, to date, the promise has not been realized. Despite a lack of research and knowledge of efficacy in using mHealth apps as interventions for lifestyle behavior, smartphone use and mHealth app downloads continue to escalate.

### ***Mobile Health***

mHealth apps delivering lifestyle interventions represent a novel, alternative solution to traditional approaches for intervention delivery and offer advantages beyond cost and scalability. The concept mHealth was first introduced in 2003.<sup>18, 150, 151</sup> In 2011, the World Health Organization (WHO) defined mHealth as “medical and public health practice supported by mobile devices, such as mobile phones, patient monitoring devices, personal digital assistants, and other wireless devices.”<sup>85(online)</sup> The WHO included technologies such as short messaging service, general packet radio service, mobile

telecommunications, global positioning systems, and other wireless technologies in their definition.<sup>85</sup> mHealth denotes healthcare or health advice delivered through devices, such as smartphones, that are always on and carried on the person throughout the day.<sup>43</sup>

#### mHealth and Smartphone Use

The Pew Research Center estimates that 95% of Americans own cell phones with smartphone use reaching 77% in 2016, up 35% since 2011.<sup>152</sup> In contrast to the digital divide that previously potentiated the healthcare divide, the demographic groups most at risk and in need of healthcare interventions now have internet access through smartphones. Increasingly, older, non-white, and socioeconomically disadvantaged Americans rely on their phones for internet connection.<sup>152</sup> Adoption of ancestral broadband service (i.e., internet home service) has been slowing in recent years, and an increasing number of Americans are smartphone-only internet users who are predominately younger, non-white, and of lower-income.<sup>152</sup> As more Americans use smartphones, the use of mHealth interventions is also increasing. This expanding segment of smartphone internet users, coupled with an increasing number of downloaded apps, provides healthcare providers and healthcare organizations with a novel opportunity. Healthcare providers and organizations might find success in leveraging mHealth technology to address survivors' health behavior needs; specifically, those behaviors that have been difficult for clinicians to treat due to time constraints,<sup>148</sup> or have remained resistant to traditional clinician-to-survivor interventions (i.e., counseling).

### Potential for mHealth Apps as Interventions

Not all mHealth apps are interventions. For clarity, the term intervention app (I-app) will refer to an mHealth app specifically used for delivering an intervention. I-apps hold the potential to improve cancer survivors' health and QoL by targeting heterogeneous populations while providing individualized interventions. Specifically, I-apps offer cancer survivors opportunities for tailored, patient-centered care. Many cancer survivors experience unique needs regarding lifestyle modification, psychosocial support, functional support, and QoL support. I-apps have the potential to provide context-specific care at the time, location, and for the duration required by the patient across the continuum of cancer care. Additionally, I-apps can transcend geographic and time limitations, reaching those most vulnerable with increasing frequency of contact, which are important considerations when motivating and supporting lifestyle modification. Unlike other Internet-based interventions and other traditional approaches to lifestyle modification, I-apps can interact with patients with higher frequency, during their daily routines, and in the context of real-time lifestyle choice or behavior. I-apps also have the potential to reach more culturally and socioeconomically diverse populations than previous internet-based applications.<sup>152</sup>

Overall, I-apps have the potential to deliver lifestyle interventions in a personalized, easy-to-use way, and in the context of the behavior. Additionally, mHealth interventions have the potential to provide a higher frequency of relevant care that is personalized to each patient when and where the care is needed.<sup>43, 153</sup> This type of engagement offers healthcare providers and patients a novel way to interact.



### ***Challenges of mHealth Interventions***

As of 2016, over 259,000 health apps were available in the major app stores; over 100,000 were added in 2016 alone.<sup>42</sup> However, lack of study rigor, lack of interdisciplinary research, and lack of theory-based design and testing limit the efficacy of I-apps in non-cancer populations<sup>43, 44, 47, 48, 50, 51</sup> and may limit their use in cancer survivors as well.

#### **Lack of Rigor**

In general, mHealth research in lifestyle behavior change is hindered by a lack of empirical rigor. Systematic reviews and app reviews of I-apps for lifestyle behavior change in the general population report mixed results in the lifestyle areas of tobacco use,<sup>154, 155</sup> physical activity,<sup>155</sup> weight management,<sup>156</sup> diet,<sup>157, 158</sup> hypertension control,<sup>159, 160</sup> stress management,<sup>161</sup> and diabetes management.<sup>155, 162</sup> Reviews identify the need to interpret results with caution due to study bias with lack of scientific rigor and lack of power being overarching concerns.<sup>41, 50, 51</sup>

#### **Siloed Disciplines**

Several disciplines are currently calling for a multidisciplinary approach to improve intervention efficacy and rigor in I-app research.<sup>47, 48</sup> The varied foci of research make consensus difficult. For example, some researchers focus on intervention content, some focus on app usability, and some focus on contextual factors such as frequency and duration of use.<sup>47, 48</sup> These differing approaches from varied research domains create a disparate collection of findings, with lack of consensus on moving mHealth research forward.

Unintentional silos have developed in the disciplines of medicine and I-app development.<sup>163, 164</sup> Evidenced-based practice (EBP) guidelines and regulations are continually changing at a rapid pace as are best practices in the app development domain. Keeping track of each domain's best practices, particularly in the high stakes areas of medicine and patient safety, as well as usability and design recommendations, may require development and testing methods not yet determined<sup>165</sup> or theories yet to be explicated.<sup>43, 47, 48, 66</sup>

Current evidence suggests app developers are also siloed from patients. For example, in a review examining content, usability, and utilization of plain language in the design of breast cancer mHealth apps (non-lifestyle), researchers noted the use of usability recommendations was low, with few apps meeting plain language recommendations.<sup>166</sup> Notably and importantly, most apps focused on non-evidenced based care. These findings align with prior research on cancer apps calling for the involvement of patients<sup>167, 168</sup> and healthcare professionals in development and testing processes.<sup>169, 170</sup> Unfortunately, these findings also align with results from systematic reviews using I-apps in the context of other chronic diseases.<sup>164, 171-173</sup>

Ease of mHealth app development potentiates concerns of siloed disciplines. With today's, do-it-yourself app development kits (i.e., Apple HealthKit ©<sup>174</sup>), lay developers are quickly reaping the financial rewards of mHealth apps, without input from content experts —healthcare providers— much less from evidence-based clinical guidelines, or app development best practice guidelines.<sup>163</sup> The U.S. Food & Drug Administrations (FDA) regulates apps used in conjunction with medical devices or those transforming a

mobile architecture into a medical device.<sup>175</sup> However, most mHealth apps are beyond the purview of the FDA. The responsibility for safety, accuracy, and efficacy falls on the app developers, consumers, and app distributors. I-app safety and efficacy issues are concerning as the dominant role in mHealth app development and testing is currently held by developers<sup>163</sup> with little engagement from other stakeholders, notably patients and healthcare content experts.

### Lack of Theory

While a growing share of the mHealth app market claims to support healthy lifestyle behaviors, few interventions incorporate known behavior change elements in their intervention designs.<sup>42</sup> Even fewer have been developed or tested using behavior change theories.<sup>43, 44</sup> Research also suggests this lack of theoretical underpinning limits intervention effectiveness.<sup>41</sup>

Current theoretical frameworks fail to explain the relationships between mHealth interaction processes and behavior change. Researchers using various approaches from differing scientific domains continue with conflicting or missing concepts important in mHealth use or behavior change.<sup>43, 44, 47-51</sup> For example, a few interventions incorporate known behavior change techniques into their designs.<sup>43, 44, 51</sup> But these same interventions fail to integrate concepts of mHealth use (usability, satisfaction) from the discipline of HCI into the design and testing phases of the research. Research suggests this lack of theoretical underpinning limits intervention effectiveness.<sup>41</sup> This lack of integrated theory and overall lack of theory use limits the advancement of mHealth intervention science, particularly given the rapidly evolving nature of this technology.<sup>52</sup>

Lack of theory-based design and testing is not a new problem in mHealth research, or for traditional lifestyle interventions for that matter.<sup>176</sup> For a decade, and almost from the inception of mHealth interventions, researchers have called for theoretically-driven design and testing of mHealth technologies to enhance intervention effectiveness.<sup>43, 44, 47-51, 66</sup> Recent questions from the multi-disciplinary research community suggest a need for a more integrative approach to theory development in mHealth.<sup>48, 66</sup> New theoretical approaches suitable to address behavior change within the context of rapidly changing systems are needed. Traditional behavior change theories fail to address concepts important in HCI or other informatics theories. At the very least, traditional theories should be critically appraised before they are used in a different context.<sup>48, 66, 177</sup> To date, the pragmatic adequacy<sup>64, 178</sup> (the extent to which a theory can be used in the real world) of traditional behavior change theories has not been established within the mHealth intervention domain. Researchers investigating mHealth interventions argue for either significant adaption of current theories or for the development of new theories that integrate content, system, and context.<sup>43, 47, 48, 66</sup>

### ***General mHealth Interventions for Behavior Change***

A growing share of the mHealth market promotes behavior change. Yet, few I-apps incorporate known behavior change elements in their design.<sup>42</sup> As with cancer-focused interventions, 2 recent literature reviews<sup>43, 44</sup> highlight the need for new theories to support the mHealth development and testing for general use. Riley and colleagues<sup>43</sup> conducted a systematic literature review of mHealth interventions focused on behavior change (i.e., treatment adherence, chronic disease management, smoking cessation) and

concluded that researchers needed to advance more dynamic theoretical frameworks and apply these frameworks to the development and testing of mHealth interventions.<sup>43</sup> These researchers advocated for new theories that use new and emerging capabilities in I-apps to help improve lifestyle behavior. Researchers evaluating the usability of I-apps echo similar sentiments.<sup>44</sup>

More recently, Zhao and colleagues<sup>51</sup> endorsed these same findings. These researchers examined the effectiveness of I-apps in achieving health-related behavior change across a broad range of mHealth interventions and conditions and reported significant shortcomings in the research.<sup>51</sup> Twenty-three studies met inclusion criteria, and most interventions were used for self-monitoring, not behavior change. While there was a positive trend in improved outcomes, results must be interpreted with caution due to limited sample size, poor study quality, and lack of scientific rigor. Zhao and colleagues suggested a lack of theoretical underpinnings limited successful outcomes and effects.<sup>51</sup> In a similar systematic review, McKay and colleagues<sup>179</sup> investigated methods used by systematic reviewers in evaluating mHealth interventions specific to behavior change in hopes of identifying best practices for evaluation of I-apps (i.e., usability, content). They identified 38 systematic reviews but were unable to suggest any single consistent evaluation method for mHealth interventions. Only 4 individual studies within all 38 systematic reviews included some reference to theory; none reported theory use.

Despite the lack of theoretical underpinnings, there have been mixed results in efficacy using I-apps in non-cancer health conditions including CV disease,<sup>20, 41</sup> diabetes,<sup>180, 181</sup> obesity,<sup>181</sup> and mental health.<sup>182</sup> For example, in the seminal work of

Burke and colleagues,<sup>41</sup> the investigators reviewed 69 RCTs focused on technology use and CV health. The review focused on health behaviors relevant to CV health as outlined by the AHA 2020 Strategic Impact Goals:<sup>183</sup> 1) reduction in smoking, 2) reduction in weight, 3) healthful eating, 4) exercise promotion, and 5) medication adherence. Results indicated mixed effects on the efficacy of interventions and suggested the need for more rigorous research. For example, there was substantial evidence that smoking cessation texting programs were effective as were medication adherence applications. Some of the included studies reported improvements in physical activity, hemoglobin A1c, blood pressure, and dyslipidemia.<sup>41</sup> However, there was not enough evidence to make such conclusions for weight loss. Additionally, many study limitations were observed which affected overall study quality. There was an overall lack of information concerning the design and development of the technology, a lack of intervention detail (i.e., dose, duration, frequency), a lack of adequate power, a lack of theoretical understanding as to how these interventions might work, and overall study biases affecting study quality.

Burke and colleagues suggested the need for more rigorous analytic methods, more diverse and larger samples, long-term follow up to examine the sustainability of effects, and more varied testing methods to keep pace with the rapidly emerging mHealth interventions. They also called for intervention designs capable of identifying efficacy in periods shorter than the conventional 5-year RCT and for mHealth tools to be incorporated into the workflow of healthcare providers to improve effectiveness and to improve healthcare delivery. Finally, Burke and colleagues cautioned against using the absence of evidence as the absence of effectiveness.<sup>41</sup>

Recently, Gandhi and colleagues<sup>159</sup> conducted a systematic review and meta-analysis of 27 RCTs focused on the use of mHealth in secondary prevention of CV disease. Their results mirrored the work of Burke et al.<sup>41</sup> outlined above. mHealth interventions increased medication adherence, helped patients reach blood pressure targets, and raised awareness of diet and physical activity.<sup>159</sup> In both the Burke and Gandhi reviews,<sup>41, 159</sup> the authors recommended the use of theoretical frameworks in the development and testing of mHealth interventions to improve the effectiveness of the interventions.

### ***Cancer Survivors, mHealth, and Non-Lifestyle Focused Interventions***

Despite the fact that a paucity of I-apps focused on lifestyle behavior change in the context of cancer survivors, apps with non-lifestyle purposes are widely available in the commercial market for cancer survivors.<sup>184</sup> Reviews have been undertaken to 1) examine the purpose and content of mHealth interventions specific to cancer,<sup>169</sup> 2) delineate inconsistencies in information provided in cancer-focused interventions,<sup>169</sup> 3) review the theoretical underpinning used in (non-lifestyle) cancer-focused interventions,<sup>44</sup> and 4) identify the use of health literacy standards in the interventions.<sup>166</sup> For example, a recent app review, accompanied by a literature review,<sup>169</sup> characterized the purpose and content of 295 cancer-focused mHealth interventions. No intervention focused on lifestyle behavior change. The majority of the content focused on raising awareness about cancer, delivering information about cancer, or supporting organizational fundraising. Of the 594 articles identified for the literature review, none evaluated a cancer-focused mHealth app. Overall there was a lack of evidence of

intervention effectiveness and a lack of evaluation in the design and development of these mHealth apps.<sup>44, 51, 185-188</sup> International researchers report similar concerns. For example, researchers in Spain investigating Spanish language apps for cancer survivors noted a lack of validity in content as a safety problem and a need for regulation to prevent harm.<sup>189</sup> Other reviewers in the non-cancer domain echo these same concerns and include lack of theory, lack of scientific rigor, lack of user-centered design, lack of evidence-based content, and overall lack of safety.

Davis and Oakley-Girvan<sup>190</sup> reviewed 28 articles to identify the purpose of mHealth apps across the cancer continuum. No studies in the review focused on lifestyle behavior change. Fourteen studies addressed cancer prevention or detection; 9 focused on treatment, 1 on cancer diagnosis, 1 on tailored text messaging, and 3 were designed for healthcare providers, not patients. Only 6 of the studies included in the review were randomized trials; the majority were pilot studies. Findings of the review were concerning, with the reviewers commenting on a large number of mHealth apps available for download versus the paucity of rigorous scientific evidence to support their use. The reviewers recommended the use of mHealth applications to help overcome gaps in cancer care delivery and recognized the unrealized potential for mHealth to circumvent current limitations of culture, language, geography, and socioeconomic status through a uniquely tailored, patient-centered approach to cancer care across the continuum.<sup>190</sup> However, the reviewers also noted the essential need for patient and healthcare professional involvement in the development and rigorous testing of mHealth interventions to help realize the potential of this approach to care.



In a recent review of breast cancer apps, researchers systematically reviewed mHealth app content and adherence to IOM literacy guidelines.<sup>166</sup> Very few of the apps focused on survivorship; most focused on information and education used for cancer prevention. The lack of adherence to evidence-based guidelines in the app content limited the utility of these currently available apps. Adherence to usability design standards and literacy design standards was also low and further compromised the utility of the apps.<sup>166</sup> These findings mirror those of an earlier review of breast cancer mHealth apps<sup>170</sup> where a lack of evidence-based content raised safety concerns for users; the reviewers called for the more robust development and evaluation of mHealth apps.

In a scoping literature review of mHealth apps specific to adolescents and young adults diagnosed with cancer,<sup>191</sup> investigators hoped to identify strengths and limitations of mHealth interventions for this population of survivors. However, only 4 pilot studies were identified using mHealth apps. The interventions helped young survivors monitor symptoms, track medication adherence, and track coping strategies for symptoms. Strengths included the potential of mHealth interventions to address the unmet needs of young cancer patients. However, none of the studies addressed lifestyle behavior change, a lifelong challenge for young cancer survivors. Several limitations were noted as barriers to using the mHealth apps and included forgetting to take the smartphone, forgetting to make entries, or feeling too sick to make entries. Researchers noted that participants in these pilot studies might have been more motivated than typical users. Thus, usability and compliance rating may have been inflated. Efficacy and sustainability were not evaluated. Additionally, large developmental variability existed between a 13-year old and a 25-year

old participant. Reviewers expressed the need for developmentally appropriate interventions using accurate and reliable content, and interventions evaluated through rigorous experimental and usability testing.

### ***Summary***

The reviews above point to an overall lack of rigorous scientific evidence documenting efficacy, effectiveness, and patient engagement with I-apps. Studies in these reviews failed to identify design and development processes to validate their mHealth interventions. Additionally, these studies failed to use principles grounded in theory to develop and test the mHealth apps. Lack of accurate content, lack of use of evidence-based guidelines, security issues, and overall clinical safety of these apps added to the shared concerns associated with most mHealth cancer apps available today.

Despite these safety concerns, lack of empirical rigor, and limited evidence of efficacy, consumer demand is high and increasing. For the potential of mHealth interventions to be realized, rigorous design, development, and testing must occur. However, without adequate theoretical underpinnings, scientific advancement and intervention efficacy will be limited.

## **Chapter 3. Methods**

### ***Introduction***

A constructivist grounded theory approach was selected to achieve an understanding of mHealth intervention use by breast cancer survivors to accomplish lifestyle behavior changes. Theoretical concepts (abstract conceptual ideas or phenomena that may not be directly observable) and their relationships were “grounded” in the data. The concepts were induced from interacting with the data rather than deduced from preconceived ideas or predetermined concepts from existing theories. The iterative nature of the approach (Figure 1) allowed for the discovery of the mHealth Engagement and Self-regulation using Intervention Apps (mHESIA) theory through an analysis process known as the constant comparison method.<sup>192</sup>

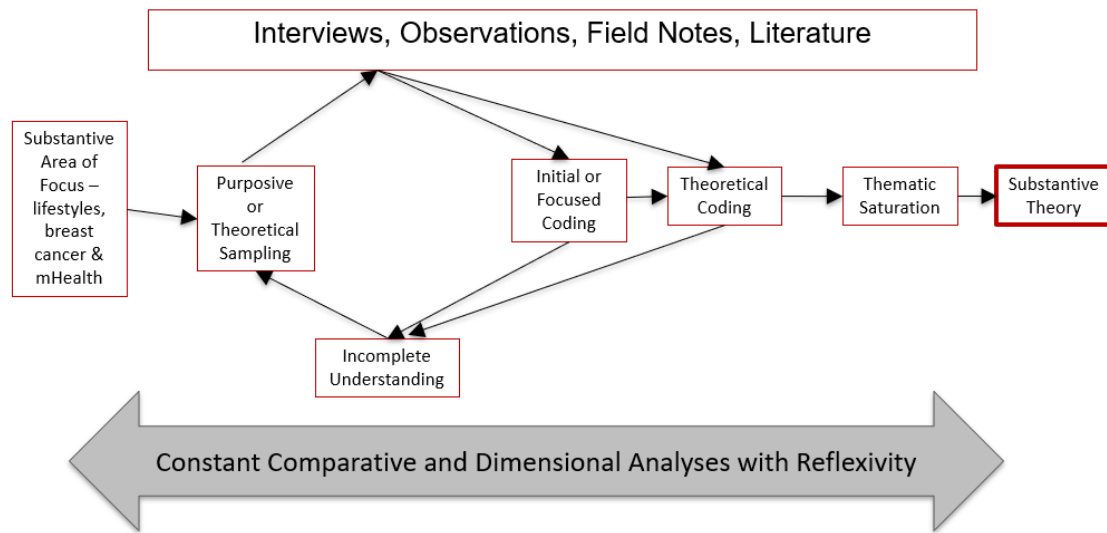


Figure 1. Grounded Theory Analysis Model

### ***Design Overview and Rationale***

GTMs are useful when exploring processes and phenomena where current knowledge is limited,<sup>54</sup> such as the relatively new and unexplored phenomena of using I-apps to improve lifestyle behaviors in cancer survivors.<sup>193</sup> Almost since the inception of I-apps, researchers have reported a lack of adequate theories to inform the science.<sup>43, 44, 51</sup>

GTMs are also useful when there are perceived biases or omissions in what is known,<sup>56</sup> as is also the case within the developing field of I-app research. For example, researchers frequently suggest the use of behavior change theories in the development of I-apps.<sup>43, 44</sup> However, this approach omits underlying human-computer interaction processes essential to understanding the behavior of mHealth app use. GTM can help overcome these omissions, as constructivist grounded theory methodology emphasizes examining processes (e.g., use of mHealth interventions) and understanding transactional

experiences (e.g., HCI, researcher-participant). Our general underlying assumption in using GTM is that humans, and specifically breast cancer survivors, share a distinct process for using I-apps to improve lifestyle behaviors and that this process is identifiable using GTM.

While the research question helped decide the selection of a grounded theory approach, a constructivist approach aligned research methodology and methods with my relativist world view. Relativism assumes multiple realities, arising from both the perspective of the researcher and the perspectives of breast cancer survivors. This relativist stance assumes that a researcher's professional background (in this case, clinical informatics, cancer, and doctoral candidate in nursing) and personal experiences (e.g., caring for loved ones dying of breast cancer) serve to inform values, actions, and relationships with the survivors and their data.

Through a relativist lens, meaning and understanding of the world (survivors' process for using mHealth interventions) are assumed to occur through the transactional construction of knowledge (knowledge generated from words and explanations from survivors and the researcher's interpretation of the meaning of the data). This approach helped evoke meaning from language, actions, experiences, values, and preconceptions of both the survivors and the researcher. The use of constructivist GTM allowed me to remain true to this relativist ontology. However, the influence of this personal lens and my experiences have been acknowledged and tempered through constructivist GTM described below under Trustworthiness.

### ***Setting***

I recruited participants from suburban and rural communities in central Ohio. Breast cancer clinics associated with a NCI-designated comprehensive cancer center and community survivorship organizations served as recruitment sites. ResearchMatch, an online national repository that matches researchers with research study volunteers, served as a recruitment mechanism. Participant word of mouth served as another recruitment strategy. Three days per week, I worked in coordination with breast cancer clinic staff to recruit participants at the clinics. The majority of participants ( $n = 12$ ) were recruited and enrolled through the breast center clinics. Two participants were recruited passively through community research flyers and both enrolled, and 4 were recruited using the snowball technique (participants referring other survivors). Only 2 of the 4 snowball recruits were enrolled.

### ***Sample***

Upon approval by the Ohio State University Institutional Review Board, eligibility, screening, and interview scheduling occurred during the first phone or in-person encounter. Adult breast cancer survivors,  $\geq 18$  years of age, and who were also mobile app users were recruited and enrolled for this study. No breast cancer survivor was excluded from the study based on race or ethnicity. Breast cancer in women under the age of 40 is rare, with approximately 12,000 women diagnosed annually.<sup>194</sup> Even less common is the occurrence of breast cancer in young adults and adolescents.<sup>195</sup> Breast cancer in men is equally rare — 100 times less common than among women, with fewer than 2500 new cases diagnosed each year in the U.S.<sup>196</sup> Therefore, we excluded children

and adolescents under age 18 and men. Breast cancer survivors with > stage IIIA were excluded from the study as these survivors have metastatic disease and are undergoing active treatment or have a life-limiting disease. Similarly, any survivors undergoing active treatment and those with other uncontrolled disease or life-limiting disease were excluded as their experience of using mHealth for lifestyle behavioral change would be different than those without active disease. The number of study participants was a function of thematic saturation, defined as the point at which no new dimensions of concepts emerged from the data, and no further theoretical insights were gleaned from the data.<sup>57, 197</sup> Therefore, an a priori sample size was not established. Sampling began purposively followed by theoretical sampling to remain consistent with GTM.<sup>57, 58</sup>

#### Purposive Sampling

Initially, purposive sampling helped identify key informants who were participants willing to speak openly about their experiences and had significant knowledge and experience using mHealth apps. Key informants were also selected to ensure a diverse representation of participants with respect to age, race, and use of technology. These first key informants provided detailed information against which subsequent information was compared. Assessment of participants' qualifications to serve as a key informant occurred during the initial phone or in-person encounter. While the first 3 participants were specifically selected for their experience with mHealth and lifestyle changes, it became clear during the interviews that although they were users of MyChart, MyPlan4Health and other types of apps (i.e., social media, games), 2 had never downloaded mHealth apps specifically for improving lifestyle behaviors and were not

currently using any technology (i.e., fitness trackers) to support lifestyle behavior improvements. The other participant had used technology and mHealth apps to support lifestyle change in the past but was not doing so currently. Theoretical sampling (discussed below) commenced to recruit and enroll participants who were actively trying to change lifestyle behaviors and were engaged with mHealth apps toward that end. Clinic staff sought participants to meet this sampling need. Early identification of users and non-users of I-apps for behavior change became a category against which future categories were analyzed.

### Theoretical Sampling

As data were analyzed and categories developed, theoretical sampling was used to develop the codes, categories, and concepts. Decisions about what data was needed to identify variations, differences, and dimensions in the categories or concepts and where to find this information (which participants) informed the questions asked of potential participants. For example, when the category of *sustaining* was being developed, I began to search for participants with longer experiences using mHealth apps for lifestyle behavior improvement. Prior to enrollment, I asked potential participants about the longest length of time they had used a mHealth application to help them improve their lifestyle behavior. Those with longer use times (i.e., greater than 3 months) were enrolled. Several of these long-time users discussed the formation of habits as important in the process of behavior change, and the category of *habit* was developed. This analysis informed a search for participants (theoretical sampling) who had made lifestyle improvements using mHealth a habit.



### ***Data Collection***

Participants engaged in 1 research session lasting between 65-120 minutes, which consisted of an interview and a mHealth app interaction to stimulate further conversation. Demographic data, technology use data (Appendix A), and lifestyle behavior data (Appendix B) were collected using the Research Electronic Data Capture (REDCap) platform.<sup>198</sup> The research session was conducted in a private, neutral setting to enable honest disclosure, open discourse, and privacy.<sup>199</sup> Locations included participants' homes, quiet study rooms at local libraries, participants' offices, and private rooms in community centers.

At the beginning of the research session, the participant signed the online consent form and was offered a \$50 (U.S.) gift card for their time and travel costs. Study data from questionnaires were collected and managed using REDCap electronic data capture tools hosted at The Ohio State University.<sup>198, 200</sup> REDCap is a secure, web-based software platform designed to support data capture for research studies, providing: 1) an intuitive interface for validated data capture; 2) audit trails for tracking data manipulation and export procedures; 3) automated export procedures for seamless data downloads to common statistical packages; and 4) procedures for data integration and interoperability with external sources.<sup>198, 200</sup>

Interviews began with general questions about health, cancer, and mHealth apps, followed by prompts, or probes, for clarification and expansion (See Table 1). Interview questions were designed to elicit information about the participants' lifestyle improvements using mHealth interventions. The initial broad questions allowed

participants to tell their stories from their perspective and in their own words. Moreover, listening to participants' stories quickly built rapport. Open-ended questions were designed to elicit thick, rich descriptions and were pilot tested before use with 2 breast cancer survivors, 2 subject matter experts (oncology clinical nurse specialists), and the dissertation chair (ST) to examine clarity and content as well as the ability to elicit storytelling from participants. In accordance with GTM, this flexible, open-ended interview guide was revised following each interview, and as categories were explored, and concepts began to be developed. Questions were added and changed to understand and develop categories and to confirm or disconfirm emerging theoretical concepts. For example, after the first 4 interviews, I included a preamble to the interview, describing mHealth intervention apps and their use for lifestyle behavior change as this was a point of confusion for participants. I also narrowed the focus of the first interview question to quickly align the interview with mHealth app use for lifestyle change (*"Can you tell me your thoughts about using mHealth apps to stay healthy or improving those lifestyle factors we just discussed"?*) as the initial question about health and surviving cancer was too broad to answer succinctly and within the interview time allotted.

Table 1. Initial Interview Guide

<p>1. Please tell me about your health and about surviving cancer?  Follow up probes for all questions:  Tell me about...  What was it like when...  Tell me more about that...</p>
<p>2a. Please tell me your thoughts about any lifestyle changes you have made since your breast cancer diagnosis. By lifestyle changes, I mean things like stopped smoking, increased exercise, changed diet, or decreased stress.  2b. Please tell me about any information your healthcare team shared with you about lifestyle behaviors and cancer?</p>
<p>3. Talk to me about any technology you use to stay healthy? (Some people use the patient portal to contact the doctor or nurse, some people use watches or their phones to count their steps)  I would like to talk about mHealth (may require a description and or show and tell via smartphone for the technology novice). Please describe your experience with mHealth applications (apps)?</p>
<p>4. Imagine the perfect technology. What would be important to include to help you (you choose the behavior – eat a healthy diet, lose weight, exercise more, decrease anxiety and stress, stop smoking)?</p>
<p>5. What things might help initiate or start this behavior change? What has helped in the past?</p>
<p>6. What things might help sustain or continue this behavior change?</p>
<p>7. Earlier, we talked about mHealth. How might mHealth help initiate or begin behavior change?</p>
<p>8. How might mHealth help sustain or continue behavior change?</p>
<p>9. Thinking about cancer and lifestyle changes, what kinds of things are most important to you?  Follow up probes: What things were important right at diagnosis? Right now?</p>
<p>10. In thinking about mHealth interventions to improve lifestyle behaviors, what kinds of things would make it hard for you to improve?</p>

As categories and concepts developed, probes were revised to focus on understanding different dimensions of the concepts (i.e., under what conditions, with whom, in which contexts) and to understand the different phases of the overall process used by breast cancer survivors when using I-apps to improve lifestyle behavior. For example, as the phases of *adopting* and *sustaining* were developed, the following probes were added: 1) how and why relationships affected the process of *adopting* and *sustaining* (i.e., “*How do your relationship with family/friends/health provider influences the adoption of mHealth apps for lifestyle improvement*”? and “*what about your relationship with your family/friends/health provider helps you sustain your behavior*”?). The probes also reflected a search for confirming and disconfirming evidence. For example, when developing the *adopting* category, the salience of the behavior, time, learnability of the technology, and ease-of-use were reported as important by several participants. Probes were added to search for confirming/disconfirming and conditional evidence around these 3 dimensions (“*Can you talk to me about the tradeoffs between time, learnability, interest, ease of use, and beginning to use an app*”?). Iterative changes to the probes were documented on a new interview guide for the next participant. Additionally, the interview guides helped with reflexivity. Reflexive notes were added to each interview guide after each research session and reviewed again before the next session.

Following the interview, participants were asked to interact with a prototype mHealth app described in a previous publication,<sup>20</sup> with the goal of stimulating further conversation about mHealth apps in the context of lifestyle behavior modification. For

example, while interacting with the prototype app, a participant with little experience using mHealth interventions for lifestyle change offered comments on the use of the colors red, yellow, and green to indicate poor, intermediate, good levels of health stating,

The red color (poor health) could make you feel less than. It would make [people] feel bad. As you go months and months, and you're always on the red, so why even try?... I think that this works well for people that are active, and so then it's [the color green] a positive feedback...some people would be motivated by that, but there are people that can't become green. What is that saying to them?

### Prototype Description

The prototype app used in this study was previously developed as a CV health tool based on heart health factors and behaviors established by the AHA.<sup>201</sup> The CV health tool can be delivered as an mHealth app and can be integrated with the electronic health record. Participants enter information into the app about CV health factors and behaviors including height, weight, blood pressure, smoking status, total cholesterol, hemoglobin A1c, medications, diet, and exercise. Based on these data, a CV health score is calculated on a scale of 0 – 100 with higher numbers indicating better heart health. Participants can find educational information about the behaviors and factors and follow their trends numerically and visually within the app. Additionally, the interactive interface allows participants to make changes to their data to identify what factors or behaviors might improve their CV health score. This feature helps participants identify areas in which to focus behavior change efforts. Data entered in the prototype app were not saved or recorded during this study.

### Data Collection Details

I used standardized techniques to record interviews and discussions using an audio recorder and an over-the-shoulder video recorder — tripod behind the participant with the focus on the hands and screen of the mobile device.<sup>202</sup> Over-the-shoulder video recordings protected participant privacy while recording tone and voice inflections.<sup>203</sup> No recordings were left on the recording devices; all were transferred to a password-protected hard drive.

Field notes were generated throughout the research session and expanded upon within 2 hours of the end of the session. Reflexive notes were added to the field notes, the interview probe sheets, and the reflexive journal. For example, after the ninth interview, I wrote the following reflexive note:

I feel like I am swimming in cement and not getting anywhere. There are so many categories, how can I classify them all? How can I put them in buckets? What if this process doesn't work? My mind races toward my old friend 'The Sociotechnical Framework' by Sittig and Singh. I know it is there. I am feeling desperate today and am worried I want to find those same comfortable categories (those beloved old shoes) within this data. I am acknowledging these thoughts, but is it enough to identify this tacit knowledge and my perceptions? How do I prevent myself from overlaying this knowledge onto the current findings? I find it very difficult to sit with the data at this point and keep these thoughts in abeyance. Perhaps a little grace is needed — time and continued wallowing to see what becomes dominant in the data. Just keep identifying the dimensions and the relationships. Wishing I had another researcher to discuss the day to day findings, to share the wallowing, to verify or validate my thinking here — it is hard to be comfortable with this chaos.

While these were the reflexive feelings and perceptions identified at a moment in time, 3 grounded theory methodologists and 3 other dissertation committee members were available to share, check, and validate study findings.

After each research session, all data were uploaded to QRS NVivo 12 software (2018, QRS, International Pty. Ltd., Boston, MA, USA) for analysis. Interviews were transcribed, checked for accuracy, and uploaded into NVivo. NVivo software created an internal audit trail (date and timestamps) of all research activity, which facilitated documentation of research activity. A methodological research journal was also used to document research activity.

### ***Data Analysis***

#### **Overall Analysis Process**

Descriptive statistics were used to characterize the sample. In accordance with GTM, data collection and analysis co-occurred and guided subsequent data-gathering to refine categories and relationships between categories.<sup>57</sup> Data from all sources were analyzed using the constant comparative analysis method,<sup>57, 59</sup> and analysis of dimensions.<sup>57, 204, 205</sup> Reflexive analysis was ongoing, in the moment, and at prescribed times such as immediately after a research session and at the time of developing the next interview guide.

Three phases of iterative analysis and coding occurred, consistent with constructivist GTM: 1) initial (in vivo), 2) focused (categories), and 3) theoretical (concepts).<sup>57</sup> Initial coding (1) used participants' words to form codes. Then, in the focused coding phase (2), codes were grouped together to form categories, and the ranges

of those categories were developed. During the theoretical phase of coding (3), categories were raised to a more abstract conceptual level and called concepts. These concepts were defined through their dimensions and the attributes of the dimensions. (see Table 2).

Dimensions demarcated the range of a concept (i.e., what is included, what is not included), and attributes described characteristics of the dimension. Therefore, the progression of the analysis moved from codes to categories and then categories to the more abstract level of concepts. See examples of the coding progression in Table 3.

Analysis continued until concepts were saturated, and the mHESIA theory developed.<sup>57</sup>,

204, 205

Table 2. Terms, Definitions, and Coding Phases

<b>Term</b>	<b>Definition and Subservient Terms</b>	<b>Coding Phase of Analysis</b>
Coding	The act of using participants' words to create codes. Then codes were grouped into categories, and finally, categories were raised to a theoretical level of concepts	Three phases of coding in constructivist GTM: Phase 1 – Initial (in vivo) coding, Phase 2 – Focused coding, and Phase 3 – Theoretical coding
Code	A label or name of a segment of data that summarizes or describes what is happening in the data using participants own words	Phase 1 – Initial (in vivo) Coding
Category	A code or group of codes that are similar or form some type of pattern	Phase 2 – Focused Coding
Concept	An abstract idea or perspective that raises a category or group of categories to a more theoretical level. Concepts and their relationships to each other form the substantive theory	Phase 3 – Theoretical Coding
	Dimensions      Descriptors of a concept which help delineate the boundaries of the concept, demarcate the range of the concept, and identify any variations included in the concept	Phase 2 and 3
	Attributes      characteristics or properties of specific dimensions	Phase 2 and 3



Table 3. Partial Audit Trail for the Concept Relationships

<i>Participants Quotes</i>	<b>Initial Codes (in vivo)</b>	<b>Focused Codes (categories)</b>	<b>Theoretical Codes [CONCEPT]</b>
<i>"[Talking] about people being more truthful, being in the comfort of their own home when they're either talking on the phone or <b>communicating</b> through an app, they may have a tendency to be more truthful [about diet or exercise]...."</i>	Communicating truthfully	Communicating with the provider	Connecting <b>[RELATIONSHIPS]</b>
<i>"I think a lot of people, they're more <b>accountable</b> to somebody else versus themselves...you'll make an excuse, oh, well, but if it's somebody else, like your doctor or nurse, you're more accountable. Or even the app where you're putting the information in, you're more accountable."</i>	Becoming accountable		
<i>"...my only suggestion is that people don't feel like they're being, um, and obviously an app isn't gonna do this per se, but people don't feel like they're being ... the <b>finger is being wagged at them</b>, you know what I mean?"</i>	Shaming		
<i>"Kind of like a gentle, <b>non-judgmental, non-threatening, no shaming</b>"</i>	Communicating positively		
<i>"Yeah. I definitely <b>find</b> support from survivorship community groups.... Casting for <b>Recovery</b>, which is a wellness weekend, fly fishing retreat for women diagnosed with breast cancer. If you would be able to [use technology] to <b>target</b> [community resources],...that would help."</i>	Finding and recovering with peers	Connecting with peers	
<i>"Yeah, it's <b>those more personal people</b> that can offer more support. Say if your children said, 'Good job <b>Mom</b>' [in a FitBit competition.] That feels better than if it is somebody you don't know so well."</i>	Connecting with family	Connecting with family	
<i>"I also think too, when you are trying to get healthy, having <b>the family</b>, having <b>my husband</b> especially committed to some of the [lifestyle] changes..."</i>	Connecting with family		

### Phase 1 Analysis — Initial (in vivo) Coding

The first phase of analysis, initial coding,<sup>57</sup> began with immersion into the data – reviewing the videos and the field notes and checking the transcripts for accuracy. Next, data segments - participants’ words, phrases, or sentences – were examined.<sup>57</sup> Initial coding involved assigning descriptive tags, usually gerunds, to the actions/processes/ideas represented in a segment of data. During this initial coding phase, the words of the participants were used to label what was happening in the data (in vivo coding) to gain a sense of action, sequence, or process (See Table 3).<sup>206</sup> As an example, the first participant interviewed spoke about “friends that you could connect with... to lean on.” That statement was initially coded as *connecting (gerund) with friends*, and additional examples of *connecting with friends* were sought in the transcript. As additional interviews were analyzed, each was reviewed for specific references to *connecting with friends*. In addition, to understand the range (“*Who were considered friends, and in what circumstances/context*”?), and variance of the connecting code (“*Was connecting important with people other than friends*”?), aspects of not *connecting with friends* were evaluated through constant comparative analysis. During this initial coding, many codes were generated from fracturing the data;<sup>57, 207</sup> 133 different codes were identified from the first 5 interviews. At that point, the most commonly identified codes included *integrating technology*, *tracking lifestyle behavior trends*, *setting goals*, *entering information*, *trying and liking*, *learning to use technology*, *initiating*, *slicing out me time*, and *encouraging*. Additionally, 3 different types of participants were identified, 1) those participants currently engaged with using I-apps to change behavior (engaged

users), 2) those who had used I-apps to change behavior in the past but were no longer doing so (disengaged users), and 3) non-users of I-apps for lifestyle change (never users).

Discussions of research findings began in this coding phase and were ongoing with the dissertation committee members. Every 2 weeks, analysis and findings were discussed with PYY to clarify category development and to identify further areas of inquiry. In addition, as categories and concepts developed, I met with MBH, JK, and ST at intervals to discuss progress, methodological decisions, and findings to validate concepts and dimensions. Throughout all phases of analysis, I wrote analytical and reflexive memos to inform the analysis process and to acknowledge and self-assess my perceptions. Memo writing helped record thoughts about the data, the analytic process, and analytic ideas as they arose. Memo writing informed theoretical sampling needs and question preparation (i.e., probe revisions) for subsequent interviews and as such, were reviewed weekly. A methodological journal was used for methodological memoing and to record procedures and processes and changes to the same in addition to the date and timestamp functionality in the NVivo software.

### Phase 2 Analysis — Focused Coding

The next phase of analysis, focused coding,<sup>57</sup> began when patterns and relationships among the categories were observed.<sup>57, 208</sup> For example, the first pattern to develop concerned the types of I-app users: (1) engaged users, (2) disengaged users, and (3) never users. After identification, these categories were defined. Engaged users were defined as those participants actively using I-apps to improve lifestyle behavior.

Disengaged users were those participants who had used I-apps in the past but were no

longer doing so, and never users were participants who had never used I-apps to improve lifestyle behaviors.

Another early pattern to be identified had to do with the *connecting* codes. The initial code of *connecting with friends* was explored with subsequent participants who talked about not only *connecting with friends* but *connecting with others*, including providers. A pattern developed as each of the first 10 participants interviewed discussed *connecting with people*. *Connecting with people* became a category. Following identification of this category, all 10 transcripts were re-reviewed for defining dimensions (i.e., “*Who was involved in these connections?*” and “*When in the process of mHealth use were these connections important/not important?*”), ranges of dimensions (i.e., “*What context/circumstances were these connections important?*”) and variations of dimensions (i.e., “*Connections seemed to be positive in most cases, but were they ever negative?*”). Searching for variations involved a search for data that presented a different pattern. During this phase of coding, demographic and lifestyle behavior information were incorporated into the analysis. For example, engaged users, disengaged users, and never users were compared in terms of lifestyle behaviors they were trying to change. Matrices were created in a spreadsheet and explored to examine context and interconnections and to ensure all aspects of a category were explored and realized. For example, users were identified and categorized as above, and then adherence patterns to the AHA guidelines for diet and exercise were explored both individually and as patterns related to the user type. Similarly, these 3 user types were later explored when evaluating emerging

concepts (i.e., *Relationships*) and when exploring the basic process of the developing theory.

Results of this second phase of analysis (focused coding) informed further theoretical sampling and interview question development for the next interviews. For example, as the *connections* category developed, participants identified different time points in the process where *connections with people* were important, namely initiating the use of technology to improve lifestyle behaviors and *sustaining* the use of the technology. The first 10 participants spoke about the category of initiating (later recorded as the phase of *adopting*), but few spoke of the *sustaining* phase of the process. Therefore, probes were added to ask about this emerging *sustaining* category (“*Can you tell me more about continuing to use mHealth apps*?”), and sampling reflected the need for participants who were engaged users of I-apps to *sustain* lifestyle behaviors. These are examples of how theoretical sampling occurred and how developing categories and dimensions of categories informed sampling needs and interview prompt development.

### Phase 3 Analysis — Theoretical Coding

In the final phase, theoretical coding,<sup>57</sup> categories were grouped and elevated to a more abstract level and called concepts. The literature was reviewed as the categories were raised to the more abstract level of concepts. For example, the *initiating* category was elevated to the more global concept of *adopting*. Theoretical relationships continued to be identified.<sup>209</sup> For example, the ‘connecting with people’ category became part of the *Relationships* concept which includes relationships with providers, family, friends, peers, groups, self, and even technology. The *Relationships* concept was then identified as being

linked with the phases of the process. These linkages or relationships between the concepts were examined using constant comparative analysis and once verified, formed the basis of the substantive theory.<sup>208</sup>

### ***Trustworthiness and Rigor***

When coding activities were complete, 25% ( $n = 4$ ) of the transcripts were re-coded to assess intra-coder reliability. Six discrepancies were identified and re-coded; all discrepancies concerned peer versus group relationships. Additionally, initial codes, categories, and final concepts were examined for factual accuracy (descriptive validity).<sup>210</sup> The codes derived from these 4 transcripts were also compared to participants' original statements to ensure closeness to participants' own words (interpretive validity).<sup>210</sup> Members of the dissertation team (MBH, JK, ST, PYY) reviewed exemplars of participants' statements and how the statements were developed into codes, categories, and concepts to also ensure interpretive validity (see Table 3).

In accordance with GTM, a final literature search was conducted to situate the resulting theory and study findings within related scientific bodies of literature. The literature served as data to explore and validate the identified concepts and theory.<sup>207</sup> How this new theory "fit" within the existing scientific knowledge base was identified at the concept and theory level.

After the substantive theory was identified, 6 engaged users, who had previously agreed to be contacted a second time, were invited to participate in a follow-up interview. Three (19%) agreed to participate; 1 was out of town, and 2 did not return email requests. Consistent with the member checking process of GTM, these follow-up interviews were

used to validate study findings. Follow-up participants were shown the theoretical model, findings were discussed, and participants were asked about similarities and differences with their personal experience and the model. These second interviews were recorded, transcribed, and field notes were written as per interview methods described earlier. Additionally, the theory and study findings were discussed with a clinical oncology nurse practitioner specializing in survivorship care, a Ph.D. nurse researcher with expertise in usability and technology development (PYY), and a Ph.D. nurse researcher with expertise in behavioral change (ST) to validate study results. Comments from these follow-up discussions were reviewed for agreement or disagreement of findings in relation to their professional experiences. Results of the follow-up interviews aligned with the concepts and the theory (see Chapter 4. Results).

Trustworthiness of qualitative research parallels the standards of reliability and validity in quantitative research.<sup>211</sup> Three standards of rigor used to improve trustworthiness and common to qualitative methods include credibility, auditability, and fittingness.<sup>212</sup> Credibility is “a criterion for evaluating the integrity and quality in qualitative studies, referring to confidence in the truth of the data; and analogous to internal validity in quantitative research.”<sup>213, p. 724</sup> Auditability refers to the ability of another researcher to follow the methods, processes, and conclusions of the original researcher as well as consistency in research methods and methodology.<sup>214, 215</sup> Fittingness refers to the applicability of the results within the larger research domain or how applicable the newly generated theory “fits” within the context of the existing body of research.<sup>213, 215</sup> In their seminal work, Chiovitti and Piran (2003) recommend methods to

enhance these 3 standards of rigor in grounded theory research,<sup>216</sup> which have been incorporated into this study.

Several examples help illustrate the specific methods used to enhance study trustworthiness. First, the participants were asked open-ended questions and freely expressed their perspectives and thus the concepts were grounded in participants' ideas and perceptions. Second, 19% of participants ( $n = 3$ ) participated in follow-up interviews and agreed that the theory and results resonated with their personal experience of using mHealth to improve their lifestyle behaviors, although all 3 were users of mHealth. Third, the participants' own words were used to generate the codes and categories. Fourth, using reflexive journaling, reflexive notes and memos, written explication of my personal experiences, professional experiences, and tacit knowledge, and an examination of my world view, I have endeavored to articulate and examine my biases and keep them in abeyance to avoid exerting undue influence on the research process or analysis. For example, I identified the code journaling and thought about how such an I-app feature would offer qualitative researchers insights into the in-the-moment decisions made by participants. However, I relinquished my bias (wanting it to be a code for my own personal reasons), and ultimately the code failed to be supported in the data. Additionally, early reflections on my interview techniques identified a need for skill improvement. I took online classes to improve these skills. Fifth, I used specific methods (constructivist GTM), in alignment with my world view, to inform the research process.

Using GTM constant comparative analysis, I asked delineated questions of the data in a standard manner. Questions asked about each code, category, concept, and



dimension included: 1) What is the process, action, or what is going on — in the participants' words; 2) What is the context and when is it true/not true; 3) Can I find other examples to confirm/disconfirm the category/concept or dimension from other participants or in other areas of this participant's interview; and 4) How are codes/categories/concepts similar/different/related. Additionally, I specified how and why participants were selected to participate in the study and delineated the scope of the research (i.e., limited to breast cancer participants). Finally, I discussed how the literature related to the newly identified theory (see Discussion). Trustworthiness was also addressed through criteria adapted from Lincoln and Guba<sup>211, 213, 217</sup> as reported in Table 4 and elaborated in Appendix C.

Table 4. Trustworthiness Criteria, Definitions, and Applications

	Definition	Application
<b>Credibility</b>	Confidence in the truth of the data and interpretations of them. Credibility can only exist if the data and results are dependable. Credibility enhances believability.	<ul style="list-style-type: none"> <li>• Methodological congruency maintained</li> <li>• Clear research question aligned with GTM</li> <li>• Complete descriptions of research procedures</li> <li>• Verbatim quotes</li> <li>• Participants words “grounded” the theory in data</li> <li>• Sought confirming and disconfirming evidence</li> <li>• Reflexive journal and reflexive memos</li> <li>• Alternative explanations and lines of inquiry</li> <li>• Multiple data sources (triangulated the data)</li> <li>• Positive and negative probed and discovered</li> <li>• 25% of transcripts were recoded for accuracy</li> <li>• Descriptive and interpretive validity assessed</li> <li>• Extant literature examined for theoretical “fit”</li> </ul>
<b>Dependability</b>	Stability (reliability) of the data and results over time and conditions.	<ul style="list-style-type: none"> <li>• Multiple audit trails</li> <li>• Memo-writing at standardized times ensured review of perceptions and potential biases</li> <li>• Checking transcripts for accuracy</li> <li>• Data triangulation as above</li> </ul>
<b>Confirmability</b>	Data objectivity - accuracy, relevance, or meaning. Findings reflect participants’ voice	<ul style="list-style-type: none"> <li>• Reflexive and methodological journaling</li> <li>• Audit trail as above</li> <li>• Checking transcripts for accuracy</li> <li>• Memo writing</li> <li>• Concept saturation</li> <li>• Concepts lacking saturations extinguished</li> </ul>
<b>Transferability</b>	The extent to which finding can be extended/supported in other settings/ participants.	<ul style="list-style-type: none"> <li>• Data triangulation as above</li> <li>• Theory review subject matter experts and participants</li> <li>• Review of the methodological decisions and ongoing results by dissertation committee</li> <li>• Use verbatim quotes in results reporting</li> </ul>
<b>Authenticity</b>	The extent to which researcher faithfully convey participants processes and experiences and convey a full range of realities.	<ul style="list-style-type: none"> <li>• Grounding the codes, categories, and concepts in the data</li> <li>• Showing how the codes, categories, and concepts were developed from the participants own words</li> <li>• Methods development with expert grounded theorist (MBH)</li> <li>• Verifying results with subject matter experts</li> <li>• Tracking rationale for theoretical sampling decisions</li> <li>• Recording complete participant responses, checking transcripts for accuracy</li> </ul>

Adapted from criteria by Lincoln and Guba<sup>211, 213, 217</sup>

## Chapter 4. Results

### *Demographics*

Fifty-three breast cancer survivors were recruited between December 2018 and July 2019. Sixteen (n = 16) were enrolled – 12 identified through the breast center, 2 from community flyer distribution, and 2 by word-of-mouth. Thirty-seven of those recruited were not enrolled: 12 were not eligible (not smartphone users = 6, cancer recurrence or active treatment = 4, not mHealth user = 2); 14 had scheduling issues; 10 were not interested, and 1 lived in Michigan. The first 5 participants enrolled (31%) were purposively recruited for their ability to function as key informants and to expand demographic diversity in the sample. These first 5 participants were selected for maximum variability on race, sexual orientation, age, and locale. Subsequent participants were enrolled based on theoretical sampling needs (see Table 5).

Four participants (25%) were from rural Ohio communities with the rest from urban and suburban communities in central Ohio. All participants were women ranging in age from 34 to 78 years old. One participant identified as lesbian. The women had survived cancer from between 3 and 29 years, with only 1 participant experiencing cancer recurrence. Most of the participants were Non-Hispanic, white (88%), and well-educated with undergraduate or graduate college degrees (88%) and all with at least some college. Eleven participants (69%) were married or living as married, 4 (25%) were single, and 1

was separated. Most participants ( $n = 12$ , 75%) worked full-time or part-time. All reported their health was good or very good. However, most participants ( $n = 14$ , 88%) failed to meet the AHA guidelines<sup>201</sup> or the ACS guidelines<sup>76</sup> for healthy diet, exercise, and weight. All participants reported being non-smokers. The 2 participants (12%) meeting the AHA and ACS guidelines were engaged users of several different mHealth interventions for lifestyle improvement. All participants accessed the internet daily using a combination of smartphones, tablets, and/or computers. Thirteen participants rated their internet skills as excellent or good, and the 3 remaining participants (19%) rated themselves as average. Three participants (19%) had stopped using mHealth lifestyle apps; however, 1 participant was still trying to exercise, and another was trying to work on diet and exercise.

Thus, the sample included participants who were currently using I-apps for lifestyle improvement (engaged users,  $n = 10$ , 63%), previous users of I-apps for lifestyle improvement (disengaged users,  $n = 3$ , 19%), and never users ( $n = 3$ , 19%) including a participant who actively chose not to use any type of mHealth technologies except for her MyChart app (Epic, Verona, WI).

Table 5. Sample Characteristics ( $n = 16$ )

Characteristics	Range, Mean (SD)*	n (%)†
<b>Demographics</b>		
Age (years old)	34-78, 57 (11.3)	
Years since initial diagnosis (years)	3-29, 13.7 (9.2)	
Race		
	Black or African American	1 (6.3)
	White	14 (87.5)
	Not reported	1 (6.3)
Ethnicity		
	Non-Hispanic	15 (93.8)
	Not reported	1 (6.3)
Education (highest level)		
	Some college or vocational school	2 (12.5)
	Undergraduate college degree	3 (18.8)
	Graduate degree	11 (68.8)
Employment		
	Retired	2 (12.5)
	Part-time	3 (18.8)
	Full time	9 (56.3)
	Unemployed	2 (12.5)
Marital Status		
	Single (never married)	4(25)
	Separated	1 (6.3)
	Married or living as married	11 (68.8)
Type of Insurance		
	Private Insurance	14 (87.5)
	Medicare & Private Insurance	1 (6.3)
	Other	1 (6.3)
Income		
	Greater than \$150,000	2 (15.5)
	\$100,001 - \$150,000	3 (18.8)
	\$75,001 - \$100,000	2 (12.5)
	\$50,001 - \$75,000	4 (25)
	\$25,001 - \$50,000	4 (25)
	Not reported	1 (6.3)
<b>Technology Skills</b>		
Self-reported general health		
	Very good	6 (37.5)
	Good	10 (62.5)
Self-rated internet skills		
	Excellent	5 (31.3)
	Good	8(50)
	Average	3 (18.8)
How often do you use email		
	Every day or almost every day	16 (100)
Have you used the internet in the past 30 days		
	Yes	16 (100)

continued

Table 5. continued

Frequency of internet use	Almost every day	16 (100)
How do you access the internet (all that apply)	Mobile phone	15 (93.8)
	Laptop	7 (43.8)
	Personal computer at home	9 (56.3)
	Tablet	1 (6.3)
	Computer at work	10 (62.5)
How confident are you filling out medical forms by yourself	Extremely	12 (75)
	Quite a bit	3 (18.8)
	Somewhat	1 (6.3)
Have you searched online for information on health and illness	Yes	16 (100)
Have you gone online to schedule an appointment with your healthcare provider	Yes	9 (56.3)
	No	7 (43.8)
Have you read on a health-related forum or social media website	Yes	15 (93.8)
	No	1 (6.3)
Asked a question of your healthcare provider online	Yes	12 (75)
	No	4 (25)
Shared online your personal medical information	Yes	7 (43.8)
	No	9 (56.3)
Logged on to your own electronic health record	Yes	15 (93.8)
	No	1 (6.3)
Posted an online healthcare review	Yes	4 (25)
	No	12 (75)
Taken a web-based self-management (health) course	Yes	7 (43.8)
	No	9 (56.3)
Posted a message on a peer-supported forum or social media website	Yes	13 (81.3)
	No	3 (18.8)
<b>ACS‡ &amp; AHA§ Guidelines Met</b>		
	Yes	2 (12.5)
	No	14 (87.5)

\*SD indicates standard deviation, †n indicates number, ‡ACS indicates American Cancer Society,<sup>218</sup> §AHA indicates American Heart Association<sup>201</sup>

### ***Substantive Theory Overview***

The purpose of this dissertation was to develop a substantive theory to identify and understand the sociotechnical process associated with mHealth intervention use by breast cancer survivors to improve lifestyle behaviors. The theory, named the mHealth Engagement and Self-regulation using Intervention Applications (mHESIA) theory, includes 4 core concepts: 1) *mHealth Engagement*, 2) *Self-regulation*, 2) *Relationships*, and 4) *Functionality and Features* (see Table 6). The mHEAIA theory posits a five-phase process explaining the synergy between *mHealth Engagement* and *Self-regulation* of lifestyle behaviors (see Figure 2). The process includes the phases of *adopting*, *sustaining*, *habituating*, *disengaging*, and *re-adopting*. The phases of *adopting*, *sustaining*, and *habituating* explain how mHealth works for and is employed by breast cancer survivors to improve lifestyle behaviors. The phases of *disengaging* and *re-adopting* describe associated behaviors of participants when attempting to engage with mHealth to improve lifestyle behaviors. Finally, the core concepts of *Relationships* and *Functionality and Features* influence the five-phase process.

The *Relationships* concept includes the dimensions of relationships with family, friends, healthcare providers, peers or groups, self, and technology. The *Functionality and Features* concept includes the dimensions of usability, content, personalization, goals, feedback, integration, and data security.

Table 6. Theory Concepts, Dimensions, and Attributes

<b>Concepts</b>	<b>Dimensions</b>	<b>Attributes</b>
<i>mHealth Engagement</i>	Engaged Users	
	Disengaged Users	
	Never Users	
		Lack experience, knowledge
		Choose not to use
<i>Self-regulation of lifestyle behaviors</i>	Positive	
	Negative	
<i>Relationships</i>	Family	
	Friends	
	Providers	
	Peers, group	
	Self	
	Technology	
<i>Functionality and Features</i>	Usability	
		Ease-of-Use
		Efficacy
		Learnability
		Satisfaction
	Content	
		Trust
		Salience
		Education
	Personalization	
		Sharing
		Comparing
	Goals	
		Setting
		Monitoring
	Feedback	
		Cueing
		Trends & Tracking
		Rewards
	Integration	
		EHR
		Digital Health Technologies
		Provider workflow
	Data Security	
<b>Processes</b>	<b>Phases</b>	
	<i>Adopting</i>	
	<i>Sustaining</i>	
	<i>Habituation</i>	
	<i>Disengaging</i>	
	<i>Re-adopting</i>	



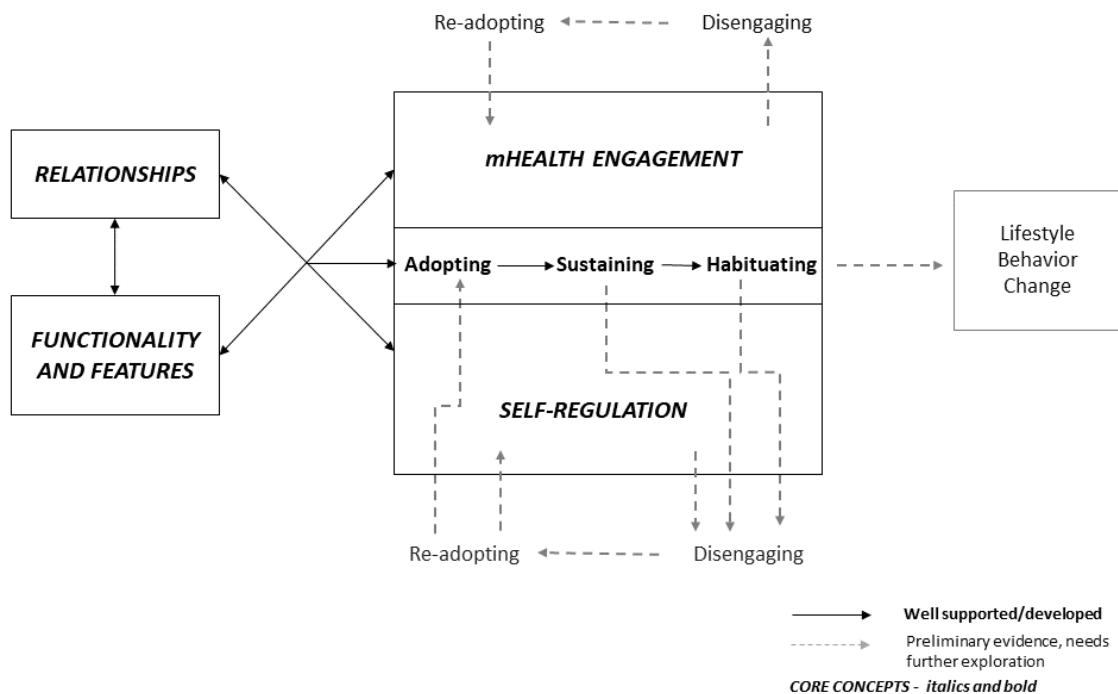


Figure 2. The mHESIA Theoretical Model

### ***mHealth Engagement and Self-regulation using Intervention Applications Theory***

The mHealth Engagement and Self-regulation using Intervention Applications (mHESIA) theory posits a synergistic relationship between 2 concepts: *mHealth Engagement* and *Self-regulation*. Each concept can occur independent of the other or can co-occur. When participants engaged with mHealth interventions for *Self-regulation* of lifestyle behaviors, they reported working toward improving several lifestyle factors at a time including reducing stress, improving diet, increasing physical activity, decreasing sedentary behavior, avoiding and decreasing alcohol use, improving sleep, drinking more water, addressing depression and anxiety, and improving the mind-body connection (see

Table 7). The analysis revealed patterns and differences in the number of lifestyle behaviors that participants engaged in and how these patterns related to use behavior of I-apps (see Table 7). For example, I-app users or engaged users ( $n = 10$ ), reported working on multiple lifestyle behaviors (ranging from 2-5 behaviors) at a time when compared with the 6 participants not using I-apps, disengaged and never users (0 – 2 behaviors). Two of the 10 participants using mHealth technologies reported meeting all the ACS<sup>76</sup> and AHA<sup>201</sup> national guidelines for diet, exercise, and weight. None of the non-users ( $n = 6$ ) — disengaged or never users — reported doing so. *mHealth Engagement* seemed to synergistically enhance *Self-regulation* through the sociotechnical processes of *adopting*, *sustaining*, and *habituating* as described below.

One disengaged user in her 60s, and 2 never users, both in their late 70s, were not attempting to improve any lifestyle behaviors. The other never user reported attempting to improve 2 behaviors: making dietary changes and going to the gym. Her sporadic gym attendance was done with ill-ease as this single woman in her mid-50s suggested, “It’s a mindset because I am fairly uncomfortable at a gym. I don’t feel comfortable at a gym. It feels icky to me. I guess I feel like it’s a meat market that people are competitive, and they’re looking at each other and evaluating. That is obviously my own perception.” This same participant comment on her reason for being a never user by remarking, “I choose not to use [mHealth technologies] as I am fundamentally afraid of data breach.” The other participants who were never users of I-apps, and both in their mid- to late-70s, suggested that they would like to use mHealth technologies to improve their lifestyles if

they were “shown how to do it.” Their lack of knowledge and skill was their limiting factor to engagement.

Table 7. Health Factor of Concern versus Health Factors Undergoing Active Improvement by User Type per Participant

Participant	Health Factors of Concern per Participant	Health Factors Under Active Improvement per Participant	Number (n) of Active Factors
<b>Engaged Users (n = 10)</b>			
1	S*, D†, PA‡, Wt§, sleep	S, mind-body connection	2
2	S, D, PA	S, D, PA	3
3	S, D, P, Wt, sleep	S, D, PA, Wt, sleep	5
4	S, D, PA, Wt, drink more water	S, D, PA, Wt, drink more water	5
5	S, PA, sedentary behavior, sleep	PA, sedentary behavior, sleep	3
6	S, sedentary behavior, sleep, depression	sedentary behavior, depression	2
7	S, anxiety	S, PA, anxiety, depression	4
8	S, D, PA, Wt, sedentary behavior	PA	2
9	S, D, PA, Wt	D, PA	2
10	S, D, PA, anxiety	D, PA, Wt	3
<b>Disengaged Users (n = 3)</b>			
11	S, D, Wt, A  , sleep	S	1
12	S, D, Wt	none	0
13	S, A, D, PA, Wt, anxiety, panic	D	1
<b>Never Users (n = 3)</b>			
14	S, D, PA, A, sleep	none	0
15	S	none	0
16	S, D, PA	D, PA	2

\* S indicates Stress, †D indicates Diet, ‡PA indicates Physical Activity, §Wt indicates Weight, ||A indicates Alcohol

### Processes Overview

When *mHealth Engagement* and *Self-regulation* of lifestyle behaviors co-occurred, participants moved through 3 phases of the sociotechnical process of *adopting*, *sustaining*, and *habituating*. Two other phases, *disengaging* and *re-adopting*, emerged from the analysis of the data and formed part of the overall process. Some participants reported *disengaging* or discontinuing use of the I-app. Other participants reported *disengaging* but then *re-adopting* use. From participants' reports, the concepts of *Relationships* and the *Functionality and Features* influenced the phases of the process.

### Theoretical Assumptions and Propositions

Theoretical assumptions and propositions are discussed under each concept below and presented in detail in Appendix D. The assumptions and propositions outline the constitutive definitions<sup>64</sup> (nonrelational propositions) used for each of the concepts presented in the mHESIA theory. Nonrelational propositions are descriptions or definitions of concepts, and relational propositions suggest linkages or relationships between 2 or more concepts.

### ***Five Phases of the Sociotechnical Process***

Five non-linear phases of the sociotechnical process emerged from the data: *adopting*, *sustaining*, *habituation*, *disengaging*, and *re-adopting*. However, not all participants traveled through all phases. Moreover, travel through the phases was not always sequential. The phase of *adopting* occurred before the phase of *sustaining*. Additionally, in the absence of the *disengaging* phase, participants described the

*sustaining* phase as preceding the *habituating* phase. Moreover, participants reported *disengaging* from the *sustaining* or *habituating* phase.

### The Adopting Phase

The process of *adopting* is defined as the initiation of the use of mHealth health technology for lifestyle behavior change. *Adoption*, in this sense, concerns a participants' willingness and readiness to accept new ways of using mHealth intervention technologies to improve lifestyle behaviors and the resultant use of that mHealth intervention to improve lifestyle behaviors. For example, downloading a meditation app to a smartphone, opening the app, and using it to meditate indicates mHealth *adoption*. If a participant downloaded a mHealth app to improve lifestyle behavior but did not use the app, this was not considered *adopting*. Similarly, if someone else in the family (i.e., husband) downloaded an I-app onto a participant's phone and the participant did not use the app, this was not considered *adoption*. Participants reported many motivating factors that drove them to *adopt* technology. Many of these factors concerned *Functionality and Features* of the technology itself. These same *Functionality and Features* were also important to *sustaining* engagement. However, most of the reasons cited for *adopting* I-apps involved *Relationships*.

Participants reported multiple reasons as important in *adopting* mHealth for behavior change. For example, a 54-year-old participant identified relationships, accountability, curiosity, and competitions as reasons for *adopting* I-apps:

Interviewer: What made you initiate using [it]?"

Participant: My daughter wanted one, so I gave her one for Christmas, and then I thought it looked neat, so I got myself one...kinda the accountability thing. I did it with a co-worker too, and that really did help because we were every day like, I'm gonna win today. It was a good motivator.

In addition to relationships and support, feedback, reminders, and fun were also mentioned as important to the phase of *adopting*. One participant, a nurse in her mid-60s stated, "My daughters all have [apps] synced to mine. So, they send me reminders. 'You haven't been walking today, what's going on?' (laughing) And vice-a-versa, which is really kind of fun." This participant also talked about the importance of an "accountability partner" when beginning an exercise program to "help motivate you."

Dimensions of the concept *Functionality and Features* were important to the phase of *adopting* as well as other phases of the process. For example, efficacy and ease of use (attribute of usability) were important to several participants when *adopting* I-apps. One participant in her early 50s stated, "first it has to be easy, and it has to work," and another echoed the sentiment saying, "It has to work...I think it has to." Another young participant stated that she did not want to "spend too much time initiating [the app], and it has to work the way I want it to." Another participant, in her mid-50s used several different apps to address several different lifestyle behaviors. She suggested that the salience of the behavior and the mHealth intervention had to be "worth it" and that she would be willing to "spend a little bit more time and effort because it was enjoyable." She went on to talk about the ability to "choose colors and choose the speed [of interaction], so it's kind of mindless, but it's pretty and it de-stresses me" as reasons for *adoption*. Another participant in her mid-60s spoke of lifechanging events and desperation in seeking relief from her deepening depression as reasons for *adopting* the

use of an I-app. However, for this participant and like other participants, the antecedent to *adopting* her I-app was a suggestion from someone, in this case her daughter (a *Relationship*). Her journey underscores the interaction between *adopting* mHealth technology, how it is related to *adopting* lifestyle behavior change, and how *Relationships* are linked to and influence the *adopting* phase of the process. She described her process of traveling through the *adopting* phase as follows,

About a year and a half ago, I had a terrible time with anxiety, just debilitating anxiety. I think it was my daughter going to college, problems with my marriage; things were coming at me from all directions. I was really pretty ill. I mean, I couldn't work for a while. I was just looking for anything and everything. At that time, I really wasn't even able to get on my iPad, but I think I had...I want to say maybe I was looking at a forum on anxiety, and someone suggested the [app]. I was just willing to try whatever; I got to the point of desperation. Just trying to reach out. The people on the anxiety forum, you know, that were talking about similar situations that they had, and what they do for anxiety [apps used]. So, I did that, you know?

Participants identified several facilitators of *adopting* lifestyle improvements. One older participant suggested it was frequent "ticklers" that kept suggesting the importance of lifestyle improvement or app use. Additionally, she reported that her friends were the most likely reason she would start to make a change. Additionally, this older participant's prior experience with successful change made it easier for her to begin the journey. Other participants also reported that their relationships with friends and family were the most important reason in *adopting* lifestyle changes, but the salience of the behavior and motivating factors (i.e., monetary reward) also played a role. For example, a participant in her early 60s wanted to lose weight for her daughter's wedding. She and her friend got

started by setting a goal, agreeing to a walking schedule, and at her friend's suggestion, using a weight loss app together.

Participants who were not currently working on lifestyle change noted several barriers to *adopting* a healthy lifestyle. Several participants in their 40s to mid-50s, who were also raising children and caring for elderly family members, reported a lack of focus on self-care suggesting their "family will always come first" and therefore "time" was not available for them to focus on exercise or diet. One participant, a woman in her early 60s, working full time, and an empty nester, reported that she had stopped using her fitness tracker and said, "I need a puppy, not an app to encourage me to actually get out and walk." Once participants had *adopted* a technology, most moved to using the technology regularly, with a participant, in her 60s, describing her I-app for anxiety and depression as an "old friend" available whenever the need arose.

### The Sustaining Phase

*Sustaining mHealth Engagement* in the context of this study means using technology regularly to work toward improved lifestyle behaviors. This phase of the process is situated between the *adopting* and the *habituating* phase of the process. One middle-aged participant suggested: "You see it and are reminded all the time that 'I have a goal for the day.' So, other things don't crowd it out." And another younger participant stated, "I think they [apps] make it easier because the information is there...certainly there's an accountability there. But also, it just makes it so that your keeping track, you can be accountable, but if you want more information...you can get that. So that's good."



Many of the same factors that were important in the *adopting* phase of the process were also important in the *sustaining* phase of the process. Accountability, as reported in the quotes above, was mentioned by many participants, across all age spans, as a driver of *sustainability*. Several participants mentioned acknowledging slip-ups and allowing for them as an important way to be in control and to *sustain* success in lifestyle improvement. For example, one participant compared herself and her success to her mother's lack of success. This participant had cared for her mother (also a breast cancer, stroke, and heart attack survivor) over the last 10 years of her mother's life. This participant, in her late 50s, stated,

I think just allowing yourself to just be okay with not being perfect, and to feel like, it's okay sometimes to eat the chocolate, but that doesn't mean you have to have the chocolate for 5 days in a row. I think that's what I really saw with my mom, especially, was she'd either be on a really strict diet, or she wouldn't be. And when she was totally off, she was totally off. It's just, that didn't work for her at all, because she always felt like there was good food and bad food, versus there's healthier food and there's food you just have less frequently...it's just more about planning and continuing to incorporating them [unhealthy foods] in a smaller amount. And just the feeling that, okay, things have gone off the rails for a day or 2, but I feel like I know what I need to get back on track. So, it's the feeling of control that's there.

Several participants noted that novelty and new information was what helped them *sustain* their I-app use and interest in lifestyle behavior. One younger participant stated, "I come to look forward to a different lesson each day. I think it is the information. It was the things I hadn't heard before." Another participant in her early 60s commented, "I guess the novelty kinda makes you do that. Then you kinda fall into a bit of a habit." Another participant, in her mid-30s, was curious about what the graphics in the next level

might look like. She stated, “It is just the curiosity factor; usually the graphics are beautiful, and this is my reward.”

And like the *adopting* phase of the process, efficacy was important to most participants in the *sustaining* phase. One participant in her early 60s spoke about a weight loss app she had been using for the last 9 months and stated, “So, I don’t foresee myself giving up, you know, on the [name redacted] app. In fact, I want to get more immersed in that anyway. It is a very sound program. It’s been around for a long time. It works.”

Another participant spoke about another program and what *sustained* her use of the I-app and lifestyle behavior. This young participant simply stated, “I just saw a system that was working.”

Many participants spoke of encouragement as a motivator during the *sustaining* phase of the process. One participant noted, “It’s the encouragement of each other, I think. The sharing of ideas and tips.” Another participant thought aloud, “Some kind of silly acknowledgment or fun acknowledgment that only you can see, helps your internal motivation.” While several other participants spoke of encouragement from competitions available through the mHealth applications. One stated, “I think encouragement is always helpful. It’s good. You know where you’re at, and then I know [through the app] people can have competitions during the week and things like that. So, I think it’s always anything that could encourage is helpful.” And on the subject of competition during the *sustaining* phase, a younger participant stated, “Competitions in the app are fine with me. I know that some weeks I might not be able to be the top person, but I think it’s

something that makes you think, ‘Oh, I want to do better because the other people are doing better.’ So yeah, it doesn’t hurt, yeah.”

Almost all participants reported the importance of setting and attaining goals during the *sustaining* phase. One participant in her 60s summed up the ideas by stating, “For me, it’s small, daily, achievable goals, and being accountable to look at them...I want to see, just Monday through Friday, during the week when I’m working, if I can do those 2 things every day. Eliminate sweets, walk eight thousand steps.” And another younger participant also talked about setting small goals saying,

I think breaking things down into smaller steps often helps a lot. So sometimes saying to someone, okay your goal is to start eating more green vegetables or having...getting rid of sugared pop from your diet or something. I think a lot of things that do things step by step can be very successful to say, you know, if you’re part of this goal, the first step is going to be get to this goal. The first step is, start with X, and it’s just 1 small change this week.

Several participants spoke about achieving goals as a form of intrinsic reward. One middle-aged participant who was using multiple I-apps and working on multiple behaviors stated,

It’s the small goals. The giant goal is not attainable. I guess I’m trying to think I probably had some of those before, and I’ve got a certain number of things or points or steps, or whatever. But I like getting my rewards which are easy to get to and then I can go on to the next one.

Other participants spoke of getting to the next level, seeing something change, or having something revealed in the app as an intrinsic reward. For example, a participant in her early 50s stated,

I have never had an app which has given me a monetary award. It’s more of intrinsic reward like move to the next level...or there’s this fish when I get to the next level that turns into a

dragon...and it's usually the graphics are beautiful, and the dragon is beautiful, and this is my reward.

For another participant who was actively using an app to decrease stress, the reward was knowing she could count on the help available in the app at any time. She stated, “[the app] gave me some tools. To be able to deal. I still rely on it. It’s like an old friend I go back to. It’s a security. Definitely a security.”

Participants also discussed in-the-moment feedback and information as important during the *sustaining* phase of the process. One 56-year-old participant using a fitness tracker and sharing her information with her daughters described the feedback function by saying, “Every once in a while, you get a thing saying ‘congratulations you’ve crossed the Himalayas’ or something...that’s kind of fun, too. I mean, it keeps it kind of fun and funny.”

Several younger participants described the haptic functions (i.e., vibrations) of the I-apps as motivation during the *sustaining* phase. While discussing things that motivated continuance of exercise behaviors, a young participant stated, “When you hit 10,000 steps on your [fitness tracker], it goes all crazy on your wrist. It buzzes a little and vibrates. Yeah, which is exciting. Because you feel like you did it right.” Another younger participant in her 40s discussed the fireworks pattern that went off when she hit her step goal for the day as something that she worked for each day and kept her engaged. Push notifications to participants' phones were mentioned by several participants as important feedback mechanisms during the *sustaining* phase of the process. While discussing things that helped participants *sustain* their behaviors using I-apps, one

participant said, “Usually I receive feedback if I met my goal. It would say, ‘great job.’ Or you have a mile to go, ‘keep going, you are almost there.’”

Several participants, all of whom were active users of several I-apps, thought it was important to integrate their health information with the broader healthcare system, such as feeding the information back into the electronic health record. One participant in her late 60s stated,

I think it would be more comforting because when you’re just looking at the medical stuff and lab results in the [patient portal of the electronic medical record], it can make you kind of... You know [sad face]. But then if you had this other place to go right inside there [patient portal] that also talked about mindfulness or the things you can control you could do better and get help... that’s really important. And it would make you more apt to come back to it because it would be good stuff that you do have control over.

All participants using mHealth applications and several disengaged users mentioned the importance of raising awareness or raising consciousness around lifestyle improvement. This consciousness-raising seemed to be an intrinsic part of the I-app which helped in *Sustaining* engagement. One middle-aged participant stated,

You know you want to do these things [exercise], but it [the app] lets you see really where you’re at, and whether you’re getting enough movement in a day. It also reminds you every hour to get up and move. If you’re in a sedentary job or you’re working at a desk or something, it’ll remind you.

Another participant in her 50s and juggling the demands of a large family suggested the in-the-moment availability of information allowed her to better *sustain* behaviors. She spoke of eating out with her family, trying to meet the needs of a special needs child, and

trying to meet her own healthy eating goals and suggested the benefit of the I-app as, “Even if you’re in the situation at the moment it [the app] allows you to look thing up.”

One participant in her early 60s spoke about the importance of working on many different behaviors and how some applications are also addressing how attitude might factor into *sustaining* change. She stated,

I think working on all those things [sleep, exercise, eating health food] together helps. One thing I think is good is they’re [the apps] not just focusing on just exercise or just what you’re eating, but they’re focusing on a lot of different factors. Some of it’s about, why are you eating, attitudes. Come on why not just have that smaller serving and enjoy it? Or why are you going beyond that, mindfulness?

Several participants, 2 of whom were nurses working full time, reported that they were more likely to *sustain* the use of their I-apps if the information was “based on current evidence.” And an older participant in her 70s commented, “And as you know as we find newer research, we wanna get that information out. That’s where the apps come in.”

Several participants, most of whom were never users or disengaged users, considered lack of time a barrier to *sustaining* I-app use or lifestyle behavior improvement. However, several actively engaged participants mentioned that *sustaining* I-app use allowed them more time. One participant in her late 40s stated, “I think apps give you more time.” Similarly, a participant in her late 60s but still working full time spoke about using her I-app for stress management. Stated using the I-app was

...like a little slice of me-time that I can carve out. And it goes with me wherever I go. I think because it is so mobile. I think as a mom, and juggling, and work and everything. I think to have something at your fingertips is convenient.

This positive *Relationship* with self seemed important to several participants actively using I-apps to improve their lifestyles. Most participants spoke of their *Relationships* as the primary reason for *sustaining* their behaviors. These relationships included relationships with providers, encouragement from friends, family, and peers. Interactions and feedback through these relationships served as motivators to keep working on improvement and seemed critical to the phases of *adopting* and *sustaining* (see Relationships for more information).

However, a busy young participant and mother of four young children explained there were tradeoffs when using I-apps to *sustain* lifestyle improvements and to make those lifestyle improvements habit. She failed to use all the functions available in a weight loss app and admitted,

I just don't mess with sometimes the recording of it. There are tradeoffs in terms of using the app.

I know what I'm supposed to do to make it a habit. I already know what I'm supposed to do to stay healthy, but it is the time for me. I only have so much time. It's the entering of the information. I only have so much time.

Later this same young participant spoke about gaining a significant amount of weight in the last 2 years and her inability to lose the extra weight.

### The Habituating Phase

*Habituating* is defined as making *mHealth Engagement* and *Self-regulation* a regular, unconscious practice or routine that would be hard to give up. Habit is defined as a repetitive behavior in the presence of stable contextual cues that improve the automaticity of the behavior, in this case, use of mHealth technology (i.e., wearables or I-apps) to improve lifestyle behavior. The timeline for habit formation is less clear. One

older participant suggested, “one week is not enough to change a habit.” In terms of reaching for technology in a habitual way, a participant in her 60s who stated that she was dealing effectively with the stress in her life by using a meditation app stated, “...it doesn’t matter whether I’m up, down, doesn’t matter. It’s what I do; it just became a part of what I do. I enjoy it.” Another younger participant stated, “Now, I’m kind of addicted, I don’t know. I feel better as well.” Another participant, a data analyst in her mid-50s with a sedentary job, talked about an I-app that vibrated and encouraged her to stand. She reported the “novelty” made her *adopt* the I-app, but after a while “you kinda fall a little bit into a habit. When it tells you to stand up...it kinda gets you thinking, so it helps.” And an older participant stated,

I think apps help make behavior a habit – they do help in that they are a tickler, that reminder to get out of your seat or to walk. Like the [wearable fitness tracker] that vibrates when you have been sitting too long, and it says get up and move. Even if I’m totally immersed in what I’m doing, I tend to get up and walk a bit. So, having that tickler on the app I think is really, is really, really useful.

Another participant struggling with “debilitating” anxiety and depression spoke about her desperation for relief and how she found an I-app suggested by peers on an online anxiety forum. She reported using it for “long, long streaks” and over “many days.” She recounted that during certain stressful months, she “was on it every single day.” She stated that now, several years later, she has some “tools to be able to deal. It is like an old friend I go back to. It’s a habit now and it’s a security.” Now she uses it when she walks, when she relaxes, and anytime she has stress in her life.



*Habituating* lifestyle improvements refers to making lifestyle improvements a regular, unconscious practice or routine that would be hard to give up. One participant discussed how she uses I-apps in an on-again, off-again manner because her lifestyle behaviors are now habit. This participant in her mid-60s commented,

Now cause when we talk about habit, the habits haven't changed in terms of lifestyle changes. But the use of the electronics sometimes changes. I don't use [mHealth tools] as frequently, and then somebody will say, 'oh, have you seen this new app?' And it's like, oh, I've got to try that. So, then you ended up trying it for a while, but it doesn't necessarily change my lifestyle habits. I mean, cause I'm still walking, I still watch what I eat.

Not all discussions about the unconsciousness of behavior were entirely about *habituating* the behavior; some were about *adopting* the behavior or the I-app. For example, a participant in her 40s eluded to the unconsciousness of *adopting* a behavior by stating that if she had a magic wand, she would just “change my brain...” and then wondered aloud if her brain “had something to do with habit, too.”

### The Disengaging Phase

*Disengaging* is defined as separating from or discontinuing the use of the I-app or the lifestyle behavior for any reason. During this phase of the process, participants might *disengage* from the *sustaining* phase or from the *habituating* phase. Two types of *disengaging* were identified in the data. Some participants disengaged and remained disengaged. These participants were identified as *disengaged* users ( $n = 3$ ). Other participants reported moving through this disengagement phase of the process and *re-adopting* I-apps. A few survivors reported *disengaging* from an I-app because they

wanted to adopt (*re-adopt*) a newer version or a different “more interesting” I-app. In other words, *re-adopting* was the reason for *disengaging*.

Participants provided several other reasons for *disengaging* with their I-apps including time, salience, efficacy, laziness, and issues with I-app *Functionality and Features*. For example, data entry was seen as “time-consuming,” “inconvenient,” and “annoying,” and a reason for disengaging. One participant in her late 60s complained about the “inconvenience” of having to download “all these things [apps] whenever you change your phone or your computer.” Another younger participant, who was caring for a disabled sister and working full time, explained her reason for *disengaging*, “I was doing better when I was using it [the exercise app], but I just got lazy.” She later noted, however, that she was now encouraged to start using her I-app again.

Several participants entered the *disengaging* phase because of issues of time. One young participant and mother of four who was also caring for her own aging mother stated, “it’s just the time issue, just not enough time for the app.” Another participant in her early 50s suggested that she *disengaged* because the app was “too much.” She needed “just quick meaningful this that, you know, that could be suggested” through the app. Additionally, some participants spoke about *disengaging* from some aspects of the app and while still using others. For example, a young participant talked about a wellness app and stated,

You enter your score every day and it has you look at 6 parts of your life. Like exercise, and sleep, and hydration, and nutrition, and self-care, and there’s one other. And every week there’s a little task. I did this in the fall. But where I fall short is recording. Getting on the app and putting in the score at the end of every day. Like that, it just felt like a task or a nuisance.

Only a few participants *disengaged* from lifestyle behaviors ( $n = 3$ ) and did not return. One participant described her experience in terms of feelings and accountability and stated,

...being accountable is a good thing unless you don't wanna be accountable. You say, 'Okay. I'm gonna do this.' Then you don't do very well and fall off the wagon. You start feeling...there's guilt. Then you start feeling like it...I was doing really well; then, I actually gained 3 pounds. I guess I have...I personally have an accountability problem. I don't like being accountable, and my phone is saying, 'Hey, you're terrible.' And that makes me feel bad.

Another *disengaged* participant in her early 60s provided a list when asked what caused her to stop using her I-app stating, "Time, boredom and annoyance would be the key reasons." She went on to complain about the "inconvenience, like if you change phones and you have to download all these [apps] and new things or if you change your computer or whatever."

However, several active users discussed *disengaging* and then *re-adopting* with another I-app in a cyclical manner. Efficacy, boredom, and the novelty of a new I-app were reasons for this turn-over. For example, a participant in her mid-50s who used multiple apps to improve multiple lifestyle behaviors stated,

When I download an app, I need that app to be precise. I need it to tell me exactly what I'm looking for because that's the reason I downloaded the app. And if it's not showing me or giving me what I need and what I'm looking for, I'm gonna get rid of the app...it has to be easy, quick, fast, and the information has to be understandable.

Often, participants spoke of hearing about a new I-app from family and friends and that conversation triggered their *disengagement* and *re-adoption* of a new I-app focused on the same lifestyle. For active users, *Relationships* were important in moving through the

*disengaging* phase, particularly when the *disengaging* and *re-adopting* phases were linked together, meaning the reason for *disengaging* was to *re-adopt* a new I-app.

And finally, several active users spoke of *disengaging* with part of the I-app's *Functionality and Features*. For example, a young participant stated, "I just don't mess with sometimes the recording of it [recording diet information about everything she eats]." As other participants noted earlier, the time it took for them to record the information was the concern.

### The Re-adopting Phase

The *re-adopting* process is defined as accepting and using mHealth solutions to improve lifestyle behaviors after having used them previously and having *disengaged*. The *re-adopting* phase of the process includes *re-adopting* the same app, *readopting* a different version of the app, or *re-adopting* a similar app. Several participants simply replaced one mHealth app for another, addressing the same lifestyle behavior, but preferring the novelty of some new features in the new app. For example, several participants talked about their new watches and the novel features in the watch that integrated with a wellness app on their phone. When they got their new watches, they started exercising and focusing on their diets again. They could follow the progress in each of these areas of lifestyle behavior from an app on their watch or an app on their phone.

Many participants suggested *re-adopting* was an ongoing process over time and over their life course. Most participants discussed the importance of awareness and consciousness of lifestyle choices in *re-adopting* lifestyle improvements. Seeing multiple

reminders of healthy lifestyle habits, including watching family and friends work on behavior change, helped participants not only *sustain* behavior change but also *re-adopting* behavior improvements after they had *disengaged*. One participant suggested speaking with others about lifestyle change was enough to initiate *re-adoption*. Again, *Relationships* with others was important when entering the *re-adopting* phase. For example, a participant in her early 60s spoke about multiple reminders and said, “Maybe it’s the reminders. Even you coming here today is gonna have me getting that [exercise tracker] back out and putting it on, and tracking everything. It really will...So, even this conversation will spur me to get back at it.” Another survivor in her early 40s spoke about re-adopting because of reminders and programs at work. She said, “I guess maybe getting more involved with the wellness [platform] thing at work, I thought more about trying to walk more again...I think just hearing it out there and being more involved with the group again. I think that makes you think more about it.”

Additionally, important relationship milestones (i.e., family wedding) often triggered the *re-adopting* phase of the process. For example, a participant spoke about re-adopting with the help of a friend and using an app associated with a nationally known weight loss system saying, “like a friend of mine who, our daughters were married the same month, and we were on this huge weight loss plan to fit into the mother of the bride dresses. We were walking like a ton, and we work together. So, it was like, you’re not going to eat that for lunch.” Another participant talked about the need for perseverance when re-adopting healthy behaviors. She had taken many different smoking cessation classes and had taken the same online course 3 different times. She finally quit. Another

older participant noted that change was on a continuum and that *re-adopting* was ongoing throughout life.

Another survivor spoke about life circumstances (i.e., daughter going to college, marriage problems, health concerns) causing debilitating anxiety. She stated, “I was really pretty ill. I mean, I couldn’t work for a while. About a month and a half.” She went on to talk about *re-adopting* the use of her “meditation app” to help her during this time.

### ***Concept 1 - mHealth Engagement***

The behavior of *mHealth Engagement* is defined as the extent (e.g., amount, frequency, duration, depth) of usage of mHealth interventions and includes the initial use or the *adoption* phase, *sustaining* use and lifestyle improvement, and finally *habituating* the use and lifestyle improvement. In addition, many participants discussed the use of other technologies and digital devices (i.e., fitness trackers, digital scales) that worked in conjunction with their I-apps. Data from these devices integrated with their I-apps and provided information to help them remain engaged. Therefore, *mHealth Engagement* for this study also included the collection of data about the participant from many different data collecting devices (i.e., heart rate, digital scales, GPS, step tracker) but integrated with the I-app. In addition, many participants spoke about mHealth in the context of a broader healthcare perspective which included the integration of data from the electronic health record (EHR) data. This broadened the definition and scope of engagement which may or may not be linked to lifestyle change behaviors. One participant summed up the broader idea by saying, “...if the electronic medical record could populate some of the information in the app, that would be nice. And it would be very interactive.” While

another participant stated, the integration of EHR data and wearable data was an “excellent idea” as long as providers had “something, a platform” to integrate everything with so to “have kind of a platform so that you could get your feedback.”

Participants actively engaged with I-apps supported *mHealth Engagement* with multiple different I-apps or those I-apps that supported many aspects of healthy behavior. For example, a participant actively engaged with I-apps said,

I think all those things, working on sleep, exercising, eating healthy food, together help. One thing I think is good is that they're [I-apps] are not just focusing on just exercise or what you're eating, but they're [I-apps] focusing on a lot of different factors. Some of it's about, why are you eating? - your attitudes. Why not just have a smaller serving and enjoy it? Why are you going beyond that? - mindfulness.

Participants wanted to be as healthy as they could be and overwhelmingly felt *mHealth Engagement* could improve well-being, particularly if the mHealth app supported greater provider communication and interaction. Moreover, the most frequently discussed concept was *Relationships* and the importance of communication and connection through *mHealth Engagement*. In sum, *mHealth Engagement* co-occurs with *Self-regulation* of lifestyle behaviors and involves the processes of *adopting*, *sustaining*, and *habituating*. Details of how the processes and the concepts of *Relationships* and *Functionality and Features* affect these processes are outlined below.

### ***Concept 2 - Self-regulation***

The concept of *Self-regulation* is defined by patterns participants used to improve their lifestyle behaviors to be healthier. However, in the case of self-medication to alleviate stress, these patterns may have been maladaptive. Therefore, these patterns

could be positive or negative. However, most participants in this study attempted to *Self-regulate* lifestyle behaviors by using mHealth interventions to help improve their health in a positive way. One participant stated, “we [survivors] just want to be healthy again.” This overarching sentiment was echoed by most participants. In their quest “to be healthy again,” participants recognized the importance of tracking health trends, setting and achieving goals, and the importance of feedback and accountability for *Self-regulation* through *mHealth Engagement*. For example, in a discussion on activity, a participant said,

It’s not only accountability, but it’s increasing activity and decreasing sedentary activity. I look for ways to say, ‘How can I be more active, even when I’m not out on a long walk?’ And it’s tracking it. So even things like walking when I’m on the phone.... walking in my house can really help a lot. [Tracking] so I can see the benefit.

Another participant, talking about diet, noted the overall importance of the tracking and the trend saying,

I think I’m someone who sometimes will have something like chocolate or ice cream when I’m stressed...But I’ve really been trying to track it. First of all, you recognize that 2 pieces of chocolate are lots...So you’re kind of more likely to say, ‘Okay, I’ve got to account for this.’ I think that’s helpful. But I also think...’Okay, things are a process. It’s not all going to be perfect.’

Many participants spoke of the importance of goals in *Self-regulation*. For example, one participant stated, “For me, it’s small, daily, achievable goals and being accountable to look at them.” While another participant talked about reaching her goal as a reward in and of itself saying “I mean, once you hit your goal for your steps, that was always exciting. It was an exciting thing.”



Feedback was important in the phases of *adopting* and *sustaining* behavior. The feedback could come from the I-app as well (i.e., achieving the step goal). Several participants suggested feedback could help them with *Self-regulating* particularly with *adopting* and *sustaining* I-app use for behavior change. When asked about what would really help in *sustaining* behavior change when using an I-app, one participant responded, “I mean, just to be encouraged or have some kind of feedback.” And another participant suggested, “So it’s kind of maybe that feedback, the education and feedback from the doctor.” Another participant stated, “a lot of times it’s just that kick in the butt, that little reminder like, hey, you need to go...you need to go. Because you get busy and forget...” And another participant discussed the importance of feedback as reinforcement for *Self-regulation*, stating, “If you don’t reinforce [what you have learned in class] then it is over. Did I go home and practice it? No. I mean once it is over...So there’s that kind of thing for the [mHealth app] ...the reinforcement, the feedback.” And another participant discussed the importance of feedback in-the-moment saying,

You know, you always want to do these things [improve health behaviors], but [mHealth apps] let you see really where you’re at, and whether you’re getting enough movement in a day. It also reminds you every hour to get up and move. If you’re in a sedentary job or working at a desk or something it’ll remind you.

Several participants spoke of accountability in terms of *Relationships* through their I-apps. One participant spoke about her daughters’ apps which were synced to hers stating, “So they can send me reminders. You haven’t been walking today, what’s going on? (laughing). And vice a versa, which is really kind of fun.” And another participant discussed how I-apps “supplemented” the “interconnectedness” with her accountability

partner and helped keep her motivated. Another participant said, “My daughter wanted one [a exercise tracker that integrates with an I-app], so I gave her one for Christmas. Then I thought it looked neat, so I got myself one... just the curiosity factor but also kinda the accountability thing.”

Additionally, *Self-regulation* includes conscious and unconscious processes. For example, *adopting* a new lifestyle behavior is a conscious process but making it a habit makes it unconscious. Several participants discussed this notion of unconscious cognitive process as habit. One stated,

I think apps help make behavior a habit – they do help in that they are a tickler, that reminder to get out of your seat or to walk. Like the [wearable fitness tracker] that vibrates when you have been sitting too long, and it says get up and move. Even if I’m totally immersed in what I’m doing, I tend to get up and walk a bit. So, having that tickler on the app I think is really, is really, really useful.

Another participant stated, “Oh, I definitely think making it a habit helps. I definitely do.”

Another participant wished she “had a magic wand, to somehow change my brain.” She wondered aloud if changing her brain “has something to do with habit too.” In talking about I-apps and making *Self-regulation* a habit, one participant spoke of I-apps providing an opportunity to “practice I [behavior improvement] and really get good at it.”

The major concern for all study participants in terms of lifestyle conditions amenable to *Self-regulation* was stress. Stress was mentioned as a concern for all study participants (see Table 7). Stress was a concern for participants throughout their survivorship period and sometimes led to “self-medicating” a different form of *Self-regulation*. This self-regulation behavior may have potentially harmful consequences.

Participants felt *Self-regulation* of stress was important to address, and several discussed their stressors while crying. With tears in her eyes, one participant stated, “Stress, stress is the big one...I tell people I feel like I’m a person who people have just picked pieces off of, you know? And there’s not many pieces left before I just crumble.” Another participant told detailed stories about caring for family members with chronic diseases, having to move, and weathering the termination of her long-term relationship while at the same time undergoing breast cancer treatment which was complicated by her own chronic diseases. She was weeping as she recounted that she felt like she had all these “losses” including the loss of who she was and that “the stress of it was overwhelming.” Later she spoke about drinking alcohol as a lifestyle behavior she might want to improve and shared, “I could most definitely drink less. I absolutely should. But I don’t. I just like, I don’t,” and began to cry harder. She continued through free-flowing tears, “I’m like, I could have less to drink. I don’t need to be drinking all this, and I’m just doing it because I’m-I’m masking, I’m I’m—I’m just kind of like-like, it’s like you don’t want to feel the pain, you don’t want to feel the hurt.” She reported being under the care of a mental health counselor and working on these concerns.

Several other participants spoke of the stress of dealing with sick family members, dying loved ones, and children with special needs or with mental illness. One participant spoke about choosing the family’s needs first - always choosing herself and her health last. This lack of self-care was a barrier for her to use mHealth technologies and to focus on lifestyle behavior change. Several participants were worried about weight gain which added to their stress. One participant lamented,

The parting words of my oncologist were ‘keep your weight down.’ But I gained a bunch of weight in the last year. And this is the first time I have felt like, ‘Uh oh,’ now I feel like a little...like I don't fricking want cancer to grow again because my body fat's up. So, this is really literally this year, the first time it's kind of messed with my head that way. I'm a little panicked about needing to lose this weight...

Most participants were focused on positive *Self-regulation* behaviors (i.e., increasing exercise, improving diet) while others engaged in negative *Self-regulation* behaviors (i.e., alcohol misuse). For example, several women admitted “self-medicating” or “numbing the pain” of the stress in their lives with alcohol.

### ***Concept 3 - Relationships***

*Relationships* was defined as connections between 2 or more persons, or a relationship with technology or with self. Participants discussed the importance of *Relationships* with family members, friends, peers, and with “the group” (i.e., survivorship groups, exercise groups). *Relationships* also included being “connected” to a smartphone (technology relationship), and the idea of relationship with self (i.e., lack of self-care, salience of experience to oneself). However, most discussions about *Relationships* involved communication and connection between the participant and other people. *Relationships* were important to the process of *Self-regulation* of lifestyle behaviors when *Engaged with mHealth*.

The *Relationships* concept linked to 2 phases of the mHESIA theory process, the phase of *adopting* and the phase of *sustaining*. In discussing *Relationships* and how relationships motivated the behavior of lifestyle improvement and I-app use, one participant in her 40s recounted,

It's the connection with people that helps. It's that synergy. I've been thinking about the synergy of us coming together. That creates more. So, I think about that even in life...It's like you get double the energy...the extra energy comes from another person somehow, from the combination of the 2 people.

### Relationships with Healthcare Providers

Participants spoke of the importance of connecting and communicating with healthcare providers through *mHealth Engagement*. They spoke of using telehealth, text messaging, push messaging, and email messaging to help them with accountability in *adopting* and *sustaining* healthy lifestyle behaviors. Easy and frequent interaction with “my provider,” meaning someone who knew them and their lifestyle goals, was key.

It brings that accountability [to the process] and for the people who need that little extra prod, so to speak, of getting active and being able to change ... it gives [my healthcare provider] an opportunity to provide you feedback, ‘I can see that you did blah, blah, blah last week and I think that's great.’

Several participants also spoke about communication within a relationship and what types of messaging and the tone of the messaging that was important to them. For example, one participant suggested,

The only thing, my only suggestion is that people don't feel like they're being, um, and obviously an app isn't gonna do this per se, but people don't feel like they're being ... don't feel like the finger is being wagged at them; you know what I mean?

Another participant concurred about the need for non-judgmental messaging and added,

The tone of [the messages] has to be kinda friendly and not threatening. Something well you know, just yeah you maybe gained weight a little more rapidly than you should. Think about what you had and think in what's happening. Kind of like a gentle, non-threatening, non-judgmental, no shaming [types of messaging is important].

Many participants discussed how healthcare providers could help them *sustain* their lifestyle behaviors using “ticklers,” “pings,” or “reminders” in the form of emails, texts, or push notifications. They felt such contact would “motivate” and “raise consciousness” about the behavior and help them be more accountable to themselves and to their healthcare providers.

Some participants reported feeling like they could be more honest in reporting and discussing behavior change using technology versus in a face-to-face conversation with their provider. For example, a participant, who also admitted to self-medicating with alcohol, suggested interacting with technology gave her more control and stated, “I can engage as much as I want and can disengage as much as I want, whenever I want.” She went on to discuss her depression and said,

there was quite a bit of time that I would not have gone to group ‘cause I would not have wanted to interact...but if I look at a screen, I don’t have to interact. I mean...in other words, nobody’s sitting on the other side of that...saying anything to me. Like I said, that’s not normal behaviors, but there are times...the darkest part of your life that you just couldn’t [interact]. But you could have possible gotten some help from a screen. Even if it was just to say, ‘This is normal.’ That would have been good.

Participants also spoke of using technology to be more honest with healthcare providers.

For example, a participant commented,

[people] don’t wanna act like they know nothing when they are face to face, but when they’re sitting in their own home and [using technology]...it’s like they can feel secure to say whatever they wanna say...like ‘I would never admit this face to face with you, but I don’t understand what all this means at all.’

She also talked about the importance of “accountability” and “personal commitment” but acknowledged the importance of “feedback into the doctors” using an app. Another participant talking about personal issues such as vaginal dryness and other sensitive topics stated,

without estrogen there’s gonna be a big problem. But, an app that’s asking you questions when you feel private and you don’t feel intimidated face to face with someone, actually you might be more likely to enter more truthful statements...If [the provider] were in the room, I might just have to let that go.

She went on to speak about how I-apps might help her with depression and gave the example of marking sad faces on an app versus going to visit a provider saying,

I’m doing fine, when you were really marking sad faces in an app on a daily basis. It might give a more realistic picture, and maybe if they didn’t even talk to you then, but the next time you came in for a checkup said, ‘it looks like you had more bad days than good days.’ Sometimes we don’t want to let our guard down, even when we’re the patient.

She also noted, “the longer you would use it [the I-app with faces] the more comprehensive all of the data would be. Give you a more complete picture of you, your habits, your trends.” Another younger participant who had struggled with depression and “drinking too much” admitted, “I was staying at home and crying from December to April. I was desolate.” In talking about possible solutions, she went on to suggest “if I had a big button on my computer that I could just click and get to the dietician, the nurse practitioner, or to my internal medicine doctor, or my family doctor, if I had a button, that would be easy.”

## Relationships with Family and Friends

*Relationships* were also important in using mHealth for lifestyle behavior improvement. Participants appreciated being able to be connected with family and friends within I-apps but wanted to be in control of the information shared. They reported that sharing online with a friend kept them motivated and made them “accountable.” One participant reported that working out with a workout buddy helped her be more accountable and helped her *habituate* her exercise behavior stating,

Just I think for me knowing there's someone waiting for me, I have to be there; I have to show up, it's helpful. Now I go 3 days a week with him but just seeing the progress. Now I feel like I'm probably in the best shape I've ever been in. It's totally different. Before where I did more cardio, running and elliptical stuff, now I lift when I work out with him. Now I'm kind of addicted. I don't know. I feel better as well.

Many participants spoke about the importance of family and friends in *sustaining* lifestyle behavior change, with one stating, “A lot of people who are closer to me know that I'm making these changes, and even a family friend I see when I'm in [town name redacted] always has fruit and vegetables out for me now.”

Some participants appreciated the aspect of competition with friends and family through competition technologies embedded in mHealth apps, provided they could control with whom they shared their data. Others spoke about comradery as a driving force that helped them *sustain* their behavior: “I think encouragement is always helpful. It's good. You know where you're at, and then I know in my [fitness tracker] also, people can have competitions during the week and things like that. So, I think it's always anything that could encourage you is helpful.”



Another participant agreed stating,

Competitions in the app are fine with me. I know that some weeks I might not be able to be the top person, but I think it's something that makes you think, 'Oh, I want to do better because the other people are doing better.' So yeah, it doesn't hurt, yeah? [It's the comradery] I think so. It's everybody trying to work on this together and encourage everybody else to be out there walking and doing stuff.

### Relationships with Technology

Participants spoke of *Relationships* with technology. For instance, one participant felt the *Relationship* with the technology increased accountability, "I think a lot of people, they're more accountable to somebody else versus themselves. Like, you'll make an excuse [to yourself], but if it's somebody else, you're more accountable. Or even the app where you're putting the information in, you're more accountable."

However, *Relationships* with technology and other digital devices were not perceived as positive in all cases. Some non-users spoke of their *Relationship* with technology, particularly smartphones and smartphone apps, as a negative factor in their lives. Two participants seemed to suggest that the always-on and instantly available nature of smartphones may have acted as an additional stressor in their lives. This seemed especially relevant within family member *Relationships*. One young participant regarded her smartphone "as the short-chain I live on....my family makes fun of me because I'm not reliable with my phone. They'll call me, and I don't answer. I think subconsciously I wanna be unreachable. I feel like I'm on a leash." She went on to describe a specific instance, "When they call me, and I'm in the grocery store, I'm like, 'For God's sakes, I'm buying the food to prepare for you to feed you, and you need to ask me this question

now?’ Like, ask someone else that’s in the house.” When asked about the role of mHealth in connecting with family and friends to stay healthy, another older participant said, “I don’t know. I’m kind of funny that way. I don’t like to be connected all the time. I like to be disconnected sometimes.”

### Relationship with Self

The dimension of *Relationship with self* manifested most often as a lack of self-care and a barrier to the processes of *adopting* and *sustaining*. The family comes first, and “not enough time for myself” were patterns identified by non-users. Details about the *Relationship* with self have been reported previously under the Process section.

### Variation in Patterns within the Relationships Concept

The most variation in the *Relationships* concept occurred around the phase of *adopting* I-apps. Some participants felt family and friends were most important in *adopting* I-apps for behavior change, and others felt healthcare providers, specifically doctors, were most important. Analysis of *Relationships* and *adopting* over demographics, lifestyle modification activity, and technology use failed to reveal any patterns. Some participants felt their friends would know “what worked.” One participant recounted, “I think I would probably rely more on my friends for information about [digital technologies]. Not to discount, you know, my doctor-Um, but probably one of my peers or at least someone who has used it and, you know is singing its praises.”

Other participants reported that the power of the group (i.e., group weight loss program) and having others “show me how to download and use the [weight loss program’s] app” was most effective when *adopting* an I-app. Other participants reported

that recommendations from a trusted healthcare professional would be most important to *adopting* and initiating I-app use and that if the technology was “from” or “supported by” their trusted institution, they would feel better about *adopting* the recommended technology. One participant, who had I-apps downloaded on her smartphone but was not using them, felt her “doctor” would be most important in motivating her to use mHealth technologies. When asked who would be most influential in motivating her to use mHealth apps to improve lifestyle behavior, she unequivocally remarked,

...my doctor, who I have these same conversations with, you know. I sit in his office with him and talk about my blood work. Well, okay, 'cause I can afford a concierge kind of doctor. I get to do that. But I am motivated to see those numbers get better next time I get blood work. 'Cause they were great when I was eating really well and a little bit younger, and more on top of things. Now I've slipped into this middle age, you know we're gonna hit you where it hurts kind of stuff is happening to my body, and I feel like, 'Oh sh#%.'

Another participant, in her 50s who engaged with several mHealth technologies to improve physical activity, diet, and stress, thought doctors were best suited to help breast cancer participants *adopt* I-app. She suggested,

If doctors initiated it [I-app suggestions], I think then the patient could take things home and work with them, with the app on their own. I don't think there's a lot of people who want to be in situations where they're not as healthy as they could be. I think sometimes they don't have the information, and I think we've kind of developed a culture where it's very hard to eat out and eat healthy. Especially as often as we are. Certain things like that are more difficult, so having the information very easily available, like in an app or information that just comes periodically can be very helpful.

#### ***Concept 4 - Functionality and Features***

The final concept identified in this study was *Functionality and Features*. The *Functionality and Features* of mHealth interventions were fundamental links to the processes of *adopting* and *sustaining mHealth Engagement*. *Features* are defined as components of the technology used by participants. *Functionality* refers to participants' interaction with the system, software, or hardware and interoperability between system components. The critical sentiment voiced by participants concerning *Functionality and Features* was that the I-app had "to work." One participant summed up this sentiment by stating:

When I download an app, I need that app to be precise. I need it to tell me exactly what I'm looking for because that's the reason I downloaded the app. And if it's not showing me or giving me what I need and what I'm looking for, I'm gonna get rid of the app...it has to be easy, quick, fast, and the information has to be understandable.

Participants discussed several dimensions of *Functionality and Features* of mHealth interventions that are important in *adopting* and *sustaining* the use of the technology. These dimensions included *content, personalization, usability, goals, feedback, integration, competition, and data security*. These dimensions linked to both *adopting and sustaining mHealth Engagement for Self-regulation* of lifestyle behaviors and seemed to be important to driving

Comments about mHealth intervention efficacy, user satisfaction, freedom from risk, and context were included under this concept. Comments about the quality of individual healthcare providers, or overall quality of healthcare systems were excluded from this concept. All participants indicated the need for simple, easy-to-use

functionality. Without simplicity and the ability to quickly access the information needed, participants were not interested in either *adopting* or *sustaining* use of mHealth interventions.

### Content

Most participants identified the importance of evidence-based (i.e., “trusted,” “from a trusted source”) content in their mHealth apps. One participant, a nurse, used the term “evidence-based.” Participants recognized that content and science change over time and wanted “up to date” content from trusted sources. They spoke about the need for expert nutritional knowledge and continuing education. One participant stated, “maybe if there was just a spot that said, healthy snack ideas, and it had healthy recipes, maybe it would be nice to have that on there. Simple ones, I don't like to cook, I just like to eat.” This same participant suggested embedding cooking classes into digital technology.

While clear, easy to understand introductory information was comforting in the beginning of their cancer survivorship journey, participants wanted the ability to do a “deeper dive into content” as they progressed. Several participants noted the importance of holistic content including a comprehensive educational component. One participant noted,

I think some of it is to have the components, you know, like a curriculum if you will, that's separate for a while. And then integrate like diet, exercise, mental health, stress. You know, in other words, you practice different pieces of it and then bring it together. Because one of the things that I found for me when I've done these programs, is that they'll touch on this, touch on this, touch on this, touch on this ... I never get good at any of it.

Another participant commented about the importance of monitoring, tracking, and learning, stating, “over time you’re learning.”

### Personalization

Another essential dimension of the *Functionality and Features* concept was *personalization*. Participants wanted to be able to personalize the *Features* of the intervention to them – to their disease process, their changing health over time, and to their in-the-moment needs. For example, several participants discussed different physical activity needs early in the survivorship process, and how these needs changed later along their care continuum. For example, a pre-set goal of 150 minutes of moderately vigorous exercise per week was identified as too much and “not realistic” for several participants. They wanted the exercise program to be *personalized* for them and reflect their current physical ability.

### Usability

Under the dimension of *usability*, participants identified aspects of effectiveness, efficiency, and satisfaction. Overall, participants wanted the technology “to work,” or to be effective. Participants relied on friends and family to help identify technologies that “worked” prior to *adoption*. Participants also wanted “easy-to-use,” “simple,” and “precise” technologies that would address their in-the-moment needs for information and education. In other words, they wanted efficient tools that worked. One participant suggested, “... [my phone] is always with me, so it’s really easy for me to look things up.” Easy access was key. Another participant concurred stating, “it has to be easy, quick, fast and the information has to be understandable.” Participants spoke of “annoying,”

“complicated,” and “confusing” technologies as barriers to use. One participant summed up the overall sentiment by stating, “When the technology works for you and you’re not working the technology, that’s what makes the difference...” For older participants, readability of small text on a smartphone was an issue, and several preferred to use tablet devices to access applications. Learnability was important; however, several participants noted that if the behavior was salient and the digital health technology was effective, they were willing to spend more time learning to use the technology. Participants discussed *mHealth Engagement* in terms of “relaxing,” “visual appealing,” “novel,” “pleasurable,” and the convenience of using the mHealth app to monitor lifestyle improvement (i.e., progress toward goal weight, steps per day). Several participants enjoyed haptic functionality (i.e., fitness tracker vibrates) as satisfying as it indicated completion of the daily goal. Another participant discussed the convenience of ordering a healthy salad from a local store through a diet app as being satisfying. A third participant described sounds included in an mHealth app as a satisfying feature stating,

[I] love that. I never thought that I would be into that at all, but it's really wonderful, and I can push on it, and it plays the rainfall. And [the host of the meditation app] has the little things she does every day, and then there's other [sounds] in the app that you can choose, like [to help with] sleep, or anxiety...

Participant satisfaction was an important pattern or attribute of the dimension usability.

### Goals

*Goals* was an important dimension under *Functionality and Features*. *Goal setting* and *goal monitoring* were important functionality for participants. Many participants wanted small attainable goals they could set and share with their providers.

One participant suggested, "...small, achievable goals and set a time period...2 weeks, see if I can do it. Yes, I did it. And then, set my new goals. And if you could see the goals and be reminded all the time that I have a goal for the day. And then other things don't crowd [working on the goal] out."

For goal monitoring, participants were interested in tracking their own progress but varied in their ideas about comparing themselves to others and to a standardized goal. Participants engaged with I-apps described the importance of comparing themselves to "people like me" and wanted to understand what the standardized goals were and where they were in comparison to these standardized measures. This was particularly evident when discussing the use of I-apps to track physical activity. Participants who had not *adopted* I-apps reported concerns when comparing themselves to others or a standardized measure. These non-users expressed concern that using color (red, yellow, green in the prototype app) might make people feel bad, particularly if they were in the red zone. And the high number of 150 min/wk physical activity seemed unattainable, "so why try."

### Feedback

Most participants identified the importance of *Feedback*, another dimension under *Functionality and Features*, for helping them improve their lifestyle behaviors. Frequent reminders in the form of emails, text messages, or push notifications would help participants keep their behavior change in the "front of their mind." Participants also talked about feedback "in-the-moment" and "at the point of need." One participant described the reminder she got from her watch when she had been sedentary too long. She said the trending and the vibrating buzz "lets you see really where you're at, and



whether you're getting enough movement in the day. It also reminds you every hour to get up and move, if you're in a sedentary job, or working at your desk or something it'll remind you." Another participant discussed the importance of having the right resources at the point of decision-making and pointed out that mHealth apps can do that. She pointed out that when eating out, her diet app provided "information on the better choice to make at that restaurant. Which is something I think is really hard, you can't figure out what's really that healthy, what's the best thing you could eat there."

*Tracking* and the ability to follow *trends* in their behaviors were also important feedback mechanisms identified by participants. One participant who did not use mHealth tools but was actively exercising even identified the importance of *feedback* from tracking trends stating, "When I first started with my trainer, I think he'd have me do crunches, pushups, and squats. Every 3 months we'd see how much more we can do each month. Something like that in an app, I think would help to see progress." Another participant discussed the need to track stress as she had struggled with depression and anxiety. She stated,

Sometimes it's all about those mini stressors that just pile up...it's every little pile that piles up and puts you in bed. [But if you could track] that your stress is starting to go up, you know, I mean I don't have that biomedical knowledge so that I could invent something like that, but it just seems to me...that the technologies are right there. I don't know if it is so much of an intervention as it is the tracking in the moment.

*Rewards* was another attribute under *the Feedback* dimension characterized as both intrinsic and extrinsic rewards. Participants discussed intrinsic rewards of novelty and pleasure. Novelty was important in *adopting* and *sustaining* mHealth use. Having a

pleasurable experience seemed more important in *sustaining* use than in *adopting*. Participants spoke about a pleasurable experience in terms of the visual appeal of the application, or feelings of accomplishment and gratitude at meeting exercise and diet goals for the day. Participants also discussed the importance of extrinsic rewards. One participant reported that her employer was giving \$50 gift cards to employees who met various health challenges (i.e., lose 5% of your body weight in 3 months). While other participants recounted the importance of less costly extrinsic rewards such as fireworks on the mHealth app screen when a step goal was met, or the haptic reward of the vibrating watch when diet and exercise goals were met at the end of the day.

### Integration

*Integration*, an important dimension of the *Functionality and Features* concept, was identified after the first few interviews. Participants continually discussed the idea of “integrating” mHealth applications with fitness tracking devices. One participant showed me a meditation app that integrated with her watch. As she correlated here breathing to the app feature, her watch buzzed gently to let her know she was doing it correctly. Another participant spoke about a sensor in her pillow, that integrated with her phone app, and when she would snore, the pillow sensor would vibrate and wake her up. Another participant suggested that “the provider needed to have something to integrate with. To have a system [that could provide feedback] ...and they [healthcare providers] have an integrated platform, they have some kind of an app which unobtrusively helps you keep track of things.” Other participants also discussed the importance of integrating their information, not only with other mHealth apps but also with the EHR. One

participant suggested that integrating the EHR data with her exercise and diet data would help her understand her health trends. She stated, “It would be great too, if you could have maybe your information from your electronic medical record put in [the application] as well. It would be helpful to see the trends.” Another participant commented, “I think it could be helpful...especially when you’re trying to work on preventative measures for different diseases...If you are trying to do that on your own, you’re collecting all of that information yourself.” Yet another participant talked about “some type of platform, that the provider could integrate” all her mHealth apps into a system and see information about her exercise, diet, sleep app and that her provider could see. However, she noted that she might feel “very annoyed if my provider [kept offering feedback]...my provider’s very holistic, [and] he would be calling me all the time and saying, why aren’t you walking? Or why are you gaining weight? That to me would be very annoying.”

Other participants thought integrating their data and comparing their information to their peers or “people like me” would help inspire them. One participant suggested personalizing her comparison group to women like her, her age, and other health concerns, and then feeding back information about “research suggests that you fall into this category and if you did 500 steps more, maybe you’ll lose 5 pounds faster because everyone in this study did. And it’s customized to me.” Another participant responded similarly desiring matches on her background, nationality, vital signs, and other health data. Participants also spoke about integrating these connected tools into their life in a more comprehensive manner. One participant suggested integrating audio content, specific to participants like her, into an audio report or a podcast so she could listen to it

while she was driving her children around.

### Data Security and Trust

*Data security and Trust*, a dimension of *Functionality and Features*, was a concern or disincentive mentioned by a few participants. One participant admitted that she did not use mHealth interventions; she only used her MyChart app because she was “fundamentally afraid of data breach.” However, most other participants discussed the importance of trusting the *content* of the mHealth app. They did not mention data breach or data loss. However, a participant who was a nurse wanted “evidence-based” information from “trusted organizations or my providers.”

### ***Subject Matter Experts and Participant Follow-up***

Six participants agreed to be re-contacted for a follow-up interview to validate findings. However, only 3 participants (19%) participated and reviewed the newly formed theory. Participants were shown the model of the theory throughout the discussion. Findings were discussed, and participants were asked about similarities and differences with their personal experience. Participants agreed that the model and the theory accurately captured their experiences, and no differences were expressed. All reiterated the importance of the *Relationships* concept, particularly with their healthcare providers. When asked if the participants had anything else to share, one stated: “survivors’ needs change over time and are different and may be different depending on the stage of your life.” She also suggested that depending on a survivor’s stage of life, the mHealth interventions may need to be different. This comment spoke to the need for *Functionality and Features* to be personalized to each survivor.

Additionally, to validate study findings, the substantive theory and study findings were shared with a clinical oncology nurse practitioner specializing in survivorship care, a Ph.D. nurse researcher with expertise in usability and technology development (PYY), and a Ph.D. nurse researcher with expertise in behavioral change (ST) to validate study results. All 3 subject matter experts agreed that study findings matched their clinical and research experiences.

## Chapter 5. Discussion

A qualitative grounded theory study was conducted to identify the basic sociotechnical processes explaining breast cancer survivors' use of mHealth interventions or I-apps for lifestyle behavior improvement. The constructivist grounded theory approach revealed a substantive theory called the Mobile Health Engagement and Self-regulation using Intervention Applications (mHESIA) theory. Two core concepts, *mHealth Engagement* and *Self-regulation*, seemingly interact in a synergistic way through the sociotechnical process comprised of five-phases: *adopting*, *sustaining*, *habituating*, *disengaging*, and *re-adopting*. Furthermore, *Relationships* and *Functionality and Features* formed important links in the sociotechnical process. These findings enhance our understanding of the relationship between *mHealth Engagement* and *Self-regulation* and highlight the importance of *Relationships* and *Functionality and Features* in influencing the overall process. These findings have not been previously reported and expand the theoretical knowledge base of mHealth intervention research which has previously been lacking.

This chapter positions the dissertation study findings in the context of the existing scientific knowledge base, related bodies of literature, and existing theories and models. Multiple facets of the mHESIA theory were easily identified in existing theoretical models and in the burgeoning literature. A comparison of concepts developed in the mHESIA theory with a broad synthesis of the literature from multiple, diverse fields,

identified similar concepts and relationships. These scientific fields and domains included behavioral science, social science, information technology systems science, psychology, and human-computer interaction. However, no existing theory was identified that captured the interaction of *mHealth Engagement* with *Self-regulation*, identified the process by which this occurs (*adopting, sustaining, habituating, disengaging, and re-adopting*), or the linkages that may affect the process (e.g., *Relationships, Functionality and Features*) in a comprehensive theory as does the mHESIA theory. Table 8 presents concepts, dimensions, and relationships between the mHESIA theory and other theories examined. The discussion below describes similarities and differences between extant theories and the mHESIA theory, study limitations, and future directions for exploration.

Table 8. mHESIA Theory Mapped to Existing Theories

mHESIA Concepts	mHESIA Dimensions/attributes or relationships	Existing Theory	Existing Theoretical Concepts
<i>Functionality and Features</i>	Usability/efficacy	UTAUT*	Performance Expectancy Perceived Usefulness
	Usability/ease-of-use	UTAUT	Effort Expectancy
	Data Security	UTAUT	Facilitating Conditions
	Personalization	UTAUT	Facilitating Conditions
		TTM†	Decisional Balance
	Content/salience	IBM‡	Salience of the Behavior
	Feedback/rewards - intrinsic	IBM	Attitude
		UTAUT2*	Hedonic Motivation
	Content/salience	FBM§	Motivation
	Usability/ ease-of-use	FBM	Skill Level
	Feedback/cueing	FBM	Prompts
	Goals and Goal setting	CSM	Action Plan
	Tracking and Trends	SCT	Self-regulation/Self-monitoring
	Personalization	SCT	Self-regulation/Self-standards
	Goal Setting and Monitoring	SCT	Self-regulation/Goals
	Goal Monitoring, Tracking and Trends	SCT	Mastery

continued

Table 8. continued

<i>Functionality and Features (cont.)</i>	Rewards/intrinsic	SCT	Self-incentives
	Content	DCBI¶	Content
	Usability	DCBI	Ease of use, Aesthetics
	Personalization	DCBI	Personalization
<i>mHealth Engagement</i>	Adopting Sustaining Habituating	FBM	Habit
	Adopting, Sustaining	CSM#	Action
<i>Relationships</i>	Provider	DCBI	Professional Support
	Sustaining Habituating	FBM	Environment
	Family, Friends, Peers, Group	UTAUT IBM	Social Influence Perceived Norms
	Self	IBM	Personal Agency, Attitudes, Experiences, Feelings
	Family, Friends, Peers, Group	DCBI	Guidance
	Peers	UTAUT	Social Influence
	Family, Friends, Peers, Group	SCT	Social Support
	Adopting	TTM	Precontemplation
	Types of Users	PAPM**	Unengaged, Disengaged, Not Acting
	Sustaining Adopting	TTM	Stage of Change -Action
<i>Self-regulation</i>	Habituating	IBM	Habit
	Adopting	CSM	Initiating
	Synergistic relationship	CCAM††	Carry-over Effect
	Habituating	CSM	Habit

\*UTAUT<sup>219</sup> & UTAUT2<sup>220</sup> indicates Unified Theory of Acceptance and Use of Technology, † TTM indicates Transtheoretical Model,<sup>221, 222</sup> ‡IBM indicates Integrated Behavioral Model,<sup>223</sup> § FBM indicates Fogg Behavior Model,<sup>224, 225</sup> || SCT indicates Social Cognitive Theory,<sup>226-228</sup> ¶ DCBI indicates Digital Behavior Change Interventions framework,<sup>229</sup> # CSM indicates Common-Sense Model of Self-regulation,<sup>230</sup> \*\* PAPM indicates Precaution Adopting Process Model,<sup>231</sup> †† CCAM indicates Compensatory Carry-over Action Model,<sup>232</sup>

## Comparisons to Existing Research Findings

### Literature on mHealth Engagement

Many concepts and dimensions as defined by participants in this study were identified within the literature. For example, The International Organization of Standards (ISO 9241-11:2018) defines usability as “the extent to which a product can be used by specific users to achieve specific goals with effectiveness, efficiency, and satisfaction in a



specified context of use.”<sup>233(online)</sup> Effectiveness is defined as task completion and goal achievement; efficiency is defined as resources – time and effort - expended to achieve goals; and satisfaction is defined as users comfort in achieving goals.<sup>234</sup> All elements of these definitions were identified by participants in this study (see *Functionality and Features/Usability*). Participants identified other key *Functionality and Features* when engaging with mHealth for behavior change, which were similar to findings identified in a recent systematic review of barriers and enablers of *mHealth Engagement*.<sup>235</sup>

Participants in this study spoke of the importance of easy-to-use mHealth apps and reliable information (i.e., content). Similarly, most preferred cueing or ongoing push notifications (i.e., communication), personalized information and messages, and *Relationships* with “their healthcare provider.” Also similar were findings about the different strategies and mHealth app functionality that might be necessary to engage non-users and to move current users from thinking about changing to actively working on change. Again, I-app personalization to the current health state of the participant was important both for mHealth use and lifestyle behavior change.

Many participants commented on the importance of satisfaction, “fun,” and *Relationships* when discussing the phases of *sustaining* and *habituating* mHealth use. Research by Hsiao and colleagues<sup>236</sup> in the social app domain supports these findings by identifying habit and user satisfaction as mediators between continued use and perceived usefulness, as well as perceived enjoyment and social ties. *Relationships* and social ties were also identified as an important antecedent to continued use.<sup>236</sup> Both online and face to face *Relationships* were important to participants when using mHealth to change

lifestyle behavior. Social support via online communities has been associated with behavior change success in smoking,<sup>237</sup> and weight loss.<sup>14</sup> Although significant, to date most health outcomes associated with online social support have been clinically modest.<sup>14</sup> More rigorous studies are needed to clearly elucidate the relationships between social support via social media and health behavior change. Beyond social support, research suggests the importance of peer *Relationships* in improving health communication, building self-regulatory skills, (i.e., goal setting, feedback), enhancing motivation, and improving engagement.<sup>238</sup> These findings parallel the findings of this study.

### ***Theoretical “Fit”***

#### **Process Models of Health Behavior**

Concepts from existing theoretical models mapped to concepts emerging from this research (see Table 8). Theoretical parallels can be drawn between the newly formed mHESIA theory and previously described process models of health behavior such as the Transtheoretical Model (TTM)<sup>221</sup> or the Precaution Adoption Process Model (PAPM).<sup>231</sup>,<sup>239</sup> For example, König and colleagues<sup>231</sup> used an adapted version of the PAPM to analyze 5 stages of change (unengaged, decided to act, decided not to act, acting, and disengaged) as they applied to adopting nutrition and fitness apps.<sup>231</sup> Participants were categorized based on these 5 stages. Similar to findings identified in this dissertation research, the dichotomy of users versus non-users was expanded. Non-users differed based on reasons for being non-users: unengaged (i.e., general lack of understanding of how to use apps), deciding not to act (i.e., fearful of data breach), and disengaged (i.e., “got lazy” and stopped using the app). As identified by König and colleagues,<sup>231</sup> and as

discussed further below, different mHealth features and strategies may be necessary to reach users based on their stage of *adoption*.

The TTM aligns with our current findings in that participants need different strategies when *adopting* or *sustaining* behavior change using mHealth interventions. These strategies are dependent upon several other factors including an individual's current state of readiness to change. For example, 6 participants were not using mHealth interventions to improve lifestyle behaviors. Fear of data breach, wanting to be "disconnected," and negative views of technology ("a leash") were mentioned as reasons they did not use mHealth interventions. Strategies to help them engage may be different from those needed for survivors who want to change but who have lower mHealth literacy or overall lack of knowledge (i.e., "I'd like to know how to use an app for exercise"). The TTM posits 6 stages of change (precontemplation, contemplation, preparation, action, maintenance, termination), 10 processes of change, decisional balance (pros and cons of change), and self-efficacy as important factors in behavior change. However, self-efficacy, also identified as an important concept in the Integrated Behavior Model (IBM) and Social Cognitive Theory (SCT), was not identified in the mHESIA theory. Self-efficacy is an internal mental process identifying a person's level of confidence in their ability to succeed. Bandura suggests that individuals guide their lives by beliefs of personal efficacy and that this perceived self-efficacy refers to a person's beliefs about their ability to perform actions necessary to attain a certain goal or effect.<sup>227</sup> Selection bias may have masked the identification of the concept as most participants had experience using I-apps to improve behavior. Additionally, as an internal

mental process, only perceived self-efficacy may be measured and was not evaluated in this study. Including measures of self-efficacy in future theory development work may add significantly to the mHESIA theory.

While the specific concept of self-efficacy was not identified in the mHESIA theory, sources of self-efficacy, as outlined by Bandura,<sup>227</sup> were identified. For example, most participants discussed the mastery of lifestyle behavior change. Mastery is an important source of self-efficacy. Several participants discussed the formation of habits and one discussed overcoming depression using an I-app for meditation. According to Bandura, such mastery strengthens self-efficacy beliefs.<sup>227</sup> Effort expenditure is another source of self-efficacy identified by Bandura<sup>227</sup> and identified in this research study. Goal attainment is partially determined by how hard one has to work. Bandura suggests the amount of effort expended affects one's perception of their capability to perform a task.<sup>227</sup> In other words, capability/ability and effort are interdependent determinants of performance. Participants in this dissertation research identified ease-of-use as a driver of I-app usability. Usability (*Functionality and Features*) influenced the process phases of adopting, sustaining, and habituating. Interestingly, however, if the behavior was salient to the participants and the participants knew the I-app "worked," they were willing to work a little harder to use the I-app. Finally, Bandura described the idea of vicarious experience as a source of self-efficacy.<sup>227</sup> Vicarious experience concerns the appraisal of one's abilities in relation to others. Normative perceptions of "people like me" were discussed by participants in this study, and a few participants discussed the idea of competition or collaboration with others in working toward a goal as a motivator.

Additionally, the concept of *Relationships* and the importance of *Relationships* in adopting, sustaining, and habituating was the most frequently discussed concept in this study. In sum, while the concept of self-efficacy or perceived self-efficacy was not directly identified (or measured) in this study, the antecedent sources of self-efficacy were identified by the participants.

The TTM helps explain the need for different processes for participants based on the stage of change. For example, different change processes may be necessary for those survivors just beginning to think about behavior change and I-app *adoption* versus survivors who are actively using I-apps for behavior change. The number of behaviors targeted for change may also be an important consideration as the mechanisms of change are not isolated to individual behaviors but may, in fact, be synergistic.<sup>240</sup> For example, participants may experience better outcomes when trying to improve both the behaviors of eating a healthy diet and increasing physical activity at the same time. The findings of this study identified a similar pattern in participants engaged with mHealth who were improving multiple lifestyle health behaviors. This multiple lifestyle engagement represents a departure from the TTM & PAPM but was eluded to in the Compensatory Carry-over Action Model and was identified in this dissertation study.

#### Compensatory Carry-over Action Model

I-apps may help survivors improve multiple lifestyle behaviors concurrently. Prior research suggests that multiple health behavior changes occur through shared motivational mechanisms (the carry-over effect).<sup>240</sup> To this author's knowledge, this dissertation study is the first to report that the carry-over effect (synergy between

*mHealth Engagement and Self-regulation*) can occur between the behavior of *mHealth Engagement and Self-regulation* of lifestyle behavior improvement.

In addition, others have suggested the importance of this carry-over effect across lifestyle behaviors but have not explicated a mechanism for the effect.<sup>232, 240</sup> Patterns identified in this dissertation research may offer insight into such a mechanism, namely the linkages of *Relationships* and the *Functionality and Features* of the mHealth intervention to the sociotechnical processes of *adopting* and *sustaining*. The carry-over effect has been described for different co-occurring lifestyle (i.e., diet and exercise), but not for *mHealth Engagement* (I-app use) and *Self-regulation* of lifestyles (i.e., diet). The mHESIA theory developed in this study offers new insights as well as insights into the mechanism of action missing from the carry-over effect in the CCAM.

The carry-over effect, described in the Compensatory Carry-over Action Model (CCAM),<sup>232</sup> may be particularly important when addressing 2 of the major health concerns of breast cancer survivors: stress and weight, specifically diet. The Compensatory Carry-over Action model suggests that different health behaviors and the mechanisms underpinning the behaviors may be interrelated and thus capable of influencing each other.<sup>232</sup> Results from a recent double-blinded, cross-over study using the CCAM found that breast cancer survivors with stress and a history of depression had metabolically challenged responses to fat in their diet compared to survivors without such stress and depression.<sup>241</sup> This poor physiological response promoted inflammation and atherogenic vascular changes.<sup>241</sup> These results underscore the importance of understanding how mHealth interventions might meet the needs of breast cancer

survivors who have significantly increased risks of depression and poor health outcomes with weight gain. More research is needed to understand these mechanisms of action. For breast cancer survivors, stress and weight may be important lifestyle behaviors to target when developing new mHealth interventions.

### Integrated Behavior Model

Concepts of the theory developed in this study aligned with those identified in the Integrated Behavioral Model (IBM),<sup>223</sup> which contains theoretical concepts from the Theory of Planned Behavior,<sup>223</sup> Theory of Reasoned Action,<sup>223</sup> and Bandura's seminal work on self-efficacy.<sup>227</sup> Under the *Functionality and Features* concept, many participants discussed the importance of content. Participants wanted the content to be provided from a trusted source and the information to be trustworthy and recent. Participants also suggested mHealth intervention features to support new knowledge delivery so they could continue to keep up with new research into lifestyle behaviors. The IBM parallels this content dimension within the knowledge concept. For example, knowledge about the goal behavior (e.g., 150 minutes of vigorous physical activity a week, 5 servings of fruit and vegetables a day) is necessary before you can have Behavioral Intent or Behavior (IBM concepts) change. IBM theorists argue that knowledge is necessary to perform the skill.<sup>242</sup> However, health behavior change is not dependent on the provision of knowledge if patients already have the knowledge. In these cases, improved knowledge only slightly improves healthy behavior.<sup>243</sup> Personalization of mHealth interventions based on knowledge and information may be an important consideration for mHealth intervention developers. For example, a non-user study

participant suggested a need for videos of cooking classes. Such functionality might not be important for every breast cancer survivor, but improved cooking knowledge might significantly improve this participant's *adoption* of an I-app. Similarly, physical activity measurements could be collected via an accelerometer and heart rate monitor tethered to the smartphone. The information could be uploaded and viewed by a health coach, and weekly goals could be individualized for that particular individual. In each of these scenarios the patient would be more engaged with their care and information would be individualized based on their level of knowledge.

The IBM concept of perceived norms was also mirrored in these dissertation findings. For example, participants discussed the importance of peer *Relationships* in both their decisions to *adopt* I-apps for lifestyle behavior change and to *sustain* the behaviors. This importance of the *Relationships* concept maps to the IBM theoretical concept of perceived norms. Perceived norms are the beliefs, expectations, and actions of others and reflect social pressure one feels to perform a behavior. What others think, and what others do, influence a person's behavior. Many study participants suggested that mHealth apps might improve behavior by connecting family members or friends in a social network designed to encourage group exercise goals or to share healthy eating recipes. The IBM theory suggests that perceived norms directly influence intention to perform a behavior which mediates active behavior engagement. Similarly, *Relationships* to family, friends, and the group influence adoption and sustained use (*mHealth Engagement*) of I-apps for lifestyle behavior *Self-regulation*.



### The Common-Sense Model of Self-regulation

The Common-Sense Model of Self-regulation (CSM) is a framework explicating how patients navigate illness threats, from perception to action.<sup>230</sup> CSM describes variables important to treatment adherence and other behaviors in managing health threats. Like our newly developed substantive theory, the CSM describes a process with concepts similar to concepts found in our research.

Briefly, the CSM suggests prior experiences, known as prototypes (prototypical self), describe the normal self and are important in initiating actions. The CSM posits that deviations from the prototypical self (e.g., diagnosis of cancer) threaten the self and activate a new representation.<sup>230</sup> These representations and prototypes have dimensions in 5 domains: 1) identity, a name, and perceptions of the condition; 2) time-line, perceived duration; 3) consequence, physical, cognitive, social disturbance; 4) causes; and 5) control, self-control versus health provider.<sup>230</sup> These same 5 domains or variables also describe treatment representations. The CSM has theoretical roots in the Health Belief Model; however, the CSM suggests that prior experiences are important antecedents to patients' beliefs and more significantly, patients' actions. For example, a patient's prior experience with illness and treatments is important in seeking help or treatment (action). While participants in our study did not describe prior experiences with illness, they did describe prior experiences with technology as important in *adopting* and *sustaining* mHealth use (action). Additionally, the CSM framework recognizes that many representations and their resultant behaviors occur unconsciously.<sup>244</sup> CSM researchers recently identified the importance of *habit* as a factor in successful behavior change,<sup>245,</sup><sup>246</sup> which is similar to the findings in this dissertation study.

CSM stresses the importance of an “Action Plan” or a specific goal including place, time, and expectations as to outcomes. *Goal setting* functionality within mHealth apps was an important function for participants in the current study and parallels the “action planning” in the CSM. Moreover, CSM researchers recognize that initiating lifestyle changes and *habituating* such behaviors may be more complex than testing blood glucose regularly or taking asthma medication each day.<sup>230</sup> For example, these researchers identified that infrequent, static assessment fails to capture longitudinal, in context, changes associated with the complexity of lifestyle behavior change.<sup>230</sup> Current cross-sectional assessment approaches act as a barrier to scientific discovery. mHealth interventions have the potential to address this barrier by collecting contextualized data, in the moment, and over time.

#### Self-regulation in the Literature

In the professional psychological and health behavior literature, *Self-regulation* is defined as the ability to regulate or moderate behavior toward a goal with dimensions of behavioral, psychological, and physiological input as important to the process of changing lifestyles.<sup>247</sup> *Self-regulation* includes planning, self-monitoring, self-evaluating, and implementing specific behaviors toward long-term objectives and goals.<sup>248</sup> Additionally, *Self-regulation* includes conscious and unconscious cognitive, physiological, and neurological dimensions as well as social, cultural, and organizational dimensions.<sup>248</sup> In this study participants discussed the conscious and unconscious processes associated with *Self-regulation*. *Habituating* was identified as an unconscious cognitive process. However, physiological and neurological dimensions were not

identified in this study. The importance of the social and cultural aspects of *Self-regulations* was evident in the frequent references participants made about their *Relationships*. *Relationships* with family, friends, peers, and the group were important in the overall process identified in the mHESIA theory, but particularly in the phases of *adopting* and *sustaining*.

*Self-regulation* and self-management are often used synonymously. However, for this dissertation research, *Self-regulation* and self-management are differentiated in that self-management focuses on the management of chronic illness and the symptoms and treatments associated with the disease.<sup>249</sup> *Self-regulation* concerns the holistic self, including the regulation of both disease and health processes. Researchers argue that self-management draws on *Self-regulation* processes to engage in care for a chronic condition, and *Self-regulation* acts as a base on which to build self-management education and skills.<sup>249</sup>

Knowledge of behavior is an important antecedent to *Self-regulation* as is self-efficacy or the belief that one can perform the intended behavior (see TTM). The Social Cognitive Theory also underscores the importance of self-efficacy.

### The Social Cognitive Theory

The Social Cognitive Theory (SCT)<sup>177, 228, 250</sup> first proposed by Bandura in 1986,<sup>250</sup> is a common behavior change theory used in the design of interventions to manage chronic health conditions. The SCT posits interventions should help individuals develop a sense of self-efficacy in specific behaviors (i.e., diet, exercise). The SCT continues by suggesting improved self-efficacy increases expectations of success and

improved use of self-regulatory skills resulting in improved behaviors.<sup>227</sup> As discussed above, the mHESIA theory did not identify the concept of self-efficacy but did identify many sources of self-efficacy as important in the overall model. The mHESIA theory also differed from the SCT in the definition of the concept of *Self-regulation*. The SCT breaks self-regulation into 3 components: self-monitoring, self-judgment, and self-evaluation.<sup>226, 250</sup> Bandura suggests that self-regulatory systems mediate the effects of most external influences and are the basis of purposeful action.<sup>226</sup> These self-regulatory skills are echoed in the findings of this dissertation research and include self-monitoring (*tracking and trends*), setting self-standards (*app personalization*), goals (*goal setting and goal monitoring*), mastery (*goal monitoring, tracking, and trends*), and self-incentives (*intrinsic rewards*).

Furthermore, SCT suggests social support (*Relationships*) not only improves the initiation of behavior change (*adopting*) but also improves maintenance of behavior change (*sustaining*). One research study tested and validated the SCT using a web-based physical activity, nutrition, and weight loss intervention in an overweight and obese, but otherwise healthy population.<sup>251</sup> The SCT theoretical concepts and relationships were validated in this new context using longitudinal, latent variable, structured equation modeling.<sup>251</sup> Findings from this qualitative dissertation work underscore the importance of the social support concept (*Relationships*) identified in the SCT. In addition to social support identified in both the mHESIA theory and the SCT, participants in this dissertation study discussed the importance of professional support or their *Relationships* with their healthcare providers.

The established benefits of effective patient-provider *Relationships*, specifically patient-provider communication, include improved chronic disease management, improved physical health, and better health-related quality of life (QoL).<sup>252</sup> Results reported in a Cochrane review demonstrated the importance of communication in significantly improving immunization rates, with all types of reminders effective in all types of practice settings.<sup>253</sup> In another, high-quality randomized control trial, mobile phone messaging support for smoking cessation, significantly increased quit rates.<sup>254</sup> Thus, improved patient-provider relationships using mHealth may improve health outcomes and QoL through behavior change.<sup>255</sup> These findings parallel those of this dissertation research in which participants reported on the importance of the patient-provider relationship and spoke of ways to improve communications and the relationship. For example, goal-directed tailored texts from providers may remind and encourage survivors to meet their physical activity goals for the day. Encouraging messages from providers may also increase adherence to a healthy diet. Another example of how this might be operationalized concerns push messages from a health coach, an idea suggested by several study participants.

### The Fogg Behavior Model

The Fogg Behavior Model (FBM) suggests that behavior happens when motivation, ability, and a prompt come together in the same moment.<sup>224</sup> The “core motivators” include sensation (pleasure/pain), anticipation (hope/fear), and belonging (acceptance/rejection).<sup>225</sup> Fogg suggests that high motivation enables individuals to “do hard things” and motivation and ability are related in a “compensatory” manner.<sup>224</sup> The

model identifies 3 paths to increasing ability: increase skills needed for the target behavior, provide tools or resources, and finally, the easiest, reducing the size of the target behavior to make it easier to do.<sup>224</sup> Fogg describes this scaling back as taking tiny steps to create “tiny habits.”<sup>225</sup> Furthermore, changing tiny behaviors creates “success momentum” (tiny changes lead to increased confidence in a person’s ability to create good habits in the future, and tiny changes in one area of life lead to other positive changes in your life).<sup>225</sup> Fogg argues that making tiny changes prevents the need for tapping into willpower and motivation.<sup>225</sup>

Patterns identified in this dissertation study were similar to arguments posited by Fogg. For example, several participants discussed tradeoffs between learnability, time, efficacy, and salience in *adopting* and *sustaining* mHealth intervention use. If the salience of the behavior was in alignment with the efficacy of the intervention, participants were willing to take more time and expend more effort (ease of use) to use the mHealth app. The FBM also identified the importance of environment and *Relationships* in *sustaining* and *habituating* behavior.<sup>225</sup> A final concept of the FBM that mirrored findings in the mHESIA theory was the notion of prompts. Prompts are external or internal cues and as identified by the FBM include facilitator prompts (good for highly motivated individuals who lack skill), signaling prompts (a reminder for individuals with skill and motivation) and spark prompts (designed to address a motivational element). Study participants validated the importance of prompts in discussing cueing and the different types of “reminders” or “ticklers” as being important to not only *adopting* mHealth interventions for lifestyle behavior improvements but also *sustaining* use of such interventions.

However, conditional aspects of prompts (i.e., skill level, motivational level) identified by the FBM were not measured or identified in this research study.

Work from the Fogg lab focuses on behavior design (i.e., mHealth, telehealth, gaming) and on simplicity of the target behavior to increase ability.<sup>225</sup> Fogg describes simplicity as a function of the scarcest resource in the moment (i.e., time, money). Again, participants supported this idea. They spoke of the need for *Functionality and Features* that were “easy-to-use,” efficient, and capable of delivering what they needed “quickly, precisely” and “in the moment of need.” Many participants described “time” as their most limited resource and lack of time as a barrier to behavior change and mHealth intervention use.

#### Further Support of the *Relationships* Concept

Street and colleagues<sup>256</sup> identified 7 patient-provider communication and relationship pathways to improve health outcomes in cancer patients — access to needed care, increased patient knowledge and shared understanding, enhanced therapeutic alliance, enhanced emotional self-management, activated social support and advocacy resources, increased quality of decision making, and enabled patient agency.<sup>256</sup> Study participants in this dissertation research discussed 6 of the 7 pathways, with the exception being access to needed care.

Grounded theory work by Pozzar and Berry<sup>257</sup> among women with ovarian cancer also identified the importance of the patient-provider relationship, specifically compassion, accessibility, and support in influencing experiences and decisions across the cancer survivorship continuum. Similarly, participants in this dissertation study

voiced the importance of tone of messages (i.e., positive) and frequency of interaction with providers but spoke little of accessibility. However, participants in both studies voiced the importance of receiving emotional and practical support throughout survivorship care. Survivors in both studies also reported that this support emanated from many different people including, family, friends, peers, healthcare providers, and other cancer survivors (i.e., *Relationships*). Additionally, survivors in both studies were interested in hearing from and interacting with survivors “like me” in terms of age, stage of cancer diagnosis, and goals. Hence, aligning demographic characteristics may be important as may be personalization in sharing of data when building mHealth interventions.

While communication and *Relationships* between patients and providers continue to be identified as important, the differences and similarities between face-to-face and online communication have yet to be rigorously investigated. Further research is needed to establish the non-inferiority of mHealth communication in all areas of a mHealth intervention. Research is also needed to identify the most efficacious way for providers to communicate (i.e., text, push notification, email), and the frequency, duration, and content needed for each phase of the behavior change process (*adopting*, *sustaining*, and *habituating*). Additionally, communication and *Relationships* while learning new content or skills (i.e., cognitive behavior therapy to manage stress and anxiety) may be different than the type of communication and *Relationships* needed to support survivors in *adopting* and *sustaining* a new exercise plan. Much research is needed in the area of



online and mHealth patient-provider *Relationships* and how these *Relationships* can help improve health outcomes.

### Information Systems Theories

Concepts from the Unified Theory of Acceptance and Use of Technology (UTAUT<sup>219</sup> & UTAUT2<sup>220</sup>), which help predict acceptance and use of technology, also map to the findings of this study. In the field of systems engineering and information science, the term acceptance means *behavioral intent*: a well-established predictor of *use*.<sup>258-260</sup> UTAUT proposes relationships affecting a person's intent to use technology as well as the actual *use* of technology.<sup>261</sup> UTAUT was inductively developed from 8 theories from various scientific domains, including information systems engineering, psychology, and sociology.<sup>261</sup> Some of these theories are familiar to the behavior change community and include the Theory of Reasoned Action, Theory of Planned Behavior, Motivational Model, and the Social Cognitive Theory. UTAUT consists of 4 concepts influencing the use of technology: Performance Expectancy – perceived usefulness, Effort Expectancy – ease of use, Social Influence – others perceived opinions about the behavior, and Facilitating Conditions – functional, environmental, or organizational facilitators or barriers to use.<sup>261</sup> The theory describes 4 moderators (age, gender, experience, and voluntariness). The *Relationships* concept identified in this dissertation research maps directly to the Social Influence concept of UTAUT. Participants expressed that their peers' recommendations would be important in *adopting* and *sustaining* use of an I-app for lifestyle behavior improvement. Additionally, under the *Functionality and Features* concept, many participants expressed the need for “simple, easy to use apps that

worked.” Such suggestions align with the concepts of Performance and Effort Expectancy in the UTAUT model. Another similar dimension important to participants was interoperability to enhance communication and information exchange between the electronic health record and the mHealth app to improve communication between the provider and the survivor. Participants felt real-time, two-way communication was important for accountability, goal setting, encouraging progress, and overall support to *sustain* behavior change. Participants also noted the importance of understanding the information displayed on graphs and within the text of the mHealth app (eHealth literacy). While these were all dimensions of the *Functionality and Features* concept, they mapped directly to the UTAUT concept of Facilitating Conditions.

UTAUT2 expanded the original model to the consumer context and included 3 additional concepts: hedonic motivation, price value, and habit, which focused on the intrinsic value or intrinsic motivation of the technology. Intrinsic motivation suggests that individuals (i.e., survivors) perform certain activity for the activity itself, to experience pleasure and satisfaction inherent to the activity.<sup>262</sup> Hedonic motivation, addressing the affective aspect of use, is considered one of the most important variables in the UTAUT2 model.<sup>263</sup> Hedonic motivation concerns the fun and pleasure of using technology and is an important and strong predictor of technology acceptance and use.<sup>263, 264</sup> In the current study, several participants spoke of the importance of intrinsic rewards, ease of use, and the “fun” of using mHealth for lifestyle behavior change. These dimensions were identified under the *Functionality and Features* concept. Similarly, UTAUT2 also included the habit concept.

As discussed previously under the Fogg model, a few study participants discussed the formation of habits both in terms of using mHealth apps and in forming lasting lifestyle behavior change. Traditional approaches to habit formation have relied on learned behaviors driven by stimulus (cues)-response (automatic behavior) associations.<sup>265</sup> Research has begun to evaluate mHealth functions that support habit formation in mHealth apps<sup>266</sup> and online gaming.<sup>267</sup>

#### The Digital Behavior Change Interventions framework

Digital behavior change interventions (DCBIs) are interventions that use digital technologies (i.e., mHealth, fitness trackers) to help initiate and support behavior change to improve health and wellness.<sup>268</sup> mHealth is a type of DCBI. In accordance with the DCBI framework, engagement is vital for effectiveness and has been conceptualized in terms of experience and behavior while integrating the context of use (setting and population), the targeted behavior (i.e., diet, exercise), and the DCBI itself (content and delivery mode).<sup>269</sup> Researchers developed a conceptualization of DCBI engagement and also developed the DCBI framework through qualitative analysis of 117 articles using critical interpretive synthesis; a method used to develop theory.<sup>229</sup> Attributes important to the engagement concept included affect, attention, interest, amount, depth, duration, and frequency.<sup>270</sup> The mHESIA theory incorporates many of these same concepts.

The DCBI conceptual framework suggests that the concepts of delivery and content directly influence intervention use and that the intervention, in turn, influences engagement.<sup>270</sup> The concept context also influences engagement. Attributes of delivery map to attributes and concepts in the mHESIA theory and include aesthetics/design

(*pleasurable*), ease of use (*easy-to-use*), control features (*personalization*), guidance (*Relationships*), mode of delivery, novelty (*novelty*), message tone (*positive messaging*), personalization (*personalization*), and professional support (*Relationships*).<sup>270</sup> Many of these attributes were identified in this study under dimensions of the *Functionality and Features* concept. Professional support and guidance in the DBCI framework paralleled the patient-provider *Relationships* dimension in the newly developed substantive theory. However, the attributes of complexity, challenge, and narrative were not mentioned by participants in this dissertation study.

Similarly, the content concept of the DCBI framework included behavioral change techniques as attributes: feedback, goal setting, reminders, rewards, self-monitoring, and social support features.<sup>270</sup> These same dimensions were also identified in the mHESIA theory under the *Functionality and Features* concept. The context concept included the dimensions of population and setting. Population included 3 attributes: demographics (age, race, ethnicity), physical, and psychological (experience, mental health, motivation, self-efficacy). The setting dimension encompassed social and physical place attributes. Social attributes included social norms, cultural norms, social cues, and physical attributes included access, healthcare systems, policies, and time.

The DBCI framework suggests that the mechanism of action might be through direct or indirect influences on engagement, and the target behavior itself might directly influence engagement through a positive feedback loop.<sup>270</sup> The substantive theory developed in this study, the mHESIA theory, identified this process but added that the feedback loop suggested a synergistic effect of *mHealth Engagement* on *Self-regulation*.

DCBIs merge digital monitoring technology with health, healthcare, living, and society to enhance the efficiency of healthcare delivery and create a more individualized experience over time<sup>271</sup> as opposed to the episodic sick-care model of traditional healthcare. DCBIs use information and communication technology to solve health concerns of patients often in real-time. mHealth, a form of DBCI, can integrate EHR, telemedicine, email, text messages, wearable devices, and many different remote monitoring sensors to offer a complete picture of the participant over time. The ability to interact with participants with greater frequency may be the key to improving lifestyle behaviors as participants most frequently spoke about the importance of their *Relationships* in the *Self-regulation* of lifestyle behaviors.

In summary, many concepts identified in other theories emerged as concepts in the mHESIA theory. However, no single, extant theory included all the concepts, relationships, dimensions, and attributes identified in the mHESIA theory. The concept of *Relationships* was identified most frequently and by all study participants. The importance of the concept of *Relationships* was not identified in other theories; however, it was identified. And finally, self-efficacy, arguably one of the most often identified concepts in behavior change, was not identified as part of the mHESIA theory. However, the sources of self-efficacy, as identified by Bandura,<sup>227</sup> did emerge as part of the mHESIA theory.

### ***Study Limitations***

Several limitations of this dissertation work are noteworthy. First, the small sample size limits the study findings to breast cancer survivors in the Midwest who are

Non-Hispanic, white, well-educated women. As with most grounded theory studies, the findings of this study are not meant to be generalizable but instead offer an opportunity to reveal concepts important to these breast cancer survivors. The goal is to offer a contextualized understanding of the breast cancer survivors' experience as they engage with mHealth interventions to improve lifestyle behaviors. Because we were interested in uncovering the core process used by breast cancer survivors when employing technology to improve lifestyle behaviors, the participant pool was narrowly focused. We actively sought survivors with experience using mHealth interventions to change lifestyle behavior. This narrow focus may have biased the findings. Additionally, our sample of participants was local to the geographical area.

A second limitation of this study involved the *Relationship* concept. *Relationships* involve 2 parties. Including healthcare families and healthcare providers as participants would have offered a different perspective of mHealth engagement needs. A recent systematic review investigating factors determining success and failure of mHealth interventions identified workflow, face-to-face communication, and clinical process alignment in addition to patient-centered needs as important considerations for intervention success.<sup>272</sup> Several of the participants in our study echoed similar concerns suggesting mHealth app integration into current healthcare workflows might be difficult. mHealth developers and researchers would be well served to understand these factors and needs in addition to the patient-centered needs presented in this dissertation. Most participants in this study also voiced the importance of family and friends in *initiating* and *sustaining mHealth Engagement* and lifestyle behavior change. The perspectives of

the friends and family members were not included in this study. Understanding the perspectives of family, friends, health care providers, and others offer an opportunity for future qualitative research.

Similarly, we did not include healthcare information technologists' perspectives in this study. mHealth technology integration into healthcare computer systems requires significant fiscal and human support. This research focused on the acceptance of mHealth technology from a patient-centric point of view. For mHealth technologies to be successful, several other determinants are important. For example, risks associated with information integration and data safety may be important determinates to evaluate. The costs of such integration should also be considered in their financial return on investment calculations. However, we recognize the importance of this broader perspective, particularly as it relates to the design, development, integration, and implementation of patient-centered technology into a healthcare technology ecosystem. One cannot occur without the other.

Another limitation of this study involved the process phases of *disengagement* and *re-adoption*. Evidence in the data suggests these phases occur not only with *disengaged* users but also active users. While these specific phases did not directly relate to the research study question, they did emerge from the analysis process. *Disengaging* and *re-adopting* may be key to guiding the development of I-apps that prevent the loss of participants from *mHealth Engagement*. Further research is necessary to explore these phases of the process and to understand the phenomena fully. For example, more research

is needed to understand under what conditions, with whom, and in which contexts *disengaging* and *re-adopting* take place.

Finally, confirmability, an aspect of trustworthiness, was limited. When using grounded theory methods, researchers have considerable agency in interpreting the data. Such agency can challenge research findings. To address study rigor and trustworthiness in the findings, we adapted methods from Chiovitti and Piran<sup>216</sup> and Lincoln and Guba<sup>217</sup> in both the study design and the study methods. However, because this work was conducted in partial fulfillment of my doctoral degree, I was the primary researcher collecting, analyzing, and interpreting the data. The possibility exists that another researcher analyzing the same data could reach different conclusions. To address this limitation, analysis processes and findings were routinely shared with the dissertation committee members as described in the methods section.

### ***Future Directions for the mHESIA Theory***

The mHESIA theory developed in this study offers preliminary theoretical underpinnings for research and development of I-apps focused on lifestyle behavior improvement in breast cancer survivors. However, this initial substantive theory needs to be studied and validated. The mHESIA theory may offer insights for researchers and mHealth developers to explore. For example, enhancing patient-provider *Relationships* using varied mHealth communication technologies or quantifying the *Functionality and Features* that are most capable of improving the synergistic process of *adopting* and *sustaining* offer new areas for exploration. However, this new theory has yet to be tested. While many of the same concepts and relationships have been identified in the well-



established behavioral change literature, these same concepts have yet to be examined in the context of *mHealth Engagement*. Caution is warranted, particularly when considering the newly identified mHESIA theoretical linkages between the 2 constructs of *Relationships* and *Functionality and Features* and the less well-developed sociotechnical process phases of *disengaging*, and *re-adopting*.

Limited information on how *Relationships* interact with the phases of *disengaging* and *re-adopting* of mHealth use offer another area for future research. Additionally, a better understanding of how *habits* are formed at the intersection of mHealth use and lifestyle behavior change offers new research opportunities. Moreover, a growing body of literature suggests a darker side to *habituating* mHealth and technology use: excessive use and possible addiction.<sup>273, 274</sup> Such problematic use is also associated with poor psychological well-being.<sup>275</sup> Additionally, several participants (never users) acknowledged that a person-to-person intervention might be the best option. If survivors cannot use or choose not to use their smartphones or mHealth apps, even the best-designed, most efficacious mHealth intervention will fail to help improve lifestyle behaviors. This underlying perception of smartphones and mHealth apps may be an essential antecedent preventing some patients from accepting, experiencing, and benefitting from healthcare delivered using any technology much less mHealth interventions.

Another antecedent barrier involves electronic health (eHealth) literacy. eHealth literacy is defined as the ability to identify and use health information from electronic sources to improve health.<sup>276</sup> eHealth literacy includes attributes of 6 distinct literacies:

health literacy, traditional literacy, information literacy, scientific literacy, media literacy, and computer literacy.<sup>276</sup> Low health literacy is associated with poor health outcomes.<sup>277-280</sup> Moreover, low health literacy is associated with decreased use of health care services, particularly in health promotion and disease prevention.<sup>281-285</sup> Overall lack of understanding, an inability to navigate complex care directions and care environments, and diminished engagement with healthcare providers add additional layers of complexity to the burdens associated with *mHealth Engagement* for persons with low health literacy. The digital divide<sup>286</sup> (the gap between users of new healthcare technologies and nonusers who, due to social, financial, language, or geographic disparities are unable to participate and benefit from these new healthcare technologies) threatens to increase these problems as expectations and pressure from mHealth literate patients to engage with mHealth apps continues to increase.<sup>287-289</sup> Healthcare policy efforts to improve efficiencies, improve health outcomes, and decrease health disparities may be limited without attention to eHealth literacy. mHealth and other technology solutions may improve health, but if the mHealth apps cannot be used by patients because of low eHealth literacy, the apps must be redesigned. However, current measures to evaluate eHealth literacy are limited and lack validity;<sup>290</sup> hence, we may not know if our applications are failing because of design or failing because our patients are unable to understand and use them. Rigorously tested eHealth literacy measures are needed both for research purposes and improved patient outcomes.

Another opportunity exists for developers and researchers to incorporate evidence-based, national lifestyle guidelines and other *Functionality and Features* outlined in this dissertation research into I-apps. As stress was identified as a concern of all participants, creative stress reduction strategies may need to be included in I-apps. Furthermore, these findings suggest a need for different behavior change strategies to address the synergistic effects of I-apps on improving multiple behaviors concurrently. Readiness to change lifestyle behavior may be an important consideration when addressing the needs of survivors. Survivors not considering change, or those just contemplating change may need different processes to engage with mHealth interventions than survivors already actively engaging in behavior change and mHealth use. Additionally, the importance of all types of *Relationships* cannot be overstated. From two-way provider-to-survivor communication to engagement and personalization strategies borrowed from social media, all such *Relationship* strategies may offer a richer stream of social approval indicators - “likes” photo tags, comments from peers, providers, family, friends – making the I-app “sticky” and more likely to become habit. However, more theoretical work is also necessary to understand the relationships between these concepts in the context of breast cancer survivorship and to verify the mHESIA theory outlined in this dissertation.

More qualitative work is also needed to understand how a nursing care system might support *mHealth Engagement* and how theoretically based I-apps might be used to help nurses work at the top of their licensure. Advance practice nursing seems uniquely qualified to focus on survivorship care as nurses focus on the whole patient and family.

Additionally, I-apps integrated with the EHR may help nurses' workflow in survivorship and outpatient clinics. Perhaps the mHESIA theory developed in this study will stimulate research into new workflows and care systems to meet the needs of an increasing population of breast cancer survivors at a time of decreasing nurse care providers. Grounded theory work, using the mHESIA theory as a starting place, may offer insight from the nursing care perspective.

Another important future research consideration involves the complexity of I-apps for lifestyle behavior change. Such interventions involve multiple components and require substantial iterative development in the usability and feasibility phases of the research trajectory; traditional RCT research designs may need to be adapted. Additionally, research conducted on interventions that are individually customizable to meet the changing needs of patients, over time, require complex research study designs. Research methods and designs from engineering and computer science may be able to overcome such challenges, as such methods are uniquely suited to problems of complex systems and decision making in systems that change over time.<sup>291</sup> Such methods and designs (e.g., adaptive intervention, dynamical systems, control engineering methods) have begun to be described in the literature for health behavior change.<sup>291-293</sup> However, having a theoretical frame of reference is the key to successful study designs.

In summary, extending this dissertation work involves testing the new mHESIA theory, understanding the perceptions of healthcare providers when helping breast cancer patients use I-apps to improve lifestyle behaviors, and investigating the concepts of *disengagement* and *re-adoption* in future work. Penultimately, a version of the new

mHESIA theory will be used to inform the design and pilot testing of a mHealth intervention supporting stress reduction and improved diet and exercise in breast cancer survivors. Ultimately, we hope to develop an intervention based on a validated version of the mHESIA theory and to demonstrate effectiveness in improving breast cancer survivors' lifestyle behaviors.

### ***Conclusion***

A gap existed in the scientific knowledge base for the design of effective mHealth interventions to modify lifestyles in breast cancer survivors. Our understanding of how various I-apps support and motivate survivors to change their behavior was limited. Lack of understanding and lack of theories to inform the design and testing of mHealth interventions limited the efficacy and effectiveness of mHealth technology. Despite a decade of calls for such theories, none had been heretofore developed.<sup>43, 47, 217</sup> The work outlined in this grounded theory study and the resultant mHESIA theory begin to establish the science addressing this critical need. This dissertation research provides the empirical grounding for theory testing and may inform future I-app design and development work focused on improving the lifestyle behaviors of breast cancer survivors. I-apps should not merely rely on digitizing current evidence-based practices but instead should use theory-based affordances of mHealth technologies to improve health behavior and ultimately, survivors' outcomes.

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## **Appendix A. Demographics Questionnaire**

This section asks questions about you. The information is necessary to understand differences between people and their use of mHealth apps. The information you share with us will not be used to personally identify you and will remain anonymous. The information will NOT be shared with anyone outside the research study team.

Thank you for helping us with our research.

**Sex:**

- ☐ Female
- ☐ Male

**Ethnicity:**

- ☐ Hispanic
- ☐ Non-Hispanic

**Race (mark all that apply):**

- ☐ American Indian or Alaska Native
- ☐ Asian
- ☐ Black or African American
- ☐ Native Hawaiian or other Pacific Islander
- ☐ White
- ☐ Other

**Method of Payment (*mark primary method only*)**

- ☐ Private Insurance
- ☐ Medicare
- ☐ Medicare & Private Insurance
- ☐ Medicaid
- ☐ Medicaid & Medicare
- ☐ Other
- ☐ Military or Veterans Sponsored NOS
- ☐ Military Sponsored (includes CHAMPUS & TRICARE)

- ☐ Veterans Sponsored
- ☐ Self-Pay (no Insurance)
- ☐ No means of payment (no insurance)

**Marital Status:**

- ☐ Single (never married)
- ☐ Divorced
- ☐ Married or living as married
- ☐ Widowed
- ☐ Separated

**Education:**

- ☐ No or Some High School
- ☐ High School Graduate or General Education Diploma (GED)
- ☐ Some college or technical/vocational school
- ☐ Undergraduate degree
- ☐ Graduate degree

**Current Employment:**

- ☐ None outside home
- ☐ Full time
- ☐ Part-time
- ☐ Unable to work (disability)
- ☐ Student
- ☐ Retired

**Income:**

- ☐ <\$25,000
- ☐ \$25,001 - \$50,000
- ☐ \$50,001 - \$75,000
- ☐ \$75,001 - \$100,000
- ☐ \$100,001 - \$150,000
- ☐ >\$150,000

**Would you say your health in general is:**

- ☐ Very good
- ☐ Good
- ☐ Fair
- ☐ Poor

**During the past 4 weeks, did you have enough money to meet the daily needs of you and your family?**

- ☐ Yes
- ☐ No

**Do you have a cell phone (include phones used for either work or personal use)?**

- ☐ Yes
- ☐ No

**How often do you use email?**

- ☐ Every day or almost every day
- ☐ 3 to 5 days a week
- ☐ 1 to 2 days a week
- ☐ Once or twice a month
- ☐ Less than once a month
- ☐ Never

**Have you used the internet in the past 30 days?**

- ☐ Yes
- ☐ No
- ☐ Don't know

**Frequency of internet use:**

- ☐ Almost every day
- ☐ Several days a week
- ☐ About 1 day a week
- ☐ Almost never

**If you used the internet in the past 30 days, how did you access the internet (select all that apply)?**

- ☐ Mobile phone
- ☐ Laptop
- ☐ Personal computer at home
- ☐ Tablet
- ☐ Computer at work
- ☐ Public computer

**Self-rated Internet Skills:**

- ☐ Excellent
- ☐ Good
- ☐ Average
- ☐ Reasonable
- ☐ Poor

**How confident are you filling out medical forms by yourself?**

- ☐ Extremely
- ☐ Quite a bit
- ☐ Somewhat
- ☐ A little bit
- ☐ Not at all

**Have you ever used the internet to (Yes/No):**

Search for information on health and illness?

Schedule an appointment with your healthcare provider?

Read on a health-related forum or social media website?

Read a health care review?

Used a health-related mobile phone app?

Asked a question of your health care provider online?

Monitored disease symptoms?

Shared personal medical information with others?

Logged on to your own electronic health record?

Posted a healthcare review?

Take a web-based self-management course?

Posted a message on a peer-supported forum or social media website?

**Primary Diagnosis:**

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**Year of Initial Diagnosis:**

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- ☐ Any cancer recurrence? YES -> Year of recurrence \_\_\_\_\_,
- ☐ No

## Appendix B. Health Behaviors and Factors Questionnaire

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### Health Behaviors

1. Do you smoke?

- ☐ Yes; I am a current smoker
- ☐ No; I quit LESS than a year ago
- ☐ No; I quit MORE than a year ago
- ☐ No; I never smoked

2. How much *moderate* physical activity do you get in a week?

*A person doing moderate physical activity can usually talk, but not sing, during the activity.*

Enter minutes of moderate activity per WEEK

3. How much *vigorous* physical activity do you get in a week?

*A person doing vigorous physical activity usually cannot say more than a few words before pausing for a breath.*

Enter minutes of vigorous activity per WEEK

4. How many cups of fruits and vegetables do you eat in an *average day*?

One cup of fruit = 1 banana, 1 apple, 15 grapes, **or** ½ cup raisins

One cup of vegetables = 1 ear of corn, 1 potato, 2 cups cooked greens, 1 cup uncooked greens, 2 celery stalks, **or** 12 baby carrots

- ☐ Less than 4 ½ cups
- ☐ 4 ½ cups or more
- ☐ I don't know

5. Do you eat 2 servings or more of fish *weekly*?

*One serving of fish is approximately 3.5 ounces, approximately the size of a deck of cards.*

- ☐ Yes

- No
- I don't know

6. Do you eat 3 or more servings of whole grains *daily*?

*Whole grain foods include whole wheat **or** rye bread, brown **or** wild rice, whole-wheat pasta, bran flakes **or** whole-grain cereals, and oatmeal*

- ☐ Yes
- ☐ No
- ☐ I don't know

7. Do you drink less than 36 ounces (4 ½ cups) of beverages with added sugar *weekly*?

*Beverages with added sugar include regular soft drinks, fruit drinks (fruitades and fruit punch), and sweet tea*

- ☐ Yes
- ☐ No
- ☐ I don't know

8. Do you eat 1,500 milligrams or less of sodium *daily*?

*If you don't track your daily sodium intake by reading the food label, to answer "yes" you should do at least two of the following:*

- *Avoid eating pre-packaged processed food or eat low-sodium versions*
- *Avoid eating out or ask for low-sodium preparation*
- *Cook at home without adding salt*
- ☐ Yes
- ☐ No
- ☐ I don't know

### **Health Factors**

1. My height (feet)\_\_\_\_\_, inches\_\_\_\_\_; Weight (pounds)\_\_\_\_\_

2. My weight is best characterized as:

- ☐ Obese
- ☐ Overweight
- ☐ Normal weight
- ☐ Under weight
- ☐ I don't know

3. My blood pressure is (enter numbers):

Top number (systolic) \_\_\_\_\_

Bottom number (diastolic) \_\_\_\_\_

☐ I don't know

4. My blood pressure is best characterized as:

- ☐ High
- ☐ Somewhat high
- ☐ Normal
- ☐ I don't know

5. My cholesterol is (enter number):

\_\_\_\_\_  
☐ I don't know

6. My cholesterol is best characterized as:

- ☐ High
- ☐ Somewhat high
- ☐ Normal
- ☐ I don't know

7. My fasting glucose is:  
Enter number

\_\_\_\_\_  
☐ I don't know

8. My hemoglobin A1c is:  
Enter number

\_\_\_\_\_  
☐ I don't know

9. My hemoglobin A1c or my fasting blood glucose is characterized as:

- ☐ High
  - ☐ Somewhat high
  - ☐ Normal
  - ☐ I don't know
-

## Appendix C. Trustworthiness Criteria, Definitions, and Applications (extended)\*

Criteria	Definitions	Applications
<b>Credibility</b>	<p>Confidence in the truth of the data and interpretations of them; for participants and in specific contexts. Credibility cannot be attained in the absence of dependability. Involves carrying out the study in a manner that enhances believability (i.e., avoiding method slurring, enhancing methodological congruency) and demonstrating credibility in manuscripts and reports.</p>	<p>To address methodological congruency, a constructivist methodology was selected aligning research question methods, my relativist worldview. Adherence to constructivist methods was guided by work by Bryant<sup>59</sup> and Charmaz.<sup>57, 61</sup> Prior to the selection of a constructivist approach, other qualitative methodologies were reviewed (phenomenology and thematic analysis – both were unable to address the research question) and other grounded theory approaches (Glaser, Strauss and Corbin, Schatzman and Bowers) but these failed to align with my worldview. Familiarity with these methodologies and methods helped prevent method slurring, a concern for novice researchers that can threaten credibility. Additionally, I wanted to focus on learning one methodology and the methods associated with that approach (as a novice grounded theorist) before combining methods in a new or novel manner. I also reviewed seminal work by Baker, Wuest, Stern<sup>294</sup> and Cutcliffe<sup>295</sup> which forewarned of the bias and rigor problems associated with slurring GTM with phenomenology methods. For example, in phenomenology, the “object of the inquiry is the description of the “essence” of a phenomenon as experienced by the individual – the “lived experience.” GTMs focus on the discovery of a process and developing a theory about that process. Phenomenology requires preconceptions of the phenomenon being investigated to be “bracketed” by being identified and put aside. To bracket, the researcher identifies and suspends what she already knows and approach the data without preconceptions. Constructivist GTMs acknowledge the perceptions of the researcher as part of the process and as part of the end product – the theory. Using GTMs, memoing and reflexive journaling help me bring preconceptions to conscious attention, where they are examined for undue influence on the developing categories, concepts and theory, but may still be useful in creatively applying tacit knowledge to the interpretation of the data. However, constructivist grounded theorist<sup>57, 294, 295</sup> recognize that some preconceptions may not be conscious and thus the assumption that reality is multiple. Other differences</p>



exist between GTM and phenomenology methods specifically in sampling, data collection, analysis, and in identifying the validity of the research. Paying attention to the specific methods of the constructivist methodology helps ensure methodological rigor and thus credibility.

Clear expression of the research question and its alignment with the methodology are important in demonstrating research credibility and were articulated in this study. Equally important are concise and complete descriptions of data collection and analysis procedures. Showing not telling is important and I tried to do this using verbatim examples of each concept and dimension.

Participants guided the inquiry process as much as possible and told their stories. The broad initial research questions asking about their cancer journey and their health not only served to establish rapport, but also helped guide the shared content. Storytelling served to ground the study in the data that was important to participants, thus lending credibility to the process.

Using participants words and phrases in the coding (initial “in vivo” coding) and in descriptions of categories and concepts (i.e. initiating changed to *adopting*) also lent credibility to the research process.

Searching for disconfirming evidence within categories and subcategories as well as within concepts helped enhance credibility.

I recorded my personal experiences and insights as well as my preconceived perceptions in my reflexive journal, and reflexive memos. I monitored how the literature was used, asking how I am using a specific theory and why. Dissertation committee members (MBH and PYY) helped me recognize when I might be inserting myself into the process and biasing the results through bi-weekly meetings. They offered alternative explanations and lines of inquiry to improve the rigor and the credibility of the findings.

Using interviews, field notes and follow-up interviews helped triangulate the data, and discussing results with participants and subject matter experts added further to the credibility of the findings.

Throughout all phases of analysis positive and negative aspects of technology were proved and discovered. For example, most participants spoke of the positive aspects of technology. A search for disconfirming evidence

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(negative aspects of *mHealth Engagement*) revealed 2 codes (negative relationship with technology, and “fear” of data breach).

25% (n=4) of transcripts were recoded to check for coding accuracy.

Descriptive and interpretive validity were assessed through the recoding process and through dissertation committee members review.

Examining the extant literature to understand how the new theory fit within the current theoretical body of knowledge also lent credibility to the research findings.

<b>Dependability</b>	Stability (reliability) of the data and results over time and conditions.	Data were collected over a 10-month period. The 7 process concepts were identified as categories after approximately 10 interviews. These process categories became concepts ( <i>mHealth Engagement, Self-regulation, adopting, sustaining, habituating, Relationships, and Functionality and Features</i> ) in the final theory and remained stable in the following 6 interviews. Concepts and dimensions were saturated lending dependability to the findings.
		Dependability of results was enhanced by keeping a reflexive journal, documenting decision making in a standard operating procedures manual, and using the date-timestamped audit trail in NVivo Software. Such measures create an audit trail for verification.
		Self-awareness was enhanced by the continued use of reflexivity throughout the research process. Memo-writing and maintaining a reflexive journal helped identify perceptions, and biases as well as the interaction of such with the data. This reflexive process added to the dependability of the research and enhanced the overall trustworthiness of the study.
		Using interviews, field notes and interaction with a prototype application helped triangulate the data as did the use of member checking (follow-up interaction to review findings) with key participants.
<b>Confirmability</b>	The objectivity, the congruency between 2 or more independent people about the data’s accuracy, relevance, or meaning. Interpretation of the data is congruent with data provided. Findings reflect	Confirmability was established through reflexive journaling, careful documentation of decision making, and the use of a time-stamped audit trail within NVivo software. Self-awareness of my place in the research was enhance through memo writing and maintaining a reflexive journal. I wrote of my identified perceptions (e.g. early in the process I imposed my tacit knowledge around the behavioral stages of change into the constant comparative analysis process only to realize, upon

	participants' voice and are not biased by researcher's perceptions, perspectives, or motivations.	reading my reflexive journal that the line of inquiry was not grounded in the data.)
		Data was sought until each concept reached saturation. Codes that lacked saturations or patterns were extinguished (i.e., journaling).
<b>Transferability</b>	The extent to which finding can be extended and supported in other settings and with other participants. External validity (generalizability) cannot be specified by grounded theory, only through thick, rich descriptions can readers transfer research to their area of interest.	<p>Data triangulation using interviews, observations, memos and field notes help ensure transferability, as did review of the final theory by subject matter experts (i.e., clinicians, informatics nurse researchers), and dissertation committee members). Review of the methodological decisions and ongoing results by the dissertation committee also helped ensure transferability.</p> <p>The use of thick, rich descriptions in the research results and discussions help show how the theory was developed as well as allowed the reader to understand how these findings might be transferred to other types of participants or patients and in other contexts.</p>
<b>Authenticity</b>	The extent to which researcher faithfully convey participants processes and experiences and convey a full range of realities.	<p>Grounding the coding (in vivo), categories, and concepts in the data and showing how the codes, categories and concepts were developed from the participants own words helps establish research authenticity.</p> <p>Developing methods with expert grounded theorists on the dissertation committee (MBH, RP) helped ensure authenticity.</p> <p>Sharing results with subject matter experts (i.e., clinicians, informatics nurse researchers) also help ensure authenticity.</p> <p>Tracking rationale for theoretical sampling decisions and video recording complete participant responses addressed study authenticity and also provided an audit trail.</p>

\*Adapted from criteria by Lincoln and Guba<sup>211, 213, 217</sup>

## Appendix D. Theoretical Assumptions and Propositions

Assumptions	
	<p>The sociotechnical phenomenon of using mHealth to improve lifestyle behavior can be described as a process and constructed through my interaction with the data.</p> <p>Constructivist theorists: Reality is multiple, processual, and constructed.<sup>64</sup></p>
	<p>My perspective and interactions with breast cancer survivors (participants) and their data becomes part of the constructed reality which is expressed as the mHESIA theory.</p> <p>Constructivist theorists: the researcher is a non-neutral observer. Researchers examine how their preconceptions shape the analysis and may or may not be aware of these preconceptions.<sup>59</sup></p>
	<p>Using flexible constructivist methods helped the sociotechnical process be constructed from the participants' stories, and their interaction with me.</p> <p>Constructivist theorists: avoid the mechanical application of methods that fragment the participant's story.<sup>57, 59</sup></p>
Nonrelational Propositions	Nonrelational propositions are constitutive definitions <sup>64</sup> used to define each of the concepts in a theory and include descriptions or definitions.
	<i>mHealth Engagement</i> is defined as the extent (e.g., amount, frequency, duration, and depth) of usage of technology or a digital device (i.e., mHealth application, fitness tracker).
	mHealth represents the phenomena of supporting and delivering healthcare for patients and the general public using always available technologies.
	<i>Adopting</i> mHealth is defined as the initial use of mHealth technology.

	<i>Sustaining mHealth Engagement</i> means using mHealth technologies to meet the needs of survivors in the present and continuing to meet their needs in the future.
	<i>Habituating</i> mHealth refers to making technology use a regular, unconscious practice or routine that would be hard to give up.
	<i>Disengaging</i> from mHealth is defined as separating from or discontinuing the use of the digital health technology for any reason.
	<i>Re-adopting</i> mHealth is defined as accepting and using a mHealth intervention to improve lifestyle behaviors after having used it or a similar intervention or version previously.
	<i>Self-regulation</i> of lifestyle behaviors is the process of managing diet, physical activity, smoking, stress, and alcohol/drug misuse.
	<i>Self-regulation</i> can be conscious and unconscious.
	<i>Relationships</i> are interconnectedness between 2 or more persons.
	<i>Relationships</i> include human-technology connections.
	<i>Relationships</i> can involve a relationship with self.
	<i>Functionality and Features</i> of mHealth concern aspects of the technology, actual or perceived.
	<i>Functionality and Features</i> of mHealth include usability, content, personalization, goals, feedback, integration, and data security
<b>Relational Propositions</b>	Relational Propositions suggest linkages between 2 or more concepts.
	When participants used mHealth technologies to improve lifestyle behaviors they reported a non-linear process of <i>adopting, sustaining, and habituating</i> for both <i>Self-regulation</i> of the lifestyle behavior and <i>mHealth Engagement</i> .
	When <i>mHealth Engagement</i> occurred in combination with <i>Self-regulation</i> of the lifestyle behavior, survivors reported changing several behaviors at a time.
	Survivors reported <i>Relationships</i> and <i>Functionality and Features</i> as important to the <i>adopting, sustaining, and habituating</i> process of using mHealth interventions for lifestyle behavior improvement.